

# **AGEING WITH PARKINSON'S DISEASE**

**Briefing paper prepared for  
Parkinson's Disease Society**

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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, Parkinson's 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 Parkinson's Disease Society who have contributed to the project. A total of 14 people who are ageing with Parkinson's Disease have participated following a request for volunteers sent to members who were known to have been disabled for 20 years or more. 6 of these (3 men and 3 women) have also participated in the follow-up interviews. The average age of this group is 71; they have been disabled for between 20 and 27 years, with the average being 22 years.

Following an overview of some of the main background issues to ageing with disability, the views of people with long-term Parkinson's Disease 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 Parkinson's Disease Society and others. The briefing paper is organised around the following topics:-

- # Concern about ageing and the need for research;
- # The experience of ageing with Parkinson's Disease;
- # 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 Parkinson's Disease 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 Parkinson's Disease 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 Parkinson's Disease Society to take this further and incorporate members concerns about ageing into their own work.

### CONCERN ABOUT AGEING (Quotes)

*"I have a very mild Parkinson which the medics appear to have under control. I am approaching my 70th birthday - slowly and I am now retired. I am still in touch with friends and colleagues and we do discuss ageing and quality of life. So, I am wondering how I might be able to contribute to your research."*

*"How lovely to hear that people are interested in Parkinson's. My husband has suffered with Parkinson's Disease for 20 years. He is getting worse - he knows this and gets depressed but, up to now, I have talked him out of it. He is 79 and I have reached 75. Nobody seems to understand - nobody seems to care. You have to live with it to understand it."*

*"I would very much welcome a personal interview which might be of great assistance to me too."*

*"We live in an old house with the loo upstairs, so you can guess it's me who pushes him (husband) up there. He cannot use a bottle or a commode. He just freezes up and gets worked up. We have been told by the doctor to get on one floor but I am still waiting for the council to find us one. I am determined that my husband stays with me. He is not a man who would ask for anything and is no good without me. I liquidise all soups and vegetables because he finds swallowing difficult. Pain in his knees is dreadful so I rub cream and that helps. I find that he is no good until about 5 o'clock in the afternoon and then he seems reasonable until next morning. He doesn't sleep in a bed but finds a chair better. I find the doctors don't seem to understand it but occasionally we see (the consultant) if we are lucky at the Royal Surrey County twice a year. He does understand it. My husband did ask him if he could have the operation but he refused because he said they don't know enough about it. Any stress is bad for him so he has to live a very quiet life for my sake. We are quite willing to be volunteers to help you if this can help other people to come to terms with it - we would be very pleased to help. I am so scared if we move into a sheltered flat that my husband will be put away. I asked for a bungalow so I could still look after him but we have been refused. After being married for 55 years I should understand him, and I do. But nobody else seems to, so I plod on - hoping."*

## THE EXPERIENCE OF AGEING WITH PARKINSON'S DISEASE

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

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

Some of the main issues identified are summarised below.

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

\* At the same time, several people felt that they were so used to dealing with problems like physical pain that they did not have much doubt about being able to cope with any additional problems they might face when they were older.

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

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

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

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

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

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

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

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

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

## **THE EXPERIENCE OF AGEING WITH PARKINSON'S DISEASE (Quotes)**

*"Society, by which I mean adolescents of 50 or younger - which is how I perceive it - seems to have a lot of difficulty coping with ageing. Our culture discourages us from talking about something which involves everyone. Take dying, for example. We have bereavement counselling, but not bereavement preparation. It's as if we're not supposed to think about it - but you do, you need to. It's not just an emotional thing - there's practical considerations as well."*

*"One of the biggest problems with Parkinson's disease is writing. I found it increasingly difficult to write and it's got to the point now where I can hardly write at all. I start off, write 2 or 3 words, and your writing just gets smaller and smaller until you've just got a straight line. That is a real problem because, when you can't communicate by writing, you become isolated from the rest of the world."*

*"I've got what they call benign Parkinson's, so it's moving only very slowly. But it has gradually got worse. With me, it's the inability to write or type that's the most frustrating thing. It makes me very angry and, of course, with Parkinson's being so closely tied to stress, it's a vicious circle. The angrier I get, the more stressful I become and I can't do anything at all. I just have to rest up - but that just makes me even more frustrated."*

*"I am 67 years old and have been retired for the last 5 years. Fortunately the disease has progressed slowly and, despite various handicaps, I am still pretty active."*

*"I retired early because of all the stress more than anything else. Physically, it had been getting worse from the age of around 40 to 60 but I'm much more bothered by tension and anxiety than physical things now. That's the thing with Parkinson's - it is mental as well as physical. I was getting much more anxious and stressful and I couldn't really do my job properly by that time. But, when I retired things didn't get very much better because it didn't feel right not working. I felt as though I was illegitimate in a way because I was retired, but I wasn't supposed to be. Now that I've actually reached the age of 65 I feel much better about it."*

*"The difficulty we've had organising help has been frustrating. But, apart from that, I think I am quite happy with the quality of our life. Even if the Parkinson's is deteriorating, you get used to that. So, I wouldn't say that I was particularly dissatisfied - sometimes yes, sometimes no."*

*"Before we go any further, I should say to you that - although I'm telling you all this - I don't want to give the impression that my life has been all bad, it hasn't been bad at all actually. Really, I've had lots of good times and it (Parkinson's Disease) had never been all that much of a problem until the last few years. I hardly had a day off work all my life."*

*"At first, they (doctors) thought I had Multiple Sclerosis - so did I for a while. So, they weren't really in a position to tell me very much about what to expect because they weren't sure exactly what was wrong with me. Anyway, I was in hospital for about 4.1/2 years and then I came out, and I have not worked since then."*

*"It's been a bloody bore quite honestly (retirement). That's mainly because, although I have a lot of mental energy, I can't do things that I want to. It's been really frustrating. When I first retired, I wanted to get involved in the local community. I was on a couple of committees (local council) and I was quite active for a while. But, it didn't last. I couldn't behave myself properly at meetings and things like that because I didn't have the energy to cope and I felt stupid because I couldn't communicate what I was thinking properly. Mind you, although I didn't keep it up myself, I do think it's a very good idea for all older people to get involved in the community. But, a lot more has to be done to encourage them. We really need to push the idea of elder citizenship because there is a lot of experience there which could be useful to people. But, all these agencies who could use that kind of help need to be more positive in their approach. You have to do more than just say - we want to use you. I'm not really sure if it applies the same way to everyone though. When you look at some of these agencies like Oxfam or U3A (University of the Third Age) - they don't really need it, because they've got people already. The other thing is that, unfortunately, a lot of this tends to be orientated towards the middle classes. What you need to look at is the older person who doesn't have the advantage of education. I know that is the case with the University of the Third Age for example. They don't really seem to want to have working class people involved. Certainly, they don't do very much to encourage them."*

*"I did retire a year early. I'd been thinking about it anyway and - with the Parkinson's - that just made it more certain. It had only been diagnosed the year before although it was showing up before then - I just didn't know*

*what it was. I'd been getting very unsteady and the main thing I noticed was that I was finding it very difficult to write a lot of the time. I suppose I just thought that whatever it was would go away."*

## 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 Parkinson's Disease. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and Parkinson's Disease 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 Parkinson's Disease, 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 Parkinson's Disease is given in Table 1 below; those reported by other groups of older disabled people are also shown for comparative purposes.

\* There was little difference between the problems reported by older people with Parkinson's Disease compared to other groups in the study. The main exceptions to this were the higher prevalence of speech/communication problems and spasms, and the absence of any coronary disease. However, given the small numbers involved, it is not possible to draw any definite conclusions from these findings.

\* 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 Parkinson's Disease 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)

*"My main disability is my legs and feet and to a lesser extent, in my hands. I can walk only very short distances and very slowly, and I find writing a bit difficult."*

*"With my Parkinson's, it goes in phases more than slowly. It's always been there, but you have good days and bad days, although, I suppose it has gradually got worse."*

*Husband: "Over the years she's deteriorated and then got better, and then deteriorated and then got better again. I think that, mentally, her condition has definitely improved but her balance and mobility has continued to deteriorate. In fact, it really is purely the balance which is the disabling factor in her Parkinson's."*

*"Yes - I get off spells, but the off spells seem to get worse each time. Although, there are still some days where you seem to be better. The balance does cause the most trouble - definitely. But, my speech has got worse and then there is this shaking, as you can see - that's only come on more recently. But, there is a whole list I could give you. My circulation has got very bad in the last few years and, although I lost a lot of weight when I was ill, I have gained a lot of weight since then and, of course, that only makes the problem with my mobility even worse because he (husband) finds it harder to lift me. Then, in just the last year, I have had a mastectomy and I also have very bad arthritis in my shoulder."*

*"Well, I think it's usually clear what's to do with Parkinson's and what might just be ageing. But, with the arthritis, I've had that because I fractured my shoulder after a fall and the arthritis only started after that. And, I have only been falling because of my balance - and that is caused by the progress of my Parkinson's. So, I think that's pretty clear."*

*"With something like Multiple Sclerosis, you do get remissions - but they can last for weeks or months - isn't that right? With Parkinson's Disease, it is on-off, but the on-off is virtually 2 hours at a time. That's what makes life so difficult."*

*"With me, the progression has been very gradual but it has definitely got worse as I've got older. It's difficult to*

*say whether or not that would have happened anyway. Certainly I would have been less mobile whether I had Parkinson's or not. But, I do think that a lot of it is because of the Parkinson's disease because I get these aches in my back and they've definitely got worse. Frustration is the biggest problem really because I'm not as mobile as I should be at this age - that's how I feel about it anyway."*

*"I do have a rowing machine which has always been very beneficial in combatting the aches and pains. But, because I tend to fall over much more than I used to these days, I'm quite frightened of using it too often - I'm always worried about falling onto it."*

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

Proportion reporting problem/change (%)	PD and other nervous system	Total sample
Decreasing agility/mobility	56	51
Difficulties with walking	37	40
Weight gain/loss	30	21
Changes in energy levels	26	27
Increased pain	22	27
Problems with vision	18	22
Problems with shoulders, arms or hands	18	18
Arthritis/Rheumatic problems	11	29
Speech/communication problems	11	5
Drug dependency/side effects	11	12
Asthma/breathing problems	11	10
Problems with hearing	11	6
Spasms/spasticity	11	5
Problems with circulation	7	12
Respiratory problems	7	11
Problems with transfers/turns	7	7
Bladder or kidney infections	7	7
Edema (swelling of joints/limbs)	7	4
Balance/co-ordination	7	4
Incontinence	7	3
Fractures/dislocations	4	9
High/low blood pressure	4	7
Limb deformity	4	7

**Table 1 Cont...**

Proportion reporting problem/change (%)	PD and other nervous system	Total sample
Contractures/muscle wastage	4	6
Stroke(s)	4	5
Viral infections	4	3
Scoliosis	4	2
Muscular atrophy	0	3
Thyroid problems	0	3
Brittle bones (osteoporosis)	0	5
Heart problems/angina	0	12
Spondylosis	0	4
Ulcers	0	2
Headaches/dizzy spells	0	2
Pressure sores	0	1
Epilepsy	0	1
Other(s)	15	13

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

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

\* Some people complained about the lack of specialist clinics for people with Parkinson's Disease. 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 Parkinson's Disease, 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 Parkinson's Disease, and very little understanding about the long-term effects of Parkinson's Disease 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 Parkinson's Disease; 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)

*"You have to remember that I was used to relying on doctors right from my youth. That's a very formative stage of life and so I grew up with the idea that doctors look after me. Even when I was in my 30's and could think about it, I was still looking for them to look after me. So, I was very much relying on the medical establishment. It didn't work, so I've developed a healthy cynicism. But, not just to establishment medicine, but all forms of medicine - the herbal remedies, acupuncture, and all the rest."*

*"When I was first diagnosed, they said there would be a slow deterioration - so I was expecting that. As far as treatment goes, I've had a slowly increasing dose of Madapar. That hasn't worked exactly according to plan. It was relieved at first, but then it catches up with you again. So, you have to keep increasing the dose - but you can only go so far with that. The other thing is that, Madapar has a depressing effect so, of course, that means taking more drugs to counter that, so you're building up the dosages again. On top of that, I've got bronchial asthma and I have to take medication for that as well - I've always had that though since I was a child, so there's not a lot that can be done. I'm alright apart from that really."*

*Husband: "I think the biggest landmark was probably in 1970 when Levodopa came in. She took it for 6 years and, right from the beginning, she did experience a major improvement mentally and physically, with her mobility. You could see the change after only 2.1/2 weeks of taking it. So, even though there has been deterioration later on, it did make a definite improvement to the quality of life. The only problem was that she had to take so many tablets. It wasn't just the Levodopa - there's the Amantadine and all the others. They all had to be kept separate so you knew what was what - that was bad enough. But, the medication had to start at 6 in the morning so it was all a bit of a job. But then, a little while ago - quite out of the blue, they changed the dosage from 15 milligrams to 40 milligrams so that means fewer tablets which is much easier to manage - it was a nightmare before. But, we get the medication sent by post and I just happened to notice that they'd changed the dosages - nobody had said anything about it. I tried to get the consultant on the phone, but he*

*was unavailable for 10 days. I think that, really, he should have discussed it with us first but - to be fair - he did apologise afterwards."*

*"I do want to tell you about going into hospital. When I went in, I had a very upsetting experience. The staff in the hospitals don't really seem to make very much allowance if you have some kind of disability. With me - but, I'm sure it's the same for a lot of people - I can't just go along to the toilet when I need to go. I need to be helped along, because I can't walk on my own. But, when I asked the nurse if she would take me, she said - you know, you can do things if you really try. That wasn't really very nice was it? Actually, another one more or less told me to wet the bed. I don't think they should treat you like that in a hospital."*

*"The medical profession don't really pay enough attention to people who are getting older. It's not quite so bad with something like Parkinson's disease, because there's still enough there to keep them interested. But with more general problems to do with ageing - I don't think they're very interested. With my back, I went to see the consultant at the (general) hospital. He said - I don't think there's very much I can do about that, but maybe you ought to go and see an osteopath. But, even then, the osteopath just said - it's something you just have to live with. They don't seem to be interested in investigating these kinds of problems. They just give you tablets and try to get rid of you. But, surely, this is very short sighted because I'm sure it would be cheaper in the long run if they tried to get to the nub of the problem right from the beginning."*

*"The check-ups used to be every 4 months, but now they're every 6 months. I don't think it is enough really - 3 times a year would be more adequate. But, I think they would probably see you if you called though."*

*"I go for a check-up once a year now. That is enough for me - it's ok, because he (specialist) is always contactable inbetween check-ups. I do think you could get much better information from the consultants though. You go for a check-up, but they only spend 10 minutes with you. They don't have the time for you, but I don't see how you can sort out very much in 10 minutes. There should be more one to one consultations - especially for people with something like Parkinson's because - with me anyway - I need to take my time so I can explain what's been happening. If I have to rush, I just get anxious and I can't explain myself properly. It's quite frustrating. My GP is very good, but I don't go to him for anything to do with Parkinson's disease - I leave that for the visits to the specialist."*

*"I got a bit disillusioned with the service from the hospitals but, perhaps they are trying to improve things now. I can't really say for myself, because I haven't been under the NHS for 5 years now."*

*"Our doctor does usually call to see me fairly regularly. But recently, we didn't have any contact for about 6 months. He always comes here because I can't go to the surgery - getting on and off a couch in the surgery is just too difficult, but we can manage at home."*

*"What I do find very good is to have a regular massage. That relaxes the body and, because of that, it reduces the tension. It's an expensive business though. It costs about £10-£15 a go, and it must be once a week otherwise there's not much point. But doctors won't accept that it's really a form of medication, so you don't have any choice except to go private. You find the same sort of thing with physiotherapy it's not generally available under the NHS. But, they are treatment really because it's all to do with maintaining your health. It's not an optional extra - it should really be funded. Apart from that (massage) I don't do all that much. I did go and see an acupuncturist about my back. That was very good. The pain went on the spot - although, obviously, it does come back again later on. I try to use as little medication as possible. You don't really know what is going on inside your body so, without too much medication, you do feel more in control."*

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

Like many other groups within the ageing population, people with long-term Parkinson's Disease 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 Parkinson's Disease 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 Parkinson's Disease Society and other voluntary organisations to act as 'information brokers'.

\* Some older people with Parkinson's Disease (particularly women) are themselves giving personal support to other family members (who may also be disabled). This is always likely to become more difficult over time - even without the additional problems which may be associated with ageing with a disability. Some people have also highlighted a need for practical support to families and back-up for informal helpers; several people are concerned about the additional strains being placed on their families by the lack of such support.

\* Some people highlighted various problems relating to information about, and eligibility for, disability benefits. There appears to be a lack of accessible advice on benefits and it is quite likely that some members are not receiving benefits to which they may be entitled. Obviously, this is an area where additional support and information could be given to members by Parkinson's Disease Society.

\* 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 Parkinson's Disease 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 Parkinson's Disease 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 Parkinson's Disease Society 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 live alone since my wife died 3 years ago and have no living relatives. I have a flat in this McCarthy and Stone establishment where, of course, no nursing care is provided. I am able to manage as I am at present, but if I get much worse my fear is that I will have to go into some sort of nursing home."*

*HUSBAND: "The biggest change for us practically has been that I had to give up work to look after my wife. She had been falling a lot and it was obviously getting dangerous because she was not always able to summon any help. So, 7 years ago I stopped work so that I could be here all the time. Since then, the troubles we've had organising the help - I can't tell you - it's been a full time job. Up to January last year we had a district nurse coming once a week. I said to our GP - I'm sorry, but we just cannot cope with the nurse only coming in once a week. So, she said that she would get a health visitor to call - which she did. But, all they could offer was an unqualified nurse - there wasn't any assessment of (my wife's) requirements or anything like that. Still, it was better than nothing - and, she did come in every day during the week. Now, that lasted until October but then she had a car accident so that put an end to it. We went back to the health visitor and she organised somebody else - a woman who worked at our local day centre. But, she was no use - she didn't know anything about Parkinson's disease and she said that they could only offer one shower a week in the way of help. Obviously, I said - I'm sorry, but that's just not good enough. So, that's when we started with this private care agency and the situation has been much much better since then. For a start, we wanted someone to come in at 8 instead of 8.30, which they were able to do. So, now, she comes from 8 to 9.30 every morning. It took a bit of organising at first, because we'd already been waiting for 3 weeks since the car accident. But they did start eventually and it has been an absolute godsend because I can go out now. But, of course, it is at a price. All of that - with the home help as well - it's costing us nearly £50 a week, and it can be quite a bit more if we have to pay for overtime in the evenings or on a Saturday. And, that's only for a nursing auxiliary - a fully qualified nurse, they charge a higher rate for that. It is a good service but I don't see how most people would be able to afford it. We can only manage because I'm fortunate enough to have a decent pension from my job - it's really far too expensive for the majority of pensioners I would have thought."*

*Researcher: Would you like to have somebody from the agency in the evenings and at weekends as well - if you could afford it?*

*HUSBAND: "Well, yes - that would be marvellous - if you had the money. But, you see, they charge £4.84 plus VAT and mileage and that's for Mondays to Fridays. At night times it goes up. Hang on, I'll give you the figures - at night, they charge £5.98. At weekends, it goes up again - £6.42. But, if you want someone to come out on a bank holiday, then they'll charge you £10.36 for that. And, as I say, that's only for an auxiliary. Now, you may well want to give them the overtime if you're on holiday, or if you are ill - but we can't afford to do that. Basically, it means I can't afford to be ill. But, what do people do about bank holidays when they charge so much - do they think that people don't get ill on bank holidays?"*

*"She (auxiliary) only gets £3.50 out of the commission - she told me that. So, they do make quite a profit. It certainly seems to be a growing area. This particular agency started up here 2.1/2 years ago with 20 nurses and they now have 200 on their books, although only 50 of those are working full time. That gives you some idea of how much it's growing."*

*"I do miss being able to have a bath. What I really need is an electric hoist because - I can't sit in the bath because of my balance, with a hoist I could sort of suspend myself in the water. We tried to get some help before we had the shower put in but, like my husband was saying, the district nurses could only promise to come once a week. I didn't think that was very good - I'm not making a great demand on the world, it's not too much to ask to be able to have a bath."*

*Carer: "That really did make me angry at the time. Because, when we first asked if we could get any help - they refused because she said she wasn't bad enough. It was only after I had a go at our doctor that they offered to*

*come once a week. But then, even though her mobility had clearly got worse when we asked again 9 months later, they still said they couldn't do any more. They could see that she was a lot worse, but it didn't seem to make any difference."*

*"The nurse who comes from the agency gets me out of bed and helps me to get dressed. If my husband is busy, she may help to prepare the breakfast some days and then she helps with feeding me because I can't use my hands very well. She does help with getting me onto the toilet. But, that's not always easy because everybody does it (ie. lifts) differently. It's very difficult when you have different people doing it."*

*"What I really need is to have someone here 24 hours a day. When the nurse or the home help aren't here, he (my husband) has to do everything. It's not that I always have to have someone helping me - but I do have to have someone here all the time."*

*"We'd love to have someone for longer but we can't afford it - and we're quite well off compared to a lot of pensioners. Ideally, we'd have to have 24 hour care - I can't be left alone at night."*

*Carer: "That's the thing isn't it. If I wanted to go on holiday for a week and we had to get 24 hour care for (my wife) - well, with the arrangements we have now, that's going to cost me about £700 for one week."*

*"What I really need right now is to have someone to come in for one extra day a week and one of the days at the weekend. It would be nice for someone to come on the occasional evening and stay the night as well - then my husband would be able to go out more."*

*"It would be better to have just one person on a regular basis, but what do you do when they can't come? I think that would be a big worry. So, you'd have to have someone else as well - maybe even 2 people - to cover for them. I think employing someone ourselves would be better but, what do you do if they're not medically qualified? I mean, how about things like injections - would they be qualified to do that?"*

*Carer: "I suppose it would be possible to train them yourself so that they get used to your routine - I can see that. But, if they're not properly trained for nursing, you might worry about there being an accident - it's not straight forward is it? But, there's certainly nothing to lose if we look into it. I certainly had no idea that people were employing their own helpers - I think it's something we would definitely want to look into."*

*"With the people we have now - the nurse and the home help - they're both very reliable. They do different things which, I suppose, if you had just one person, you could organise them so that you didn't have to have different people. But, I am reasonably happy with the arrangement we have now - they're both very good in their own ways."*

*Carer: "The attendance allowance (higher rate) on its own is nowhere near enough to cover the charges from the care agency. It's only with having the mobility allowance and my superannuation which makes it possible. But, even then, we still can't afford enough hours. I don't know what people who are just getting a state pension and benefits do. It's impossible - all you can do really, is barely survive. But, it's not right. You should get more help financially when you need it because - as we are - we're saving the country money, and if you think of all the years I've been looking after (my wife), they would never pay back all that money we've saved for the health services."*

*"Our home help lives just around the corner. She does occasionally help out in emergencies and her husband has been very helpful as well. He helps with little repairs and things like that, because I'm not very good with technical matters. But, they have their own family to look after, so I couldn't really expect them to do any more."*

*"When you can't dress yourself anymore, or you need any kind of physical help in that way, you're in care - whether you're in a home or anywhere else. As far as I can tell, having people go into people's homes to do that sort of thing - you're basically just providing a hospital facility, except that you're providing it in everybody's home at the same time. I don't know that having the money to employ your own helpers instead is really the answer. You've got all the responsibility for their salaries and all that sort of thing, which is the last thing you want."*

*"That (ie. on-call support) would be much better. I can see how it would be less institutionalised, but I would*

*have thought it would be very expensive way of organising things I don't know if it's a realistic option."*

*"One thing which I think is very much needed is some kind of alarm you could wear round your neck - especially if you live on your own. It's like with my Parkinson's, some times you just freeze and you simply cannot move - even to get to a telephone. It would be comforting to know that you had that kind of safeguard, just in case."*

*"It's very important for me to be able to write. It's not just that I still like to write (poetry) when I feel up to it. It's so frustrating when you get a letter and you can't answer for yourself - you have to get someone to write for you. It might just be a simple question which needs answering and I can't do it. What I would really like is to have a secretary, but I can't afford that. Anyway, with a secretary, I'd have to dictate and I'm no good really unless I can see what I've written in front of me. The only other possibility is to use one of these word processors, but I'm not sure if I'd be able to manage the keyboard. I don't really want to spend that kind of money unless I was sure I'd be able to use it. There are some courses you can go on to try it out - but I'm not really sure if that's the answer for me."*

*"The home help we employ is marvellous really. We used to have a council home help. They were so irregular - you never knew what time she was going to come, or even if she would come at all. She always used to come at different times - interrupting lunch and things like that. She'd say - I'll see you next week - but you never knew for sure if you would. Then, when she did come in, it was only for 2 hours a week in any case. Eventually, the home help organiser rang one day and said that she wouldn't be coming in because they were short of staff. We were so fed up by that time that I just said - well, don't bother coming back at all."*

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

*"It's not always easy to find out about getting equipment, or where to go for help. I haven't had very much experience of this personally - only when I was trying to get a shower unit. We managed to solve that one in the end but, there again, that was only through talking to someone else at our local Parkinson's group."*

*"We had the shower and the hand rails supplied by the council and they met 85% of the cost. We were very pleased about that - it has been a great help. But, we could still really do with a hoist as well. I have tried, but we didn't have so much luck there. They asked me if we'd had a grant before. I said - well, you'll look it up and find out anyway, so I may as well tell you that we have. When I said that, she said - oh, in that case, all I can do is put you on the waiting list and it will be at least 6 months before we can consider it. I was a bit taken aback at that, but there wasn't much I could do about it. It's been over a year now but we still haven't heard anything - I suppose they won't take any action unless I get on to them. We have thought about trying to get one for ourselves - although, it would have to wait because we can't really afford it just at the moment. But, I don't really know where you go to find out about these things."*

*"The other thing we looked into was getting one of these Aidcall set-ups. We get possibly have had one actually, but it wouldn't really have been suitable because she (my wife) wouldn't be able to reach the alarm if she fell - so it wouldn't really work. We did think about a cordless phone but, again, her dexterity is not all that good and it would be difficult for her to dial the numbers."*

*"We moved here (to a bungalow) 5 years ago. I had started to develop a fear of going up and down the stairs by then so - thinking ahead - it seemed like the best thing was to move to somewhere without stairs. So, now, I don't have to worry about falling or getting stuck halfway up the stairs. But, if people are living in a house, then I think you should have a lift because so many older people do have a lot of difficulties with the stairs."*

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

*"Transport is getting increasingly difficult. Physically, I get so tired and it would be good to have some kind of transport for longer journeys. Driving is out - I gave up driving quite a few years ago and even buses are quite difficult sometimes because I'm so unsteady on my feet. I've fallen off a bus before now. Our family is quite removed geographically - we don't want to be a burden on them anyway. They do visit, but it would be nice if we could visit them. So, transport - other than public transport, which is a hazard if you're handicapped - that's something we definitely could use. That's probably the most important thing of all - some kind of facility to enable us to make longer journeys. A courtesy bus of some sort maybe."*

*"The trouble is that, whatever you want, you have to deal with institutionalised attitudes as well as practical difficulties. I'll give you an example. When you go to the hospital - if you need transport it's a volunteer service they have here. It's very good, but it is a volunteer service so it's not guaranteed. Now, it's been threatened because the government are introducing taxes on travelling expenses, so a lot of the drivers have stopped."*

*"Transport is obviously a problem. I can hardly go anywhere on foot now. I do go up the road to get a paper and things like that, because I know it's good for me to try and keep mobile. But, it's only short distances. Even that can wear me out, so I can't take on any more. It's much worse if you live in an area like this. There's no buses and the nearest station is about 3 or 4 miles away - so you are pretty much cut off. Maybe it wouldn't be so bad if you lived in town - although, you do have other kinds of problems with all the crowds and that sort of thing. We do manage to get out, but we have to use taxis for most journeys and, obviously, that can work out rather expensive."*

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

*"Our culture tells us - stand on your own feet, be responsible, and don't be a burden to others. Well, I am standing on my own feet, I'm responsible for deciding to stay alive, and I make it easy for others by trying not to be a burden on our families or anyone else. But society makes this very difficult because I can't find a home that I can afford to live in. You see, we've been looking for a home in some kind of sheltered accommodation for a while now. I fall about quite a lot these days and I am really a bit of a hazard to myself as well as to other people. My wife had a stroke about 5 years ago as well, so neither of us are particularly fit. There are lots of*

homes - especially round here (south coast), but we can't afford the sort of prices the private homes are charging. It's a bit of a sham really because the government says we're supposed to have more choice but, if you can't afford it, there is no choice. Anyway, some of the ones we've looked at, I couldn't possibly live in them. They're homes for vegetables, not for old people. There are a couple which would be suitable. In fact, we are on the waiting list for one place and, hopefully, we might be able to get in there. The other, there is quite an amusing story about that. My wife is West Indian and I'm Jewish. She rang them up to enquire about places. She put on her best middle class accent and everything was going along until she mentioned that her husband was Jewish. Then, they said - oh no, we couldn't possibly help. Maybe she should have told them she was black as well - then they really would have had a fit, wouldn't they."

"We're not looking for nursing care as such. Basically, we just need the simple facilities - laundry, transport so we can get out, and a warden. A friend of mine is in one of these places where they have a graded set-up - flats with just a warden, flats with a warden and nurses coming in, and a home with full-time staff. That's seems to be quite a good idea because you've got everything you need if things go wrong or if one of you is left on your own. But, I don't think we'd actually need that much in the way of help."

"It's hard to find homes which are reasonably affordable. The place we've got our name down for is £265 a week. We'd only just about be able to afford that, even with both our pensions. So, I don't know what other people are expected to do - they won't be able to afford that. These places are registered charities but I'm not really sure if I understand how that works. They must be making a profit but they don't call it that - I think they just put up there own salaries."

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

"Financially, we're reasonably comfortable. That's because I was fortunate enough to have a good job and so I secured a decent pension for us to live on. I'm always saying this to people - you must do something about securing a pension, otherwise you won't be able to live any sort of life. Actually, we're probably better off now than when I was working - or at least, we would be if it were not for having to pay so much for care."

"The allowances you get are some help - but it's nowhere near enough. It's like when they told me I could have the Invalid Care Allowance. I thought - this is wonderful, it would be a great help. What they didn't tell me, of course, was that - because of my pension - I'd be taxed. So, they take it away again. It's always the same. We've saved and worked to look after ourselves but, the extra that you have - they take it away in tax. It's true - you are forced to be more sort of dependent. There's no reward for trying to be self-sufficient."

"I've never really been able to understand all the ins and outs of the tax you have to pay, and I had the same problem with trying to find out if there are any other allowances which we might be able to get some help with. I did here about this - Severe Disability Allowance I think it's called - where do you find out about that?"

#### **(6. General views on Parkinson's Disease Society)**

Carer: "The Parkinson's Disease society do have a welfare service for giving out information to members. But, when you reach our stage, you need something more than that. I mean, she (my wife) has lived far too long with Parkinson's to need any more information - it's help that she wants."

"I think that, perhaps, the organisation is not as good as it could be. There doesn't seem to be enough contact between head office and the local branches - not down here anyway. The last time I went with my sister - we couldn't even get in. The office was up 3 flights of stairs, so that wasn't very good. But, they do produce the newsletter which is excellent - I think it's probably one of the best from any of these kind of organisations. I don't know what else they should be doing - they only seem to be bothered about getting money in - I think that's their main priority at the moment."

"I have found that belonging to the local Parkinson's Disease Society has been a great help in terms of getting information - and advice as well sometimes. It's very useful as a forum for sharing ideas, and just being able to meet up with other people. I used to be very much against it. I didn't feel like I wanted to see lots of people with

*Parkinson's sitting around shaking and all that sort of thing. But, you adjust to the idea and I'm very glad that I did get involved now. I think it's very important to be able to share ideas and experiences - especially as there isn't really anywhere else you could go for that in any case."*

*"I think you get more out of belonging to a local group because, with a national organisation - even though they might be very good - you don't have the personal touch. You need to have a national organisation to co-ordinate things, but you also need the individual touch which you can only get if you have face to face contact with other people. The only problem is that, with all of these kinds of things, it really relies on one or two individuals having motivation to get a local group started. We're lucky in this area because we have 2 or 3 groups. But, you probably would need to have trained field officers or something like that - funded by the national office - so they can help to get other groups started. It's alright after that because, once they're established, groups tend to keep going by themselves - as long as there's enough people. It's getting started in the first place you really need to worry about."*

## THE NEXT STEP

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

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

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## Appendix A: Details of project participants

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### Breakdown of impairments (by gender)

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

## Appendix A: Details of project participants

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

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

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

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

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

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

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

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

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

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

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

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

Oliver, M. (1992) 'Societal responses to long-term disability', Chap. 20 in Whiteneck, G. et al Ageing with Spinal Cord Injury, New York: Demos Publications

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

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

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

### **Main project report**

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

ISBN 0 900822 04 X

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

### **Briefing papers**

## Appendix B: Dissemination materials produced

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

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

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

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

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

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

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

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

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

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