

AGEING WITH ARTHRITIS

Briefing paper prepared for Arthritis Care

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Autumn 1992

Price: ,2

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 London based branches of Arthritis Care who have contributed to the project. A total of 19 people who are ageing with arthritis have participated following a request for volunteers who have been disabled for 20 years or more. 18 of these (17 women and one man) have also participated in the follow-up interviews. The average age of this group is 73; they have been disabled for between 20 and 66 years, with the average being 26 years. 10 out of the 18 have rheumatoid arthritis, 6 have osteo-arthritis; the other two did not specify which type of arthritis they have.

Following an overview of some of the main background issues to ageing with disability, the views of people with long-term arthritis 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 Arthritis Care and others. The briefing paper is organised around the following topics:-

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

- # 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 arthritis 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 arthritis 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 Arthritis Care to take this further and incorporate members concerns about ageing into their own work.

THE EXPERIENCE OF AGEING WITH ARTHRITIS

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.
- * 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.
- * 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.

* 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.

* Whilst most of these concerns were shared by older people with arthritis, it is interesting that levels of satisfaction were generally higher amongst this group. One of the reasons suggested for this was that, unlike some other groups of older disabled people's experiences, people with arthritis do not generally experience sudden or unexpected deterioration. Consequently, they are perhaps better placed to gradually accommodate themselves to changes they experience with ageing.

THE EXPERIENCE OF AGEING WITH ARTHRITIS (Quotes)

"If there was anything I felt I needed (health services), I'd ask for it. The thing is, when you've had something like this for a long time you learn to accept it and make the best of what you've got. You've either got to make the best of life, or you're going to go under. So, I do just that."

"I don't think it's so much getting older that's going to effect my independence. As long as I sort of keep as I am now - if I just get older without any sudden deterioration or anything else - then I would say that it would be as good as I could expect it to be. I mean, the limitations are to do with the arthritic problems, and not to do with getting older. I'm sure that, if I didn't have this, I could run a marathon or something. I do think about it, but not in a sort of despondent sort of way at all. You've got to think about it really because it is happening, but you have to have a positive attitude."

"They're trying to build up more on the hobbies and handicrafts side (at the day centre) for those who want to

work. Of course, there are some who don't intend to. But, for me, it's always been a matter of pride - you feel as good as anybody else if you can do something. But, they're not brought up to have that sort of attitude now. A lot of the youngsters are quite happy to just sit and gaze - which is a shame. There is a lot of different attitudes these days. I think that, if you can do something - whatever it is and however long it takes - you're much better off than just sitting around with a grudge against the world."

"We're not grumbling. We've had a good life - but you can't pretend there haven't been problems. We're both very independent and we'll fight for as long as we can to stay together. We have our independence now, but we don't know if we might become completely helpless. But, it's impossible to tell what's going to happen in the future, so we always try and make the best of what we have now. We still have a good life anyway. The only thing is that we can't go abroad anymore - but you accept that."

"It was 1939 and 1940 when the arthritis first started. In the summer I had a sort of sore upper arm but I didn't think anything of it. But, in the autumn, it had reached the knees and by the Spring of 1940 it started in the hip. But, they never took any notice of it because they said - you don't get it in the hip. But, you do - only it's very rare with rheumatoid. Then, by 1942, it seemed to have got a little better. The thing was that - I was 16 then - you had to register for war work. I thought to myself - if I can't find something that I can do, they might find me a job that I can't do. Probably they wouldn't have - but you feel like that don't you. So, I got a job in a tannery workroom at the local Co-op. It was a good workroom. They didn't mind keeping up the junior's job and not giving them to me. You see, the juniors had empty the bath for the pressing cloth and make the tea etc. Well, I could just about walk the distance - but not twice a day. So, they said I didn't have to do that. I stayed there until 1948 and then I got taken into hospital and I was in there for 22 months altogether."

Researcher: Why did you have to stay in for so long?

"Well, they didn't have so many drugs in those days for fighting these sort of things (arthritis). All they had was aspirin and codeine. They were very limited, they put me on penicillin because my temperature was going to 104 every day - that was 8 injections a day. But, it didn't do a bit of good. You see, it was before they knew that you have to clobber it with penicillin before because, once you've had the smaller doses and increase to the bigger doses later, you were immune. So, by the Christmas I weighed about 5 stone and I had about a fortnight when I had one ice cream a day, and that was about all. I developed a heart condition and got rheumatic fever - I was all purple. I was just laid flat out. I couldn't bend because the bones had grown so much and the cartilage had just all disappeared, so the hip joints had no room to move whatsoever. Then, it took about 6 months to get the temperatures under control. Then, they tried M & B. That was something new that they tried in the war as a healer for wounds. They tried several different ones and the last one worked. But, mind you, I was sick as a dog with it - but in the end it did work. After they transferred me, I was in a research ward. They were trying out what they could find instead of cortisone because that was still only available in America. Cortisone was supposed to be a wonder drug, but they didn't have it here then so, I was put on male gland extract - like the weight lifters have nowadays. But, really, they were just looking in the dark. Of course, now, they reckon that actually attacks the cartilage - I didn't have much left after that. It's always the same - they're in the dark for about 20 years after they start something. It was very unusual for people to get arthritis so young in those days. They used to call it Stills disease, but it wasn't - it was rheumatoid. With mine, it was active up till about when I was 53 (40 years after onset). Of course, as that stopped and I had less pain it got more stable. I still get pain, but it's not so inflamed. The trouble is though, that was when the left hip started to crumble - when I was about 54. So, just as I'd got a bit of comfort, the left hip started to crumble. It turned out that half the socket had disappeared, so I had nothing to stand on - it just disintegrated. I had to wait because they'd closed down the local ward for financial reasons and I didn't get in for about 2 years. Then, all they could do was a girdlestone - which is like a tent pole in a cup. Anyway, I survived that with a struggle and then, 3 years later, I had a tumour. I survived that, and then a couple of years later, it was diabetes. Some people said it was the shock - but everybody's got a theory, haven't they. Still, anyway, I'm still here."

"I had to retire from work when I was 47 and I went to Middlesex Hospital after that and I was there for a long time (treatment for arthritis of the spine). When I was there, I read a lot. I've got an enquiring mind and I read as much as I could about it and learnt as much as I could. So, I suppose I just sort of gathered information as I went along."

"Of course, the worst thing was having to retire so early. On the other hand, it didn't take me very long to realise that I could occupy myself very nicely and now I'm glad I'm not going to work. It's one thing to make an effort to do something you're going to enjoy, and another thing to make an effort to go to work every day when

you've been in pain all night, and you've got to drag yourself out of bed in the morning and go and do a day's work. You know, that's horrible. It was a joint decision with the doctor. I felt that I really couldn't go on anymore. Actually, for the first 10 years or so - if I felt that I couldn't go on - I used to have 2 or 3 days rest. But, I never actually had a whole week off until after that had gone on for 10 years. So, I did very well but during the next 3.1/2 years I did have to have a lot of sick leave. So, I decided that I really just couldn't go on - it was wearing me out. My employers were very good to me. If I'd felt that I could have gone on, they would have let me go on."

"The first couple of weeks after I stopped (work), I was pretty depressed because the pain was really bad at that time and I really did think it was awful having to give up work. I can't remember how long it lasted but I know that after some time my sisters were saying - how did you find time to go to work? You know, I had friends who used to take me by car to classes and I had a lot of help - so I was very lucky."

"In the early days I didn't have any rehabilitation or physio - nothing at all. How it started was that, I had pain in one foot and the doctor sent me to the Royal Orthopaedic Hospital and there, they told me the pain was pressure on a nerve. Then, I had the same trouble in the other foot so then I had blood tests and it was then that it was diagnosed as rheumatoid arthritis - but, I wasn't told so they just put me onto aspirin and wax baths for my hands and feet. So, after 18 months of not getting anywhere, that's how I came to go to the Homeopath. But, of course, when I had to give up work I couldn't afford private treatment. So, after that, my GP sent me to St. George's department of physical medicine to see about physiotherapy and the doctor there - I didn't even take my coat off - he saw me for about 5 minutes and he said that he didn't agree with exercising joints like mine and I should go somewhere where they specialised in my complaint. So, he referred me to the rheumatology department at Middlesex Hospital and I went there for over 20 years. In the beginning, the drugs they put me on upset my stomach and my bowels so after that I didn't have any medicine. I said that I preferred not to have any drugs. But, the rheumatologist was very good. He still used to see me regularly and I had hydrotherapy and different kinds of splints for joints, injections in the knees and things like that. But, he was very good - he didn't force medicine on me anymore after that - except when the trouble flared up in the spine. It was very bad, and he put me on a drug called Methrazone - an anti-inflammatory drug. But, I'd only taken it for a few days when I had very bad side effects - including waking up in the middle of the night and struggling for breath and having a rash all over me and feeling ill and having more pain. So, I just said to him - I prefer the devil that I know than you very much - and he said - you're probably right. So, that's how it went on and I never had these strong drugs that can have the side effects. I found that when I had to retire from work at the age of 47, I was very sort of depressed about it at first because it seemed awful that I'd got to retire at that age. But then I decided that I must do the things that I can. I was able to sing, so I did quite a bit of singing in different classes and I went to a french class and another class called Speech and Self Expression - that helped me quite a lot. It occupied me and gave me things to think about. Then, eventually, I sort of stopped going to those and now I quite happily occupy myself with music and doing crossword puzzles, reading. I do the light chores about the place, and I have somebody come in once a fortnight to do a good going through. That's how it is now."

"When I first came out of hospital, I went back to live with my mother - I was the youngest of 9. I couldn't go back to work because - in those days (1950's) there weren't all these beds and chairs and things. My mother had got my brother to make four wooden blocks with recesses in so the bed was high enough and she got a local builder to see to the outside loo so that was high enough. But, of course, I couldn't get out there the first few months. I had to walk with plaster splints then anyway. So, it would take me 6 steps just to get off the bed onto the carpet. So, it was a very slow job. With all that, it would have been impossible for me to go back to work - I've never been back since. But, gradually I was able to take proper steps. Then, they sent me for these two hip operations which they said I was right for. They didn't promise there would be any improvement because they said the tendons and muscles might be absolutely useless by then. But, it did make some improvement - although not as much as the other people were getting. Then, about 1965, I started up on drugs again. These were the anti-inflammatory drugs - which were quite a new thing then. That quietened the joints down when they started to get painful. But, taking drugs doesn't really solve the problem because the pain just spreads. These bouts of pain would last for about 3 or 6 months and you just go on like that."

"I haven't noticed any change (in the way I feel). Obviously, you do change as you get older and your outlook changes, but I haven't really noticed it - it's been gradual. I think that all I have gone through is just the natural process of getting older. I mean, apart from the very bad times that I had in the earlier years - particularly with rheumatoid arthritis, when life was very hard. But, otherwise, I just think I've got older just in a natural steady way. I haven't noticed any deterioration in my mental state - apart from memory lapses that everybody gets - you don't even have to be very old to have those do you? I mean, I haven't become crabby or

anything like that. As you get older, you realise that you're getting older - I mean, we had a big family, there were 10 of us and then 5 of us have died. You know, things like that happen and obviously it makes you aware these things have got to happen. One of my sisters will be 80 this year and you think, you know, 80 is getting old - and my eldest sister died last year, she was 82. But, they're the sort of things that happen - they're inevitable aren't they."

"It (arthritis) definitely affects the quality of your life because it's so restricting. And, in the days when the rheumatoid was very active, the pain is very severe - which is hard to cope with, and you do get depressed at times. But, not now - it's eased off to quite an extent. I do get flare ups, but in the main it's more livable with."

"I think I cope with it (disability) very well. I know that because medical people have told me that I cope well. Also, I know that compared to lots of people who moan and groan about minor things all the time - which I don't. I think that I've always done the best I could with it over the bad years. I mean, I wouldn't have kept on at work for all those years if I wasn't the sort of person who really made the effort to cope. But, they were bad years. I'm lucky really in being able to use my mind, when there's a lot of physical things that I couldn't do. If I didn't do things that I enjoy so much I would probably find that time was hanging heavily quite a bit. Now, I never find that time drags - so I'm really quite happy."

"There is a problem with a lot of people with arthritis. You do tend to dismiss it for a long time until it just gets so bad that you can't ignore it anymore. But, having said that, you don't have to make it feel as though you are a disabled cripple - you just get on and make the best of it."

"We've got one bloke (at the day centre) who refuses to do anything. He's got MS, and he's got a grudge against the world. He won't do anything - he just sits and has a sleep or a smoke. That's it. Some of the other fellahs have talked to him - they've got the same MS - but it doesn't make any difference. It's rotten, but what can you do with him. You see, he was fine until he was about fiftyish. After that, he was always ever so sorry for himself. I said to him once - what about these youngsters here that have never walked. He says - oh, what you never have you never miss. I said - don't you believe it. There are lots of things you can do - as long as it's possible. Of course, if they're spastics, they haven't got the same chance have they? I've got a spastic friend. She'll make things - not perfectly, but good enough. Then, there's another young fellah there and he does carpentry. It took him 15 minutes the other day to get one screw in - but he didn't let it beat him. You admire that don't you."

"I am very satisfied (with leisure time). I do different things now - but I'm never bored. I would like to be able to do more with my hands though. I used to be a good knitter. I used to do needlework and embroidery, and I can't do things like that anymore. I would like to do handicrafts as well but, those sort of things, it's just too painful and difficult. There are some restrictions though. I mean, I would like to be able to go all over the shops. I mean, with things like that, there are restrictions. I mean, here, I can go to the shops but it's a miserable shopping centre. I'd like to be able to do like my sisters do and go to Croydon and Kingston - all over the place and go to all the nice shops. But, if you're going to have cars to Croydon and cars to Kingston - apart from the fact that it would be too tiring - it's too much money. But, I am satisfied because I've accepted what I can't do and I enjoy what I can do."

"My family come and visit me and here (sheltered accommodation) we have quite a lot of social activities going on. You need never be alone if you don't want to. I have friends here and we visit each other - we meet and have a cup of tea and a natter. And, if you want them, they have indoor bowls, table tennis, darts and that sort of thing. Now, they are things that I would actually like to be able to do now you come to mention it. But, you know, I can't really do those sort of things but I would like to be able to although they are available for people who can do them. But, I'm quite happy with things as they are."

"Well, I find that I need some quiet days in. I'm over at the day centre on Wednesdays all day - that's when I get my bath. Tuesday mornings I go to a lace making group and I still do quite a bit of lace work at home - that keeps me occupied. Actually, I have been making the altar boys' robes for our local church. They were looking for someone who could do it and there was only me, so I volunteered. I've done 29 so far - that's over about 3 or 4 years. But, that's doing odd half hours - not sitting for a whole session like a professional would. Anyway, it's a nice hobby. I've been doing it for 7 or 8 years now. Mostly, we teach ourselves and teach each other. That all started at the workshop - it was organised by the social services. The occupational therapist suggested it at the start, and it just sort of grew from there."

"I still keep very busy, although I do like to put my feet up in the afternoons. I do what I can when I can. Of course, as time goes by, I don't do as much as I used to - but, then that's the same with everybody isn't it. You see, the last hip operation took a lot out of me - so I've had to cut down since then."

"After my wife came back from the rehabilitation centre, it was obvious that some things were going to have to change. To give you an example, I'm 84 years old and I'd never cooked before this year but, it's never too late to learn and now I'm baking cakes and allsorts."

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 arthritis. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and arthritis 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 arthritis, 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 arthritis 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 arthritis which should be highlighted for further investigation. For example, fractures and dislocations, strokes, osteoporosis, drug dependency or problems associated with side effects of long-term medication, muscular atrophy, pressure sores, difficulties with walking, and problems with transfers or turning were more likely to be reported by people with arthritis.
- * On the other hand, there were some problems which have a lower prevalence, or are even non-existent amongst this group. These include coronary disease, respiratory problems, contractures, and changes in energy levels.
- * 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 arthritis 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 CHANGES/PROBLEMS ASSOCIATED WITH AGEING (Quotes)

"I've had one hip replacement already (approximately 15 years after onset) and now I'm waiting to have the operation on the other knee. I don't know when it will be - I've been waiting for 16 months already."

"I have had some pretty bad digestive problems. That is down to the tablets I'd been taking for the arthritis - they were just building up this digestive problem. The doctor told me that actually. He said that 20 years of taking them had done that to me and that I should cut them out. In the end, I did stop taking them - that was a year or two ago. The thing is, I had to balance that with not being able to relieve the pain - from the arthritis. But, I'm not too worried really because - the way I look at it, I'll probably live longer without being full of chemicals."

"I did put on quite a lot of weight - I don't really know why that is. I suppose I started putting on weight about 6 years ago (34 years after onset), but I'm still quite a reasonable weight."

"It's a bit difficult to tell what problems are due to getting older and what are due to arthritis. I mean, if I didn't have arthritis I would be a very young 74. Because, naturally, you can't get about as you would like to. I mean, I would much rather be able to do all my own housework. But, that's not to do with getting older - it's because of the arthritis."

"The diabetes I've got is myelitis - a mild one. I don't take insulin, just the tablets. I'm pretty careful because the smallest amount of sugar affects my eyes and I like to be able to see to do things - so I'm very careful. You need a lot more knowledge when you first become a diabetic - instead of having to find out everything for yourself - you have to be a detective. You know, it's the silly little things. There's leaflets with recipes, there's leaflets about hypoglycaemia and this and that. But, when it comes down to it, you might find that so and so suits somebody, but not you. But, they don't mention things like that. Then, you find out things like tins are labelled wrongly. They stopped putting sugar on them - they put 'energy'. There's lots of people who are diabetic who

are elderly - they don't know what that means, and they haven't got anybody to ask, in any case, a lot of people can't read that small writing. It's only by trying it and finding out - oh, my sugar's gone up, what the devils caused that - that you find out."

"After taking the drugs for about 5 years, the pain did start to gradually go down. But then, that was when they found my left hip was starting to crumble. So, they operated on that one and took it away. They said the right one wasn't too bad. At that time - after the operation - I was walking to and from the workshop instead of using the wheelchair. But then, after 18 months, the right hip started feeling a bit tetchy so I thought - right, I'll only walk when it suits me. So, I don't do very much walking now and I'll have to enquire whether they can do the right hip or not. If it gets too bad, it might mean no more walking at all. We'll just have to see."

"I'm almost completely blind now. I had an eye operation in October this year (1991). It didn't work, so I probably lost the sight of this eye for good. I'm not at all happy about it because they should have really done the operation in 1983 when the problem first started. They kept putting me off. You know - come back in six months - all this kind of rubbish. If I'd had the operation earlier, I'm sure it would have worked - or at least there would have been a better chance of saving some of my sight."

"I couldn't really tell you exactly how long I've had arthritis, but it has been progressive - it's got very very very much worse over the years. I used to take dancing classes - that's what I did for a living. Now, we've lived here for 24 years and I gave up just before that. I've not been able to do it since. So, it's been about 30 years altogether I suppose. What's really finished me off was when I fractured my hip last January. I was laid up in hospital for about a month and then they sent me to a rehabilitation centre. I think it must have been June by the time I came home, and I've been like this ever since. Actually, I didn't go straight to the rehabilitation centre - that was only after I'd been home first. But, it was terrible and we just couldn't manage here on our own. That's the trouble with the hospitals you see. They only ever look at what they've done. I've never had any bother with my hip after the operation. But, they just sent me home and said - there's nothing else we can do. But I couldn't get out of my chair - I needed to build up my strength but, just because the fracture was healing, they said everything was ok. They haven't done any manipulation or physiotherapy. They knew about my arthritis but they didn't seem to take any notice. It was all done by x-ray and, even then, they only looked at the job they'd done."

"I've been disabled for the last 20 years or so. I've had both my hips replaced now. Then, on top of that, I was involved in a road accident in 1989. That really finished me off I suppose because, whenever I'd been laid up before, I always used to be able to get back to work after about 8 weeks. Now, it will be more like 8 months. Like my wife I was quite unhappy about the treatment you get in the hospital. They seem to think that, just because you're 84 you're not bothered. So, they don't seem to want to do very much for you. You just don't get the personal attention. They never do any exercises or ask any questions. It's just straight into x-ray and send you home as soon as they've patched you up. Nobody said anything about what I should do when I got home. I still do the exercises I learnt 16 years ago - there's been nothing since."

"The girdlestone was a hell of a struggle. I was in bed for a month and the first time out of bed all I could manage was a yard and a half - and that was with 2 physiotherapists and crutches. A yard and a half an inch at a time, and then they wheeled me back. I shook for an hour or more after that - with the struggle. So, maybe the diabetes was brought on by the stress. They say that stress has got a lot to do with it - but nobody really knows."

"My hands have got all knarled up and my legs are all twisted. There's a lot of things I'm not able to do - I can't do simple things that I used to."

"It's been progressive over the last five years. It's got a lot worse (arthritis)."

"I had a hip replacement about three years ago - that's how bad it was getting. The most awkward thing was not being able to get up out of the chair - I just used to get stuck there. Now, I've got one of these chairs to lift you up - I'm hopeless without it."

TABLE 1: PHYSICAL PROBLEMS/CHANGES EXPERIENCED WITH AGEING

| Proportion reporting problem/change (%) | Arthritis | Total sample |
|---|-----------|--------------|
| Difficulties with walking | 61 | 40 |
| Decreasing agility/mobility | 54 | 51 |
| Drug dependency/side effects | 38 | 12 |
| Problems with vision | 31 | 22 |
| Increased pain | 23 | 27 |
| Problems with shoulders, arms or hands | 23 | 18 |
| Fractures/dislocations | 23 | 9 |
| Weight gain/loss | 22 | 21 |
| Changes in energy levels | 15 | 27 |
| Problems with transfers/turns | 15 | 7 |
| Stroke(s) | 15 | 5 |
| Brittle bones (osteoporosis) | 15 | 5 |
| Problems with circulation | 8 | 12 |
| Problems with hearing | 8 | 6 |
| Bladder or kidney infections | 8 | 7 |
| Muscular atrophy | 8 | 3 |
| Thyroid problems | 8 | 3 |
| Pressure sores | 8 | 1 |
| High/low blood pressure | 7 | 7 |
| Heart problems/angina | 0 | 12 |
| Respiratory problems | 0 | 11 |
| Asthma/breathing problems | 0 | 10 |

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 arthritis 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 local specialist clinics for people with arthritis. 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 arthritis, 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 arthritis, and very little understanding about the long-term effects of arthritis 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 arthritis, or the effects of long-term medication; in others, these were more general problems (eg. impotence). Whatever the specific nature of these problems, it does appear that the medical professional 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 see our doctor twice a year. He is very helpful. The only thing that does annoy me is when he says things like - you're not 21 anymore you know. That does get me down a bit. I don't think they should go on about that - it's not a very nice thing to keep reminding someone of. I do find that you have to be very determined as far as the doctors are concerned. It's no good them telling me that it's just my age - which is what my doctor does as well. You have to go on at them."

"I don't have very much contact with my GP. I've never had to contact them about anything really serious anyway - so I don't know how that would work out if I did. But, I don't want to see them anymore. I only see them if I approach them."

"No, I don't (have check-ups). I don't need to see a doctor very often - only for minor things. I don't want to go on a regular basis at all. If I felt the need, then I'd go to see the doctor."

"I've had two knee replacements at the Middlesex Hospital. I think one was probably about 20 years ago. But, it wasn't very successful. It was in the early days of the joint replacement and it wasn't successful. It went wrong very quickly. Then, I had to wait 7 years to have another one. They kept saying - if you can hang on, they're improving greatly. So, I had that one about 12 years ago I suppose. Apart from that, the treatment was fine generally - I didn't have any complaints."

"I've not been to the (specialist) hospital for years. I just get the tablets from my doctor. But, at the moment, my right hip is playing up a bit and I keep thinking I ought to go. But I put it off because I've got to find out if they can do something about it first. If it gets really bad I can always go and see my GP, or she will come here. But whether or not she knows enough about it, I don't know. Some GP's have their own pet subjects don't they. They are experimenting up at Adenbrooks with bone grafting - but it'll be another 5 years they say. It's something like that which I think I'm going to need. But, I'd have to find out if it would work for me before I

could tell someone - yes, please do that for me. Then, of course, you've got the waiting list anyway. Actually, I don't mind if I have to travel somewhere else - except perhaps London. I've tried going before and it's murder. We wouldn't want to drive into London and I don't think the ambulance would go that far (from Kent) - I think 25 miles is there limit. Of course, we might just be able to manage on the train. But, the thing is that if you need to take someone with you, they only refund the fares for one of you. So you've got that extra expense to worry about as well. So, I don't really know what else there is. I suppose there's the hospital taxi service. But, there again, if you need to take someone with you they won't always promise to bring them back with you. You know, they say it's because they're officially well so they can't take them - it doesn't make much sense."

NOTE: Above respondent attends 2 clinics at the same local hospital every 6-12 months. One for diabetes and the other for check-ups related to the tumour

"When she (my mother) was discharged from hospital the last time, they gave her a letter to give to our GP. I opened it to see what they said and, this letter, it stated that the problem was - 'inability to cope'. I was really angry. I mean, she'd just had a stroke and they discharge you after only 2 weeks. Yes - you aren't coping, but that's because they just throw you out of the hospital. There's no follow-up or support at all after discharge - it's always been the same. It's not as if they don't know about our situation. But, there's never been any proper assessment. How do they think I manage? They know how my mother is but no-one comes to see if we need any help."

"The most amazing thing about the hospital was when they changed her (my mothers) medication. They didn't ask us about it, or even tell anyone they were doing that. Then, on top of everything else, they gave her the wrong one. It was someone elses. If I hadn't checked myself she could have died."

"It's the same with hospital food. When you're in the hospital there's no Caribbean food. You're not asked what you'd like to eat - they just tell you what the menu is. She (my mother) had to have food brought in from home - she wouldn't eat the hospital food."

"In the 1940's they used to try radio therapy on arthritis. And, do you know, it was the fire brigade who used to come - with an ambulance and put them on a stretcher to take them to hospital. This was in Bath. It was very odd. There was a nun having cautery on her knee. Well, one of my brothers came home from Egypt in 1938. He'd been in Aden before that and, when they used to go over to Somali land, the natives in Somali land would make a burn over a pain. When this nun was cauterised, I find out what that was for. This person told me - if you do that, it brings more blood to the area because of the inflammation, and that helps to heal the arthritis underneath. So, the Somalis knew something - it obviously worked."

"It's like when she (my mother) was in hospital. I had to take her own clothes in for her because - for her - you can't be seen in hospital clothes. She would have felt ashamed. Plus, you've got the stigma attached to going into hospital anyway. That's something that's very strong with my mother's generation and, from what she's told me anyway, a lot of that is to do with all the outbreaks of TB they had when she was growing up in Jamaica. So, going into hospital, it's a very stigmatized thing. It's just the same as what we were saying about going into a home. It's all shame and stigma - and that puts a lot of pressure on the family as well. It's just not possible to think of not being able to stop at home."

"I think I had it (arthritis) for a long time before I took it seriously. So, I don't know exactly when it started - some time in the early 60's. I don't think people find out about it soon enough. You tend to just say - oh, it's just a touch of rheumatism - or something like that. So you keep on wearing out the joint. You let it go on and that's how you run into problems. Unfortunately that's what I did until, in the end, I had to go and see a specialist. He said - yes, you must get that knee done. He said it was urgent and they gave me priority - but I still waited 3.1/2 years for the operation. The trouble is, it never really set properly. I think, if I'd had it done sooner I wouldn't have had so much trouble as I have done. But, you see even when you decide to go into it, you still have to persuade the doctors. My doctor (GP) didn't take it seriously until I really pushed."

"I have to say that when I first went to hospital I wasn't told anything. I wasn't even told that I had rheumatoid arthritis - I just found it on my treatment card - and I knew nothing about it whatsoever. That was at the Royal Orthopaedic Hospital (Stanmore). I just wasn't told anything at all. In the early years, after that hospital experience, I did have homeopathic treatment for 6 years - after I was told a bit more about it, but that didn't help. Then I had several years of naturopathic treatment and that's altogether different because they really

treat you as a whole person. They talk to you and explain things and help you with the mental side of things. That was very good - although it didn't appear to help the arthritis, it did me an awful lot of good."

"The carers at the rehabilitation centre - they get very poor training. I blame the people at the top - they've not trained the staff properly. I mean, I can see the sense of it - sending me there. It's clearing the hospital and that does seem like a good thing on paper. Anyway, I did think it was a good thing until I got there. There were a lot of problems - put it like that. For a start, there are problems with getting staff to help me with my dressings. In the end, I was sent home with pressure sores and we had to have a few hard words with the head carer about that. They were just trying to tell me what to do - but you can't help yourself if they don't give you the right advice. Then the other thing was - this place had thick carpets all the way through. You couldn't pull up chairs yourself or anything like that, so you had to wait for the carers to get you to the table and sometimes they couldn't lift you. In the end, we said to the doctor - please get me out of here - we'll struggle at home."

"When they discharged me I was in a wheelchair. The doctor never asked me if I could get up out of the chair or anything like that. As I said, because my hip was healed - he'd done his job as far as he was concerned. There seems to be a different policy these days - they're only interested in the job they did. They don't look at anything else."

"The rehabilitation centre was paid for by the county council. The charge was £700 a month I think. Anyway, we had to pay some of it - £85 a week. It's terrible really. You get a shocking service and that's more than your pension anyway. I remember one time while I was there - I couldn't get my hands around the crutches. So, the carer just banged my hand down to make me do it - it really hurts and I was bruised afterwards."

"It's not for us now (physio). We've managed alright on our own for so long, so I don't think that we really need to bother about it now."

PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING

Like many other groups within the ageing population, people with long-term arthritis 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 arthritis 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 Arthritis Care and other voluntary organisations to act as 'information brokers'.
- * Some older women with arthritis 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 Arthritis Care.
- * 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 arthritis 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 arthritis 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 Arthritis Care 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 used to do all my own housework, but now I have to pay someone to help. I used to have a home help from the council but that got too expensive - about £5-6 an hour. Now, I pay £4 an hour for two hours a week. I think - if I could afford it - it would be nice to have another hour or so. That would be just about right, but I can't really manage that. I do think it was a bit much - what the council were wanting us to pay. The thing was that, when they started charging, they had to go into all your income and that. So, because I had a little bit of money which my husband left, they said they'd have to charge me £6. Anyway, we managed just about. My son is my real help. He's my right hand."

"I have to pay for the gardener as well. I used to be able to do a lot of the gardening - but I just can't manage that anymore. That cost me another £4 an hour, so it all adds up. I think you should be able to get a care allowance for all of this kind of help but, it's always the same - if you've got a pension, even a small one, you just can't get the extra help."

"The trouble with the council home helps is all these rules - they're really rigid most of them. They're not supposed to do any climbing, any lifting - any heavy sort of work at all really. In the old days, they used to do anything and everything - but not now. So, for most people, I can't see that it's a lot of use anyway. I know they've got to protect themselves from accidents and things like that - there's nothing wrong with that. But, there's got to be a more sensible way of organising it."

"We've had problems with the home help service as well. They never say when they're not coming so you never know where you stand - it's completely unreliable. I have to rely on the good will of the home help herself. Now, if she's off sick or anything she will ring me herself to let me know. But, if it wasn't for her, you're just left to get on with it. I really don't think I could cope if she left. If that happens, I'm almost certain that we'd stop using the service altogether because it's so useless."

"We get some money from the Independent Living Fund, but we really need more - I'm trying to get it. We need to be able to get our own home helps and personal assistants. It's no use using the council services. I mean, I can't send someone out shopping for example because they don't know my culture. They don't know what food to get. I need to be able to leave instructions and know that they can do it right away. But, all of this is lost on the social services. It's not enough to just send round a black woman. She has to have the same ethnic origin - the same background. It's no good otherwise."

"I do lighter chores myself and then, once a fortnight, I have somebody come in. I could have a home help but I prefer the arrangement I've got because I like to think I'm doing what I can for myself. Actually, it's probably better than some of the home helps to be honest. The person I have is extremely good and she comes in once a fortnight to do the heavier housework like the hoovering and washing the floors and windows. It's a very good arrangement. We have our own laundry here (sheltered accommodation), and I never do any ironing - I never buy anything that needs ironing. Oh, and she does my shopping as well. She comes in once a fortnight for the housework, but she does my shopping once a week. It's a very good arrangement - she's a very thorough worker. I did use the home help service years ago. I'd say it was just alright. I mean, the home helps I had weren't really very thorough - they just did a sort of superficial job. You see, in the beginning, I never thought about having private help and that was the only service that was offered. I mean, I was very glad to have it but I can't say that the work was done very thoroughly. So, this arrangement is so much better - I much prefer to employ my own worker."

"There are some days when I can hardly get my clothes on - I just have to walk around half undressed if my son's not here. But, I don't think I'd want to be phoning anyone up for things like that - I'm still a very independent woman, and I wouldn't want to do that. In any case, the days when you would maybe need something like that (ie. on-call support), you're usually not feeling too good and having any visitors is the last thing you want."

"It's very difficult having any help from outside if it's not your family or someone you know really well. Anyway, it's no good having different people coming in and out all the time. If you're going to have any help, you want it to be regular - you've got to be able to trust them. With us - if my son isn't here - the neighbours will always help out. I think that's the same for most people really. Without neighbours, I think you'd find a lot of people dead in their beds. Society doesn't seem to care."

"Like I say, my son is my right hand really. We do most things together round the house. I do the organising, and he does all the physical sort of things - unless I can still manage for myself."

"I don't need anymore services for me as I am, but there are other people. I do think it's a shame that services are being cut these days. I think that is a great shame because a lot of severely disabled people need every bit of help they can get. So, I'm always sorry to hear of things like that happening. You know, they've been planting shrubs on the common. I get a bit cross about that because, at the same time, Wandsworth are closing down day centres and old people's homes. I think that sort of thing's not important, but people are important. So, I do get uppity about that because I think they shouldn't cut down on services to people who really need them and then go planting shrubs on the common. It's all very nice, but that money could be diverted to more important things - it doesn't make sense. So, I think probably I'm quite lucky that I don't need a lot of help that some other people do."

"There is a lot of pressure on the younger generation because of the way they feel about their parents expectations. It's difficult because of other pressures which really come from the British culture they grew up in. So, they won't always know what to do for the best. Then, on top of that, you've got the problem of social workers and the way they stereotype the black family - there's not much help coming there either. The pressure, you know, it's very strong."

"My biggest problem is with having a bath. We got in touch with the social services but, first of all they said there wasn't room to put a hoist in, so then they said they could put in a shower unit - but it would cost us a ,1000. We couldn't really afford to spend that sort of money - not straight off, anyway. So, now, we have one of those compressor bath seats - you know, the ones that go up and down. But, even with that, I have to have help from my husband to get onto the seat in the first place. Actually, it was because of the problems my husband's been having that we had to change. If we didn't have that (bath seat), we'd have to have a nurse in to help - we just wouldn't be able to manage otherwise. That probably would have cost more than the shower unit in the long run, so I can't see where the saving is really. I think they just want to make you spend your own money."

"If I needed to, I could go to the day centre once a week to have a bath. And, we have a meals service at the local Age Concern. So, that helps you to get out as well because they send someone to pick you up. There isn't really much else we need help with at the moment. We do have a home help that we pay for ourselves - and someone to do the garden. We're in a fortunate position though, because we have the money to do that."

"I need a lot of help during the day, but getting into bed is awkward because one leg is stupid, and the other one is stiff. There are times when I can't quite make it so my sister has to help me swing up onto the bed. Bathing is out, like I said, but I'm OK with my little washes. Then, with my hair - I have to go somewhere to get that done. It might be a good idea if I could get one of these people who come to your house. I have a chiropodist who comes once every 8 weeks. Clothes used to be a problem because there never used to be dresses with zips at the front and I always used to have to make my own. But now, you can get them. Shoes - I send away for because it's the only way you can get them if you want wide fittings. If you go locally, you might get into a shop after a struggle, only to find they don't have wide fittings in the size or the style you're after - so that's no good. I don't think there's anything else I need really. If I ever did have a problem, I could have a word with anybody at the day centre."

"There is a local branch of Crossroads in the town. We send them a bit of money from the day centre. We each have 20p a month deducted - we agreed to that years ago. It's worth supporting them because it's quite possible I'd want to use them one day in any case - although that isn't the only reason we do it. You see, if anything ever happened to my sister - if she was ill or anything - I would need a bit of help. But, of course, there are fewer home helps and things like that nowadays. But, in any case, if you needed one - you'd need one quickly. You wouldn't want to have to wait until there's one available. So, in that case, it would probably have to be someone from Crossroads or something like that. You see, it's something you might want regularly, or just from time to time. You can't really plan ahead for that sort of thing until it happens. But, as long as you know

who to go to for advice and who to contact - then you'd be alright."

"They (neighbours) are very good. But, you see, that couple on that side - they're two elderly people with a 90 year old mum. I think they've all got heart conditions as well. Then, on the other side - they're a young couple, but he's up in London all day and she's out a fair bit. So, you couldn't really ask them to do too much could you."

"Our daughter's been so good. We've always managed without any outside help."

"I have got family living around here. If I want shopping that you can't get locally, they'll get it for me - things like that. My brother will come up and do any odd jobs that I want done. So, with my sister and my brother living locally - and with the helper I've got - everything is pretty much OK really."

"I'd say I am happy with the arrangements I have now. I don't know what it would be like if I needed more help. I can only speak for as I am now"

"The main help we get is with shopping - that's twice a week. Usually the home help or my daughter will do it, or sometimes I go with them."

"I had a very good social worker. I already had a wheelchair from the hospital but she got me things like a high seat chair, rails in the bathroom and I had council holidays. I think that was about all that I really needed - because, I have got family so I am luckier than a lot of other people. But, I mean, I'm really a very independent person - that's all I really need."

"I've always done everything myself more or less. I mean, sometimes in the really bad years I did need a bit of help in washing sometimes, but I've always been very independent. There was a time when I had to use a wheelchair but now I only use it for sitting out in the garden. It's an old out of date one anyway - so I'm not stopping anyone from having it."

"I have my bath at the day centre because I can't get in the bath at home. You see, once my feet are up, I'm like a plank - I just can't get up again. I've always had a high chair, a high wheelchair, and a high bed because I can't bend my knees enough to get the weight over my feet. I have to lift straight up - and you just can't do that in a bath."

Researcher: Have you thought about having a shower unit or something like that - or would that not solve the problem?

"That would solve the problem. But, my sister hates having workmen in. And, as she's the one who would have to clear up after them it's not very fair. It's not so good when you're in your 70's that they expect you to clear up all the mess - but they do. So, as it doesn't matter too much, we'll leave it. Anyway, it's such a treat to have a bath over there (at the day centre) because then I can have a long soak. Once a week's enough for me because I can wash inbetween. I can't reach everywhere - but it's enough to keep me going nicely. I get a very nice bath over there - it's not just a quick slosh - they're very good. Anyway, I know the staff very well - I've been going there since 1968. I've been going since the first week it opened, so I feel quite at home there."

"There are so many problems with the council services in general. It always feels like you're put in the position of having to beg. It makes you very weary. That's why so many people just give up. You take someone like my mother. She's worked for 30 years to pay into the National Insurance and then - when she's like this - she gets nothing back at all. But, I have to say that this is a situation where there is racism in the community services. It's not just because she's disabled that she gets a low priority because we do know white people in exactly the same position who do get the services. We have had first hand experience of it when we wanted to get a ramp put in to the front door. This flat and the next three flats are all for disabled tenants. The other three are all white families and they have all had ramps put in whether they need them or not. Then, when we asked for one, they say we don't need it - it's just a little bit too obvious isn't it?"

"I'm not in touch with them now (social services), but if I needed them I would get in touch. I have had help in the past - a long time ago. It was at various times when I was attending hospital, according to need. I was very happy with the support I got so, if I ever needed their help again, I know that I could just get onto the phone."

"One thing I really do think is important is - you need regular contact with an adviser. Someone like a social worker, but independent from the social services. There's all sorts of things. We have to have assistance with lifting and things like that when we go out. At the moment, I have to rely on friends but that should be looked into. Then, with respite care in general - it's so difficult to find out about it. I only found out from a friend - there's no-one you can go to for information."

(2. Aids and adaptations)

"My husband got me a special walking stick. The hospital one - all they could offer was a standard stick, and it wasn't any use for me. He just happened to mention this to another OT at the rehabilitation centre and she showed him all these other ones you could get from a catalogue. That was a very useful piece of information. But, the stick we got only cost £17 - so I don't know why the hospital couldn't have got one for us in the first place. You have to find out everything for yourself."

"We had a downstairs loo put in last year - and a utility room. Altogether, that cost about £10,000 - which was more or less all I had left from my husband's insurance. We couldn't get a grant for the toilet. Well, actually they said they would have paid something towards the toilet, but not the kitchen. You see, we had to cut the kitchen in half to fit the toilet in. They said that the kitchen wasn't essential because my son was here - otherwise, they would have paid the share of the cost for the toilet itself. Anyway, it didn't seem worth all the aggravation. I had the money so I thought - what the hell, you can't take it with you anyway. It has made life a lot easier because, even though I've got the stairlift, it's not always convenient. Trouble is, it tends to go at its own pace and, half the time, that's just not quick enough for me, if you see what I mean."

"This flat is supposed to be for a disabled tenant. But, it's a bit of a joke really. They just don't put enough care and attention into the design and we're still trying to get it sorted out after 4 years. For a start, all the doors are in the wrong places. When we told them they just said they'd have to knock the walls through - that was all they could do (local council)."

"It's really quite difficult to lift my mother in and out of the bath. We got the council to put a shower in eventually - but we had to keep on at them for about 2 years. But, even then, we've had nothing but trouble with it. They wanted to save money so they cancelled the installation service contract with the manufacturers and got a local contractor in. They made a complete mess of it and they had to get the manufacturers round to sort it out in the end - but that was only after I threatened to take them to Court."

"We got hold of a second hand wheelchair for when we go out. But, it's really a bit too much for my husband to push me in a chair, so we only use it if there's other people around to help. But, we don't go out very much now anyway."

"We've got rails by the back door. I suppose we could use having some at the front as well, but we haven't asked anyone about that. I'm not the sort to ask for everything that's going."

(3. Transport needs)

"My husband can't drive anymore, so we probably don't go out as much as we used to. But we are very lucky because our son will always help with going to the shops and things like that and, if I want to go out to the Arthritis Care meetings, or if we've organised an outing somewhere, we do have the mini bus that comes round to pick us up. The only problem with that is that they don't always have enough helpers to cope with a wheelchair, so the driver has to manage on his own. Then, both of us need to go to the hospital quite often but, we are very lucky there as well - we get very good attention. They always send a hospital car round to pick us up and bring us home."

"I use taxis most of the time to get out and about. I got the mobility allowance when I was 60, so I've used mini cabs since then. Before that, I didn't really go out very much."

"I still drive in the trike. But, I only go around town and up to the workshop (day centre). I wouldn't go any further - my reactions aren't what they used to be. And, in winter they take me in the ambulance to the workshop because I don't really want to drive in the dark if I can help it. So, that's very good. I'm not too badly off for transport really. The trike - I couldn't really get anything better for what I need. Then, there's always the ambulance for day's out. They always make sure we have 3 or 4 days out every year - they give you a list to choose from and we all go together. They lay on a bus for the more mobile ones, and the ambulance for the wheelchair ones. So, that's pretty good - we always have a good laugh."

(4. Housing needs)

"We've been here about 15 years now. Actually, we did have a house just around the corner and then - when we saw this bungalow was going - it seemed a good move to make. By that time, my husband was having almost as much trouble getting about as I was - and with it being so close, we couldn't really say no. We won't be moving again. They'd have to take me out in a box. You couldn't have anywhere better than this - it's all on one level and it really suits us."

"I lived on my own immediately prior to coming here (Shaftsbury Housing Association). I was living on a council estate and I had a little bungalow which was alright, but the environment was dreadful - the harassment and the unpleasantness. So, that's why I applied to come here. I was turned down by the Shaftsbury actually because my accommodation, in itself, was satisfactory. So, then, I wrote to the council and said - would they consider me for sheltered accommodation and they nominated me for here because they have to take so many council tenants. So, I came here after all. Actually, coming to live here, I always say it's one of the best things that ever happened to me in my life - it's very good and I love my little flat, and the environment is nice."

"I wouldn't want to change where I'm living now - no way. I hope I'll be here until they carry me out or throw me out. I mean, if I go doolally I might have to go. Hopefully I'll be staying here but, if it became necessary, I might have to move into a home. I mean, then, there's just no two ways about it because here you've got to be able to look after yourself - there's no nursing attention and people have had to go into homes from here because they got to a stage where they couldn't look after themselves. With the Shaftsbury, they do have some schemes for the frail elderly now where people that have lived in their accommodation can move on to, rather than go into a geriatric hospital or an ordinary residential home. They have got a few of those now, so that would probably be the next step if it was necessary - but I just hope it won't be necessary. You do get nurses come in sometimes to help with washing and dressing people and putting them to bed - and home helps - and that's it. If you really need looking after all the time, then that service is not available. It's not meant to be - sheltered accommodation doesn't cover that. Anyway, you've only got one bedroom so you couldn't have somebody living in in any case."

"It's difficult to say how we might feel (about moving into sheltered accommodation). You can't break away from old habits. You shouldn't have to anyway if it's at all possible to avoid it. But, sometimes, beggars can't be choosers. If I died and (my wife) was on her own - the situation would change overnight. But, apart from that, it's hard to know exactly what we might do. We're too proud you see - we wouldn't want to impose. So, if we haven't got that much time to go anyway I suppose it would be some kind of charitable home. At least we wouldn't have imposed on our daughter that way."

"We certainly wouldn't want a place in a residential home but I do agree with having sheltered housing and things like that located as part of the local black community. I'm not necessarily thinking that it has to be exclusively for black residents. But, what you have to realise is - it's very upsetting for families to think about what they do with old people. You just can't send them away to a home. That kind of thing is unheard of in Jamaica - it would be unthinkable to send the elderly relative away like that."

"There is one thing which I think we really do need - an Arthritis Home. But, it's such an expensive thing with having all the adaptations and staffing it. I don't think I'd ever want to live in a home like that for myself. But, it would be ideal for when you're just out of hospital because that's a very difficult time. If you could go somewhere like that for a while, it would give you the time to readjust and get yourself sorted out. I think a lot of people - especially the older ones - would find that very useful."

"The mortgage has been paid for a few years now. And, of course, with it being a bungalow I've got no snags."

There is a couple of little steps at the back door which the wheelchair can't do - but I can walk that little bit even when it's very bad"

(5. Financial needs)

"We've suffered financially after my mother had her strokes because I just haven't been able to work with having to look after her. I am trying to do something about that because I really would like to get back to work on something like a regular basis. I'm trying to get our Independent Living Fund put up so that we can get some more help, but I don't know if it's going to come through."

"I wouldn't say they (social services) haven't ever helped at all - that wouldn't be fair. But, there's always this thing about - if you've got any money of your own, you never get so much help. These days, there's always this means test which isn't really fair. It's as if you're getting penalised for trying to look after yourself - the more you do, the less help you get. It's not as if I've got all that much. I did work, so I've got a small pension on top of my old age pension - but it doesn't come to all that much - you need that little bit extra. Mind you, I'm lucky compared to a lot of people. Some of them hardly have anything at all - I just don't know how they manage."

"If you take the mobility allowance into account, then my finances have improved more than slightly. It really has been a great help, because I would never be able to afford to get about with mini cabs without it."

"I get the invalidity benefit and then, on top of that, I get a very small pension from my employers. When I first went there they didn't have a pension scheme. So, after they introduced one, I'd only paid in for a few years before I retired. It's quite small, but it does pay my electricity bills. Obviously, if I'd been able to work till I was 60 it would have been quite nice I expect. But, there we are."

"We have a private home help. We use the money we get from (local trade association). They're very good - they never question how we spend the money, but it's always there every year. When you've got two people in their 80's like us - and you're both disabled - there's lots of special things we want. So, that sort of money really helps because the government won't give me any more pension even though it's obvious I need it."

"I really enjoyed my job and, although it was getting more difficult and I was getting tired, I would have carried on for a bit longer. But, with my mobility being so bad, I had to get taxis to work and it was getting to the point where I was spending more on taxis than I was earning. So, it didn't really make much sense to carry on."

"If anything, I think I get too much (mobility allowance). I think they should have two grades because - people who are working - they get the same mobility allowance as I would, but they should get more than me. In fact, I spoke to our local MP about it at one time but he said it would cost too much to administer - just have it and enjoy it he said. So, what I do, I pay for my helper out of it because - the way I look at it - I'm releasing a home help for someone else and, it's to do with my disability that I have her so it's OK for me to pay out of that money. Quite honestly, I have too much for transport so I use it in that way. I mean, officially, you're not supposed to are you. Also, I save some of it because I think - well, you know, that will stop when I'm 80, so I'll have some to fall back on."

(6. Self-help groups)

"There's all sorts of little things you need to find out about. It would be good if there was someone you knew who you could just ring up to see if they've got any ideas. It doesn't have to be a group where you actually meet once a week or something like that - just a group of people who know each other. It's like, after I had my tumour, I've always kept in touch with the woman who was in the neighbouring bed. If she has had more trouble, she's always got in contact with me and I talk to her. They also have a meeting once a month over at the hospital. Now, I don't often go to it because of getting there and getting back. But, I still know what's going on. It's like being part of an army isn't it. You know, if anybody is ill or anything, you wish them well and rally round. That's all part of the fight against it. And, if you've got any questions, you can always take them to the group. The nurses at the hospital are involved as well and you can always ask them. They'll always try and answer your questions instead of saying - oh well, we don't want to be bothered with that. It's much better that

they tell you what they know. Whether it's good or bad, you need to know. After all, it is your own body - if you don't take the interest, who will. It's like when I was in hospital for that year, I used to pretend that I was asleep sometimes when the doctors came round. But, I still never heard anything - that was the usual attitude, just say nothing. Mind you, the physios and the nurses tend to be a bit more talkative. But, the main thing is that people help each other. When I was in hospital everybody helped everybody else. There was a woman who came in 3 or 4 days after I had my op and she was in a terrible state of shock. Of course, we knew what was coming because we'd had it. So, I told her to come over and sit on the edge of my bed. I even held her hand and we talked about nothing in particular until it was time for her to have her pre-med injection. Then, I said to her - now, tomorrow you'll be walking about and you'll be fine. She didn't believe me then, but she did the next day. So, that was how we used to see each other through it."

"I feel very isolated. It would be good to have more organisations or some kind of local group - people with similar experiences so you don't have this feeling that it's just you. In a way, it would be good to know that other people have the same kind of problems and, in any case, I think there's more chance of doing something about it if you join together."

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 Arthritis Care 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

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 | 2 | 17 | 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 |
| TOTALS | | 130 | 194 | 324 | 45 | 80 | 125 |

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

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)

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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

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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

`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:-

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