

# **AGEING WITH MULTIPLE SCLEROSIS**

**Briefing paper prepared for the  
Multiple Sclerosis Society**

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## ABOUT THE PROJECT

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

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

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

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

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

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

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

This briefing paper is based on information given by members of the Multiple Sclerosis Society who have contributed to the project. A total of 37 people who are ageing with MS have participated following a request for volunteers sent out to local branches. 17 of these have also participated in the follow-up interviews. The average age of this group is 64; they have been disabled for between 20 and 56 years, with the average being 32 years. 30 are women and 7 men.

Following an overview of some of the main background issues to ageing with disability, the views of people with MS on specific topics covered by the research are outlined. Each section contains a summary of the main issues raised and (where appropriate) the possible implications for the Multiple Sclerosis 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 Multiple Sclerosis;
- # 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 it's 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 MS 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 MS itself.

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

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

## THE EXPERIENCE OF AGEING WITH MULTIPLE SCLEROSIS

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 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 MULTIPLE SCLEROSIS (Quotes)

### (1. Early experiences)

*"They discovered I had it (Multiple Sclerosis) in 1983. They sent me to (a nursing home) and after that they just sent me from place to place. I was pushed around for 10 miserable years until I ended up here - that was about 5 years ago."*

*"I didn't know straight away. They (doctors) put you off - they don't want to tell you anything."*

*"When they find out at work, they wasn't any help at all. The manager turned round and said - 'It's MS, isn't it - there's not much we can do about that'. They didn't say anything about retraining, but they did say about giving me some job in the office. But, I never been any good at head work, so that didn't suit me all that well. I kept up 'til I was 60, then I packed it in"*

### (2. Later experiences)

*"I am now 68 years old and have had MS for the past 34 years. It first manifested itself when I was pregnant with my second child, a daughter. I was lucky enough to have a remission of 7 years after her birth. I'm also lucky enough to have a very caring and loving husband. My two children are also very caring and loving people. Perhaps because of this, and perhaps because of a lucky temperament, I have never suffered bouts of depression. I was also lucky enough to be able to work in a wheelchair for 13 years. I was a teacher. When I found it difficult to write, I gave up my work. I did voluntary work for some time after. Then, gradually the disease has worsened and I am now unable to use my hands and have to be fed and washed. My husband gave up his work to look after me. I now have to be washed, dressed and fed by him. He also lifts me onto the toilet and into bed. Age has affected me by an increase in incontinence. My bowels do not work as well as they should do now. A district nurse comes each day and checks my skin and anoints my rear and sometimes my heels with cream to avoid trouble. In the last few years my eyesight has deteriorated because of MS. I am now registered as partially blind and have much pleasure in listening to the huge selection of books supplied by RNIB. I was finding that I didn't sleep and purchased a Nimbus floatation mattress, which I find aids me to sleep throughout the night and so I do not have to wake my husband 3 or 4 times to move my position. On my regular yearly trips to the Royal Victoria Infirmary, I was first introduced to the mattress and have found it to be an invaluable aid. It cost a lot, but it is worth every penny. I am now being catheterised for a few days each month as fluid builds up. I have found that spasms in my bladder mean that I can't tolerate a catheter for too long."*

*"I was diagnosed as having multiple sclerosis 20 years ago, but I had been experiencing symptoms for a year or two previously. I deteriorated quite rapidly and this was partly due to the fact that in 1971 (2 years after onset) I had to have a mastectomy, followed by radiotherapy treatment. This resulted in damage to a nerve making it impossible for me to raise my left arm. By 1974 I was unable to walk unaided. I now have no use at all from the waist down. Eight years ago I had to be catheterised and have to have my bowels manually evacuated. I still have reasonable use in my right arm and hand. I regard myself as a 'burnt out case'. I may be wrong, but I might still lose my eyes and ears or speech, but on the whole my health is good."*

*"I've had MS for many years. I had my first wheelchair in 1965 when I was 54. I am 80 now. I used elbow crutches before then. I've had three bad illnesses but managed to get over them. When I'm better I am busy knitting dolls, reading and playing Canaster. Last Christmas I was in hospital for the holiday and stayed several weeks. I was very helpless and cannot get back to my usual strength. It's hard work getting around in my wheelchair and it's not very comfortable either. My husband died in 1959 and I think that was the cause of my illness."*

*"Personally, I think that, to see groups of MS sufferers together is most depressing. Normality with normal people - especially younger people - is vital. For me, it is important to remain as alert as one can and stimulated by people, activities, visits, leisure pursuits. Local churches and social groups, as well as official visits from social workers and medical professionals are also important."*

*"I don't think too much about MS really. It does lead to frustration sometimes - especially now I can't get about so much - but, what can you do?"*

*"I don't worry too much about the future. My MS may get worse, or it may stay the same - you don't know, so there's no point in worrying over it. I suppose the only thing that bothers me a little bit is, what would happen if I became incontinent - I don't think I'd be too pleased about that, obviously. But, there's no point worrying until it happens."*

*"That's the thing that does annoy me. When you think of the things you can't do anymore. You just don't have the energy - it's very frustrating."*

*"I've never really thought of my disability as being anything more than being a bit awkward - except, maybe, at the beginning because you don't really know what to expect then. Obviously, there are some difficulties, but it's no more than a slight aggravation. The only thing that does bother me a bit - especially now that I'm getting older - is if anything happened to my eyes. I'm an artist you see, so that really would be devastating for me."*

*"We are always so tired, so after 20 years - you're just completely knackered. Something like your survey is bound to be seen as pretty low priority."*

*"Having a disability can be good for you in some ways - it depends how you approach it. It makes you grow up as a person. You learn a lot about yourself and how to deal with life - as well as all the practical things, like being able to put up with a lot of pain. You learn how to deal with that sort of thing over the years."*

*"I wasn't all that worried about using a wheelchair. It made life easier in many ways. In fact, I felt I used to get much annoyed staggering about everywhere with my walking stick - that was much more frustrating."*

*"There are changes with ageing, yes. You need to be able to adjust - you mustn't hanker after the things you can't do. You just pace yourself differently and work around any problems. People are always surprised at how I cope. They say - you've only got MS. And, when I'm in bed and I'm totally flat out, they're always a little surprised. They say - what's wrong with you? Of course, most people only see me when I'm up and about, so they probably don't realise how it can get you down the rest of the time. But, I'm not complaining about that - you have to be positive."*

*"None, if anything I'm much less likely to worry about things than I used to be. When I was younger I used to bash about the place and get all het up but, you learn after a while that it's just wasting energy - so why bother. In any case, even though I've got this disability it's never been as bad as I thought it would be. I mean, after I first found out I wondered whether it was worth going on. I thought - what's the point. But, as you go on you find you can just get on with it and it doesn't have to be as bad all that it's made out to be. It's up to you really isn't it. Some people are always moaning - oh, I can't get to the shops very easily, or that sort of thing. But I always say - why worry. If you learn how to get rid of your impatience and life seems a lot easier."*

*"I'm about the third youngest here (78). I'm always talking about the old dears, but then I remember that I am one myself which is quite funny really. But when I look around and see how most of them are going on I don't think I'm doing too badly. Really I'm much more active than most of them here - that makes you feel younger in a way."*

*"It's probably true that - if you have been disabled for a long time - you have to look after yourself. Some of them here just seem to stop and wait for people to do things for them. I've always had to be fairly active. I worked part time till I was 60 in any case. But before that I had the house and family to look after so you need to keep going. It always amazes me how little some of the older ones do - they just sit around most of the time. Then they say - oh, I couldn't do what you do. It's always - you can do it because you're different. That annoys me actually. I'm not different at all - I'm perfectly normal - just a bit more physically handicapped that's all."*

## 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 MS. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and MS 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 MS, 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 MS 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 MS which should be highlighted for further investigation. For example, weight gain/weight loss, speech and communication problems, and spasms and spasticity were more likely to be reported by people with MS.
- \* On the other hand, there were some problems which have a lower prevalence, or are even non-existent amongst this group of people with MS. These include coronary disease, arthritis and rheumatic problems.
- \* 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 MS related conditions are often cumulative, and can have significant consequences for the quality of individual's lives. There are also implications for the provision of practical support which are discussed further below.

## PHYSICAL PROBLEMS ASSOCIATED WITH AGEING (Quotes)

*"I can't walk at all now - it's all I can do to get myself into the wheelchair, and I have to have help with that a lot more than what I used to. I do have the Zimmer, but I only really use that for standing - like when I'm getting dressed - I don't actually walk about with it. That's the only big change I can think of. So, I have to get more help than when I was younger and I hardly ever go out anymore - that does affect you like that. But, apart from that, I wouldn't say it's all that different - the MS has always been about the same so I've been lucky like that because I haven't had any of this going up and down like some of them get."*

*"I have put on a lot of weight, I must admit. But, the thing with that you see - it's a vicious circle. Because you're sitting around all day doing nothing, you do tend to put the weight on, but I can't do much to get rid of it."*

*"My eyes are going now. I've been almost blind in this eye for quite a few years now and, now, I've got cataracts in my good eye. So, that's a bit of a problem. They did say they could operate on it, but I don't want to risk it because, if anything goes wrong, I'm not going to be able to see at all - so I'm going to try and carry on like this. The only thing they did give me was this (magnifying glass). It's OK, but you can only use it close up for reading - it's not much good for anything else."*

*"With my MS, I've never been up and down like a lot of people I know. After about the first six months - I did deteriorate quite quickly at first - but after the first six months it levelled out and it's been more or less the same since. You do worry at first because you don't know how you're going to end up, but, touch wood, this is about as bad as it's going to get."*

*"Since I had the fall - I was in hospital for six months off and on - since then, I really can't walk at all. I can just about get to the bathroom on the frame, but that's definitely my limit."*

*"That's something that does get you when you're older. I have become slightly incontinent. You do need to go much more - I used to be able to hang on all day when I was younger but I usually manage to make it in time - I've just had one time when I had to lie in a wet bed, so it's not too bad."*

*"I've got rheumatoid arthritis in my hands and all up this shoulder. That can be very painful but the main*

*thing is that it means I can't really lift anything. I have to have everything made very light, otherwise I can't manage." (ie plates, cups etc)*

*"I'm much better - physically - than I was 20 years ago. But, each time you go down, you never quite get back up again. So, you need to pace yourself - that's very important. Obviously, you gradually get worn out with ageing. But, a lot of it is down to the way your mind works - if you think positive, it's much easier to cope with."*

*"I get very bad pain - but it's only in my feet, nowhere else. That's been in the last 5 or 6 years (14 years after onset). The main thing is it effects my walking. It's far too painful, so I can't do any sustained walking. The other thing is this problem with my arms and legs - the muscles are just going. That's been very recent - only in the last couple of years. My doctor says that, as far as he's concerned, there's nothing he can do about it - which is fair enough."*

*"When it (MS) was first diagnosed, they gave me ACTH. It worked wonders for a time, but the next time it didn't do a thing. I've tried it again on and off, but it's never really worked since the first time. What I have found though is that diet made a lot of difference. I investigated various allergies for myself and adjusted my diet. That's made all the difference - there's just no comparison. For a time, I could even walk quite well. Well, that didn't last but feeling better did and I've never felt that bad again since I changed my diet."*

*Husband: "She (my wife) had problems with her arms and hands - no co-ordination. That was when it started to get bad (10 years after onset). She'd been working up till then, but she had to stop because it was obviously too dangerous to carry on. Then after about 20 years, her legs gave out. So mobility has been the biggest change really. At first she was using a wheelchair just occasionally, but about 12 years ago it was getting to the point where she couldn't climb the stairs any more - she used to sort of crawl up, but she had a few nasty falls while I was out at work and that's why we moved here (bungalow)."*

*"I have got scoliosis. That's been over the last 10 years (ie. 12 years after onset), but I don't think it's connected to MS - I don't see how it could be really. Then, I have had a touch of angina in the last 18 months - I could have done without that."*

*"It (MS) has deteriorated - but only gradually. I think I've been lucky because I haven't had any trouble with my eyesight or any of that kind of thing. Actually, I'm totally unaffected from the waist up. It's just my mobility - I can't get about as well as I could - that's the only real change. But, it's difficult to know how much of that is because of the MS because I think age has a bearing on this as well."*

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

Proportion reporting problem/change (%)	MS 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
Contractures/muscle wastage	4	6
Stroke(s)	4	5

Proportion reporting problem/change (%)	MS and other nervous system	Total sample
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 MS 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 MS. 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 MS, 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 MS, and very little understanding about the long-term effects of MS 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 MS; 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.

## **HEALTH SERVICES/HEALTH CARE (Quotes)**

*"Although I was only told in 1979 that I have MS, I know my first attack was in 1958 a little while after the birth of my second child and from then on, over the years various things happened which to me were very unusual. On seeing various doctors, I usually had these symptoms passed off as different reasons. Then, after the age of 40 everything was blamed on - the change, my dear. I am now 65 and find life difficult, especially as my husband has severe arthritis and also blocked arteries."*

*"I'd been suffering very badly with migraines. In the end the doctor sent me to the neurologist at the National (Queens Square). That was in 1952 but it wasn't til about 1964 that they actually told me what it was I had (MS). They (doctors) never said an awful lot - there wasn't much information about any of it. I don't think they knew all that much about it yet in those days - they know a lot more now, but not then"*

*Wife: "That's right. The doctor said to me - 'we'd like to try an operation on his spine'. They wanted to see if they could get down to where the multiple sclerosis actually was - where it was affecting him the most. But, when I asked what his chances were he said - 'we don't really know - it could do the trick, or he might be in a wheelchair'. Well, we said no. I didn't tell him (husband) then, because he probably would have told them yes. But, you hear about people who have had these operations all the time, and they come out worse off than before - and, for what?"*

*"I did have check-ups with a specialist - at the National (Queens Square). I used to go every six months - more than that sometimes. Then they changed to every 12 months, and then a couple of years. But, now, I can't get there anyway because they stopped doing the ambulance. They used to come up and fetch me in the ambulance, but they can't do that anymore - they can't get through London you see. But, it's a waste of time me going anyway - they couldn't do anything for me now."*

*"I haven't seen a doctor for years. I never really wanted to bother with having any (check-ups) - I was too busy enjoying myself. I won't be doing any of that here, but I don't really care about that anyway."*

*"The medical care here (nursing home) is very very good. The doctor comes in to check on me very regularly but I always get hold of him whenever I need to. Someone would come out right away if necessary - I only have to call or ask someone to call them."*

*"It would be a great help for older patients if they could have a check-up every 6 months, or at least once a year. A lot of people don't want to go to their own doctor because they feel that they're just going to be put off. Fortunately, not all GP's are like that - mine certainly isn't. But, the GP isn't necessarily in the best position to give you a thorough check-up. I think that - for MS anyway - a neurological hospital would be the ideal set up. They're the best people. When I used to go to the National Hospital (for nervous diseases), you used to have a proper assessment and then they'd take you in if they thought it was necessary. I think that's definitely the best approach."*

*"I suppose I should go every 6 months. But, I don't like to go too near a doctor if I don't have to."*

*"When I went into hospital (for a colostomy), they had no idea about MS. I remember the nurse coming up to me and saying - we're going to give you your bath today. I said - oh no you don't, please will you wait until I'm ready. They looked after everything to do with the colostomy - that's what I went in for. But, the MS side of things wasn't considered at all. I do have a card with all my medical information on it - I always carry that with me - but how much notice do they take?"*

*"I can understand people worrying about going into hospital. Certainly, with MS, the doctors in most hospitals - I don't think they know very much about it at all. I know when I had my colostomy, that it was a bit of a step into the dark - I just put myself in God's hands when I went in there."*

*"I'm getting that I think I know myself better than most of the doctors. The last time I went into hospital - they wanted to give me anaesthetic. But, I know that it's no good for me, so I was able to tell them. You have to think of all these things because, like I say, they don't really understand."*

*"Our GP - he's very thoughtful. He's always asking us if there's anything we need and making sure we've got all the aids we're going to need and things like that. It's good, because he doesn't just wait for you to ask - he's always thinking ahead. We are very lucky with the help we get. I know it's not always like that because you hear about all the problems people have had down the disabled club, but we've been lucky."*

*"My GP is very good. It's comforting to know that he'll always listen if I've got a problem. Actually, he comes to the house every 3 weeks. I don't ask him to - but it's very reassuring all the same. He also arranged for the district nurse to call. She comes every 2 weeks to give me my injection."*

*"He's OK. But, I made the wrong choice - I should have picked the woman doctor. But, you don't really like to change do you - they might think you were being awkward."*

*"There's not very much I can say about him (GP) because I hardly ever see him. He's very good though and, being quite near, it's OK if I ever did need him. He always says - call me if you need me. You always know he's there."*

*"I used to go to the general hospital (Southampton) once a year, but the last time they didn't do very much. They just got me to walk a little and asked me how I was. A few years ago they used to do a bit more but there's always been a problem with getting feedback from the doctors. It's always been left to me to find out. They used to tell you a lot more but, now, you have to ask and if you don't, they don't tell you anything."*

*"I would probably go to the hospital more often for physio if they could fit me in. You have to be able to go quite regularly if it's going to be any good."*

*"I was a bit stuck when I went into hospital. They put me in plaster of course, but it was so heavy that I just couldn't do anything myself. I was completely incapacitated. What they'd done was, they used the heavy plaster - it was the wrong one. The specialist said - even a normal person couldn't lift that leg, you need the lightweight plaster. So it was all right after that. The treatment was really good apart from that. But I didn't like being put on a geriatric ward. They were all a bit gaga - it wasn't a lot of fun. There was a young chap who came in for a couple of nights - he was the only person I talked to really. They (family) brought my wheelchair in after a couple of weeks so I could get around and talk to other people - it wasn't so bad after that. The only thing that did annoy me was the way nurses would make you wait so long when they took you to the toilet. They just used to leave you hanging around there. I didn't like that."*

*"When the muscles in my arms and legs started going, the health visitor came to see me. She said - we might be able to get you a Roho cushion. I said - oh, what's that? So, she said she'd send me to see the doctor (at local ALAC). So, I went over there and he (doctor) said - why do you want a cushion? Do you have pressure sores? No, I can't possibly let you have one of those. He was very cold. I came out of there in tears. I think they could do much more in the way of being preventative. Without that cushion, I could well have got pressure sores later on. But, he didn't seem to think of that. In the end I did get a Roho from the local MS branch. They were very good - they gave me a spare wheelchair and a ripple mattress as well - which was a great help."*

*"I don't have any physiotherapy as such - only what I do myself. But, that is based on advice from the National Hospital. I don't really need to go to a hospital for physio - not on a regular basis anyway. What I would like though would be a refresher course every 2 or 3 months - just to see if there are any new ideas, or to think about any new things I could try - the rest is just commonsense. Ideally, I'd go to the National (hospital), but the travelling would be the problem there. Anyway, it depends on the physio. The last one I had was pretty useless - she knew nothing at all about MS."*

*"My health visitor arranged for me to have swimming sessions once a week at the local hospital. I was very lucky to get that because the public pool is too far for me to travel. I would really like to go once a day because I do feel so much better after being in the pool. But, really, it would be too much of an effort to do that just for a half hour session."*

*"I have been to the (general) hospital to see about having some physiotherapy. I haven't actually had any yet - I'm still on the waiting list. But, if it works, I would like to go on with it if they could show me some things I could do at home. Like I say, I have found that walking is getting more difficult. Sometimes, I can still manage with just a stick if I don't go too far. But, most of the time I have to use the frame for walking. I'm rather hoping that physiotherapy might be able to help with that - we'll just have to wait and see."*

*"If I want to go somewhere a long way off, I have a battery car but he (my husband) has to come with me to put it in the car. I don't think I actually need more help now, but it is getting a little bit more awkward to manage with things like that."*

*"I was going for physiotherapy once a month as well at the local hospital. It wasn't really enough, but it wouldn't be much benefit to me now in any case. They were trying to put me on parallel bars and things like that. Its a bit silly really at my age - it probably does more harm than good. There's no point trying to get me walking now, its too dangerous and - with all the effort - its not worth it. I'd only fall down and do myself an injury - I crashed my head through a glass door the last time."*

*Husband: "No, there's no real benefit but we wanted to keep going mainly just to support it so other people could go - so they didn't try and close it down altogether."*

*"I have pain killers - well, so called pain killers. I was really suffering - sleepless nights and everything - because of the pain. It was a deep ache almost all the time. But, I gave them up - when was it, about 3 years ago. It just wasn't any good - I was like a zombie most of the time. Before that, I had been going to the pain clinic at the local hospital. But, it didn't work - the doctor just gave me pain killers and injections. Then, they said - did I want to go to a day centre for some physiotherapy - that was a waste of time. After the pain clinic, I tried acupuncture. I saw an advert in the local paper for an acupuncturist. I asked him to come and see me, and he came about 6 times altogether. It really helped some of the time, but it was very expensive - ,20 a go. I couldn't really afford to keep paying that - although I would have done if I could. So, I went back to the pain clinic and then I discovered that the doctor there was already doing acupuncture on the NHS. I was amazed when I found that out. I said to him - why didn't you say? He said - why didn't you ask. So, now, I go there. It's not as often as I'd like - because their budget is limited - but, I don't have to pay anything. I go for 3 consecutive weeks and then there's an 8 week gap. I'd much prefer to go every week, but they couldn't do that. If it wasn't for that, I'd go private, but I can't afford that at ,20 a go."*

*"I am not personally affected by ageing. But, with carers - they get older and there is a need for both practical health and some compassion."*

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

Like many other groups within the ageing population, people with long-term MS 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 MS may need additional practical support in the form of assistance with transport; domestic help with cleaning and shopping; alarm calls (particularly for people living on their own); provision of mobility aids; district nursing services; day care facilities; and, in several cases, personal assistance.

\* A few people had, or were considering, making changes in their living arrangements and this most often meant moving to warden controlled sheltered accommodation; along with other groups of older people, however, there is often a problem in finding sheltered accommodation at an affordable price; also, the standard of back-up cover available is extremely variable. Some people were very concerned about the possibility of having to enter institutional care if they could not obtain appropriate support at home. Some also highlighted difficulties in obtaining information on alternative living options which may be available. While statutory agencies should be providing such information, they often fail to do this so there is a potential role for the Multiple Sclerosis Society and other voluntary organisations to act as 'information brokers'.

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

\* Some people highlighted various problems relating to information about, and eligibility for, disability benefits. There appears to be a lack of accessible advice on benefits and it is quite likely that some members are not receiving benefits to which they may be entitled. Obviously, this is an area where additional support and information could be given to members by the Multiple Sclerosis 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 MS 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 MS 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 their local MS groups on the other hand, had mostly found this to be very helpful.

\* There is also a clear need for organisations like the Multiple Sclerosis 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)**

*"My husband has had angina for some years, a situation which is not helped by having to lift me, although he still insists that he can. Obviously, I have to watch my weight. Until recently we went on holiday every year, but now my husband finds that the bathrooms in the hotel rooms are not particularly suitable for coping with a wheelchair bound person. As he has angina, no extra stress or strain is advisable. We are well aware that there are specially run homes for MS patients, but so far we are not very keen on a nursing home holiday. We have always liked to go on holiday by ourselves in a quiet place. We can still go occasionally, for a run in the car, but it means that my husband has to lift me in and out of the car. I am only frustrated at the help we receive from the Government being so mean. If I had to go into hospital it would cost much more money than my husband receives for Invalid Care Allowance."*

*"I live with my sister who is aged 76 and her husband. So, I expect I will have to go to a home to get help. At present I go into the local hospital for a fortnight and then home for a month. Thankyou for being interested in MS."*

*"It would be better if I could at least pick what time I go to bed. You don't have any say about things like that - you just wait your turn."*

*"I have to have help with having a bath. It's not too safe for me to try on my own and I can't use the shower they have here at all. I didn't need help with the bath when I was at home though, because I knew my way around my own bathroom, and there was a bit more space anyway."*

*"She (home care aid) does all my shopping. She makes a regular trip once a week when I give her the list. But if I ever need anything else she's always quite happy to get it when she's doing her own shopping. I just ring her up and she gets whatever it is next time she goes to the shops."*

*"I'm very pleased with the help from the home care people. You have to work with them and try and get on. They are very good like that - that way you get the most out of them."*

*"In a place like this you need to be able to look after yourself. They are all very helpful, but they don't really understand that everything takes longer. You need more time just to move about from one part of the room to another - every little thing just takes more effort."*

*"I manage to get myself out of bed and into the chair at the moment. I may well need more help with that later on, but I'm sure that they (home care aids) would be able to do that if I asked them. If I asked for more hours, I could get them but I would have to pay more of course - that would be the only problem. Although I've always been pretty good at managing my budget."*

*"I don't do very much once they've (District Nurses) got me in the chair, so there isn't much help I need after that. I might need a bit more help if I got any worse, but I'm alright at the moment."*

*"They (home care aid) come once a week to give me a bath. I would like to have them more often - especially seeing as I can't use the shower here. But, it's not really possible is it. They are so short staffed - if I had an extra day, that would more than likely mean some other poor soul going without. I don't think it would be fair at the moment."*

*"You know, when you got something like what I got, a lot of it is down to the kind of family you've got. I have been very lucky like that because of the wife and kids - they give me all the support I need. But, with a lot of the younger ones you see today - their wife or their husband might just walk off and leave them. I've seen it happen. So, if that happens, or when people don't have any family - it must be terrible to cope with."*

*Wife: "We all get on quite well here (neighbours), everyone is very friendly. But, we can't ask any of them to help if he falls or something. It's all old people in this block you see, and a lot of them are sort of invalided*

*themselves, so you can't ask them to do that sort of thing - they couldn't do it anyway."*

*"It's very important to have friends - they make all the difference in the world. With this being such a small village, nearly everybody knows everybody else. The local parson set up a CB radio link which goes round most of the village. It's funny, we have a role call every morning at 9.30 to check if everybody's alright, or if anybody needs anything so, it's very unlikely that I'd ever need to get any help from outside. Even if I wanted help with getting in and out of the bath or something like that - the village would support me."*

*"The District Nurses come in every day - that's to help getting me up. They help me get dressed and see that I'm comfortable in the chair and then they go. That's about 20 minutes in the morning, then they come back at night. We are really lucky with the nurses - we've an awful lot to thank them for. We got all that fixed up through our doctor (GP). He arranged all that - and the hoist, because they need that to help get me out of bed."*

*"They are really good, we really don't want for nursing care at all. And, the good thing about the nurses we've got - they've been with us a long time, and they do watch out to see if you need any extra help. If anything comes up, they'd always check into it and make sure they spoke to the doctor. So you know if you need anything, they'll always do what they can. They always come along if we get in touch - they always send someone very quickly."*

*"When I was in hospital (after falls), I did think about what would happen if I was on my own all the time - I suppose you do really. To be honest though, it doesn't bear much thinking about - I just hope I go first. It's not a very nice thing to say I know, but I wouldn't be able to stay here on my own - not really. I couldn't do any cooking for myself for a start, and I'd have to have someone here most of the day in case I needed anything. I suppose I would prefer to stay at home but I don't know if it would work. I don't think I'd be too keen on having someone living here and, even if they just come in during the day, they would be around all the time so you don't really have any privacy when it's like that, do you. Anyway, the thing is that - when you're used to living with someone for all those years, it's a bit much to suddenly get used to someone else. No, if there was anyway I could do it (ie. stay at home) that would be better, but I think I'd probably go into a home so I could be looked after properly without any worry. Somewhere like I went while they were doing the bathroom would be alright (local convalescent home). They looked after you real good there - it was like being on holiday."*

*"We get the home help for two hours a week. It would be nice if they could come a bit more than they do but, the thing that does really bother me is, when she's off, they don't ever send me anyone else. I don't think it's very fair - to be honest, if it goes on like that, then I'm going to put them off."*

*"She's really very good (home care aid). She's the sort who pays attention to everything, which I think is very good. You know, little things like making sure everything goes back in the same place so I can reach it when she's not here. And, she always checks to see if there's milk in the jug, or if I need any more butter in the butter dish - that sort of thing. She's so thorough, that's what I like about her. She says - I just look after the place the same as my own home that's all. I've had the same one since the beginning and we get on very well so I'm very satisfied with the arrangements, yes."*

*"We were offered a home help. But they said I would have to pay for it ( , 5.40 per hr) and I can't afford it - so that never happened. It would be a help to have someone for a few hours, but not if I have to pay. It makes you wonder - how do they think people can pay that sort of money on their pensions."*

*"I have a home help for one hour a week. I don't really want more than that - that would be greedy. They charge , 2 here - it's a flat rate. That doesn't seem to make much sense to me."*

*"I employ my own home help - I've had the same one for years. Generally speaking, I prefer to get people in myself if I do want any help with anything."*

*"We (ie. respondent and husband) work together. We're pretty organised and we both have our particular jobs around the house. So, I don't really want a home help - there's no need."*

*"If you pull the alarm cord, the warden always comes straight away - they're very good about that. We have two wardens actually. So there's nearly always someone around. But the rest of the time the call goes through*

*to Careline and they get someone to come over. That's a fairly good system too - you have to give the phone number of another neighbour here, plus a relative, so they have someone to contact if they need to. The only trouble is that - although they are usually very fast, I have known them to take a quarter of an hour to answer a call sometimes. That could be a bit too long if it was a real emergency."*

*"We do have an Aidcall set-up here from the council. I don't think I can remember ever having to use it myself. It's just a question of it being there - it's very comforting."*

*Husband: "My wife does go to this home for - respite care I think they call it. It's a home run by the County Council for the elderly and they keep three rooms spare so that people like her who need a lot of attention can go in for a while. We have to pay for that though. She's been twice so far when I went away for a short holiday. The social worker who arranged it asked me why don't we do it more often. They want people to use the places because they're worried that if the rooms stay empty for too long, the council will say they're not needed and take them away. I can see their point, but you don't want to go in there unless you actually have a reason to go do you. I mean, if I want to have another holiday say, it's got to be when it suits us - not just for the sake of it."*

*Researcher: If you are ever in that position again and you wanted some kind of respite care, would you prefer a home based alternative, with any help you needed coming here instead of you going into the home?*

*Respondent: "Well, it's not too bad there and there are one or two people I am friendly with. But, mostly they just sit around sort of thing - there's not much to do while you're in there"*

*Husband: "That's right. Some kind of home based alternative would appeal - definitely. But, it's never been offered - that's the thing."*

*"I wish there were somewhere you could go for a few days - but, without it costing the earth. I don't know how you can find these places though. There's lots of homes around here, but I don't know if any of them let people go in for short breaks. There are a couple that I do know about, but they charge such a lot of money. The thing is, it's not something I need to do, I would just like to do it. So, I don't want to spend too much money because it's not essential. I just think - I mean, my husband never complains of anything - but it would be good for us to have a break from one another sometimes. I don't know if I can really explain - I just think it would be good for both of us."*

*"I was going to the local day centre for a few hours a week. The occupational therapist arranged that. But I stopped going for a while when I wasn't well and now I can't get back in. My GP has been trying for me to get back, but they say there's a two year waiting list."*

*"I go to Osbourne House - it's run by the MS Society. It's a day centre. They do meals, physiotherapy and hairdressing as well if you want it. It's a wonderful place."*

*Husband: "With things as they are, it's quite difficult sometimes because, with the lack of space and everything, I have real problems when she falls off the toilet or out of the hoist. I can't always get her up on my own so I have to call out the ambulance - that's happened quite a few times now. It seems a bit daft really because, if we had the proper space I would probably be able to manage - so that's wasting their money as well."*

*"Something like that (on-call support) could be useful in that kind of situation. We do have a Careline number but they're not absolutely reliable and it's quite limited what they will come for anyway. I think we've only ever called them once."*

*"It is a good idea to have the same people - but we already have that with the District Nurses. They're people we know - they are more like friends than workers, so maybe it's even better. That's one of the reasons we wouldn't want to move really - because you don't know who you would get somewhere else."*

*"That sounds like a wonderful idea. If I had someone there who could help me - someone who listened to what I wanted - I don't see why I couldn't manage outside. You've seen what they're like - they just come in and give you some tablets. Well, I can tell somebody to give me the tablets just as easily."*

*"We do get a holiday every year. That's all organised through the local Disablement Association. They take us up there - we go in a group of about 20 of us - and we stay for two weeks. We really do enjoy that - it's worth*

*every penny."*

*Husband: "Maybe meals on wheels a couple of days a week - that could be useful so you make sure you get a decent meal. But, I don't think there's anything else - we don't really know what there is anyway."*

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

*"The Social Services paid for the bathroom to be done, and having the flat fitted out. Before that, I kept falling all the time and - my wife, she just can't manage to get me up like she used to. It was getting ridiculous. So in the end, after the doctor had a word with them, they said I could go into hospital for a couple of weeks and they'd get it all fixed up. So, now it's much better because I can get about independently. I can transfer from my chair into the bath or onto the toilet. I can get in there on my own so my wife doesn't have to worry. The only thing is, we still don't have all the rails for holding on, but I hope we can get that sorted."*

*Wife: "That's only been just recently though. I was getting really worried because I just can't lift him - it takes two of us in the morning even with the hoist. And, if I was out when he fell - that meant that he'd just be lying there. I used to be able to manage it, but not for quite a while now. So, everytime he fell I used to ring the police and get them to come round. They would help me get him up and if he was hurt, they would call the ambulance because they can always get them out quicker than I can. So, it was only because of him falling all the time that they did that. When it got to the stage where we were having to get the ambulance out, then we got it done very quickly - it only took a few weeks from when the social worker came round to see us before they started work."*

*Wife: "The only other thing we could still do with is the Alarmcall. I have been onto the social services about it, but they won't give us a definite answer so I don't know if we are going to get it or not. We should really though because, I can't be here all the time and he could still get stuck if he falls - even if it doesn't happen all that often. He has to have something doesn't he."*

*"I am now 69 and my husband is nearly 71. He has been a wonderful support to me and is my lifeline. His main problem at the moment is the catheter. It overflows and soaks everything and, he has to change me and wash me and the clothes and everything. We have had good support from our family doctor and the district nurses, the home helps, the Red Cross supplying the ripple bed and ripple cushion and hoists for getting in and out of bed. The social services got me an Elap car seat to make travelling easier. The DHSS provided me with an electric wheelchair for getting round the garden. This was much appreciated at the time, but this year I bought myself an Everest and Jennings powered wheelchair which is a joy to me as I can travel at a good walking pace and accompany my husband on walks round the park. This has a very sophisticated steering system and is very very easy to use. I wish I had bought one earlier because I found the DHSS one so tiring to use. But, I thought, I might spend £2,000 wastefully."*

*"All your muscles get very weak with MS - you need to have everything very light. I couldn't use my old wheelchair anywhere, but since I got this stowaway it's so much better. I can even get in a car with this one - I couldn't do that before."*

*"I've got a batricar (scooter), which I bought on Motability. It's wonderful, because I can get about the village on my own - it's my lifeline. I do have a wheelchair for when we go shopping - but my husband does most of the shopping anyway. I only go occasionally."*

*"You see this wheelchair - look, it's broken. I can hardly move in it anyway - it's such an awful squeeze but, nobody's been to see about it. They come in and out all day long - but nobody's asked me about it."*

*"I took my NHS chair back (to local ALAC) the woman there was very good. She didn't just take it back - she took the trouble to warn me about having to pay for the repairs and everything if I just kept my new one. On the other hand, when I asked her if I could keep the cushion, she said - Oh no, you can't possibly do that. It didn't seem to make much sense to me because I still needed the cushion whichever chair I was going to use - it's just a cushion."*

*Husband: "The only real problem we've had is - it was getting really difficult to get her (my wife) into the bath. I couldn't do it on my own and so we had the nurses (ie. bathing auxiliaries) come in every day, but they had problems because there isn't enough room for them to work in that bathroom. In the end we got one of those hoist things so that I could get her up out of the chair and lower her into the water. But, that didn't really solve the problem because there isn't enough space for me to get the wheelchair in and get down beside her. So, now, they (District Nurses) come in and give her a bed bath three times a week instead. They said they just couldn't cope with the bathroom so that was the best they could do. It's not their fault really - I can see their point. And, they have always been very nice about it. In fact, they offered to keep coming every day, but we said there wasn't any need for that."*

*"The social services weren't a lot of help (with the bathroom). First of all they said we couldn't have the hoist because it couldn't be fitted in that space. I told them - you only need to reverse the door so it opens out instead of in. Then they said - OK, but the radiators going to be in the way. So I said - that's easily fixed - we'll just take the radiator out. Anyway, they wouldn't believe it so, in the end, I persuaded them to give me the hoist and I fitted it myself."*

*"The other thing which they (social services) did give us was a closomat toilet but its completely useless - she (my wife) can't use it unless there's someone with her. What we really need is for the wall separating the bathroom and toilet to be knocked through so we can move the bath over to the other wall. That way we can use the bath because there will be room to get round and see what you're doing. That's what the district nurses wanted and the occupational therapist they sent round to have a look agreed it would be the best solution as well. But, the social services said they'd only do it if I paid for it. It would cost ,4,000 - I just haven't got that kind of money. If I had then I would do it - anything I can do for my wife, I'd always do it, there's no question."*

*"It doesn't make a lot of sense does it. I mean, all this money has been spent on a hoist and the closomat thing - that cost ,1,500 - but none of it is any use. Then, they refuse to pay for what we really want. Plus the fact that, it would probably save a lot of money because you wouldn't have to have three nurses to give her (wife) a bath. But, I suppose they think - that's somebody else's budget, so we don't have to worry. So, now the only thing they say they can do is, they're going to give us a hospital bed. You know, one of those you can raise and lower - because the nurses say it's too difficult to manage a bed bath on there. I don't know what we'll do about that. I suppose I'll either have to get another bed in there, or maybe I'll just sleep in the spare bedroom."*

*Researcher: Are you happy with that, or would you prefer some other alternative?*

*Respondent: "Its not ideal, no. But, there doesn't seem to be much choice. Still, they'll probably take months before they get round to it, so we won't have to worry for a while."*

*Husband: "When we had the kitchen extension built, they (social services) asked if we wanted to have all the worktops and everything lowered so my wife could reach them in her wheelchair. The problem with that though is - its a question of who is going to use them. It's all very well, but I do nearly all the cooking so it wouldn't be much use for me. So we didn't bother with that - its not such a good idea."*

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

*"I do go to the social club at (Disablement Association) two days a month. That's good - we always enjoy going up there. They and pick you up in the ambulance and bring you back again. But, I would really like to go out more. You do get fed up just sitting here looking out of the window all day. I suppose we did go out more before, but without transport there's not many places you can get to and I can't drive no more - even if we could afford to get a car."*

*"When they first stopped coming with the ambulance, I used to go up (to hospital) in a taxi. We packed that up though, because it was costing a fortune. If I have to go again, we might see if the Dial A Ride can do it - it might be a bit far, but we'll have to see what they say."*

*"We've just started using the Dial A Ride - I've only been the once so far. I think its very good. You can't just go anywhere whenever you want because you have to tell them before. It would be good if you could just pop out if you feel like a day in the country or something like that, you can't do it with them. But, I think its understandable that you have to book otherwise it wouldn't work - it wouldn't be right to complain about that."*

*"I don't get out so much these days, but there is some transport when I do. There's the (local) MS group, and the rotary club - they bought an ambulance for us to use. I would think about getting a car if we could get one to take the wheelchair. But, it's getting through the test that's the problem - I don't reckon there's much chance they'd pass me."*

*"I used to have my scooter, which was marvellous for getting down to the shops and that sort of thing. But when I moved here, I had to get rid of the scooter mainly because I just didn't have the room to keep it here (ie sheltered accommodation)."*

*"Transport's pretty well taken care of. We are lucky because we have a very good ambulance service round here and I quite often use that if I don't feel like going in the car."*

*"For the last 5 years (29 years after onset), she's been in the wheelchair more or less all the time. She can't stand up any more - she just hasn't got the strength - and I've had to give up working so that I can be here to give her the attention she needs. Even so, I am finding it more and more difficult to manage lifting her myself - especially in and out of the car. Last year I bought this mini-ambulance thing. The floor lowers down at the back, so I can just push the chair in and that's it. It cost a fair bit ( ,7,500 second hand) but it does mean we can get out a lot more so it was well worth it."*

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

*"I loved it there and I didn't want to leave. They never gave me any warning. I was there on the Thursday, and on the Friday I was gone - I just came here. If they'd asked me I would never have agreed to go. They said it was because I was getting worse and I needed more help. But, I think they just didn't like me."*

*Researcher: What kind of extra help did they say you needed? Do you get any different kind of help here?*

*"The only difference here is that I have my tea made for me - that's the only difference that I can see. I hate it here. The atmosphere is just horrible. The care attendants are so rude - I'm very depressed. I haven't been out once - they don't take me out. I can't even get to the telephone, because I can't fit in the booth. When I was in my own room, I had a phone - now I can't even talk to anyone. I only needed a little bit more help - they didn't need to bring me here."*

*Note: Respondent was recently moved from a residential hostel to present nursing home against her will, and was clearly very distressed about this.*

*"When you're living in a house, at least you have neighbours who might be able to help out with a bit of shopping or something like that. Here, they're all too old really."*

*"It's all old people here - I can't stand it. But, I wouldn't take the risk of going anywhere else. If I can't go back (to previous home) I'll stay here. I want to be somewhere with people I know. If I went anywhere else I wouldn't really be any better off."*

*"I'd been in the nursing home for six months when they eventually let me go home. I say eventually because they were a bit reluctant at first. But I told them that - as long as the kitchen was adapted properly - I would be able to manage. So, once they'd finished the work I was able to come back."*

*"When I came out of hospital (following a fall) I couldn't do anything for six months while I was waiting for them to do the kitchen. It's so much better now because I can be a bit more independent. The only problem is that - since I got my new wheelchair - I'm a bit lower, so I can't reach these tops so easily. It's a shame really, because the Occupational Therapist had made sure that everything fitted me exactly when they first did the adaptations - but now it's not quite the same. It's only a couple of inches but, with being very short anyway, it makes quite a difference."*

*"It's much easier for me here. There wouldn't have been much point trying to keep on the house on my own. It would have been a lot of extra effort. The only thing I miss is, I would like to have just a bit more space, but on the whole, life's much easier here."*

*"I had a house of my own before I came here. But I had to move - I couldn't manage the stairs. Maybe if I hadn't been on my own I could have stayed on, but it's very difficult when you haven't got your husband around to help."*

*"I would have moved even if I could have had a helper I think. Actually I did have a girl coming in twice a week to clean round but - no - I wouldn't have been able to stay, not with the stairs. I'm sure it was the right decision. I'm perfectly comfortable here and I can be pretty self-sufficient in my own way."*

*"I chose this place. The doctor recommended it and I got my name down on the waiting list. I had to wait 18 months to get in though because I needed to have a ground floor room - there's no lift here you see."*

*"You don't know what's going to happen do you. That's why we moved here in the first place really (ie. to bungalow). Things were already getting more difficult, but we didn't know how bad it might get."*

*Husband: "That's it. It seemed pretty unlikely she'd be able to keep on struggling with the stairs - even with me to help - so a bungalow seemed the obvious choice. I don't know what happens next. We will stay here I would imagine. But, it all depends on the support - that's the crux of it really isn't it."*

*"You do have to think very carefully about what kind of home you're going to need when you're older. We were*

*lucky - we had a big house to sell, so that did make it a lot easier. But, a lot of people don't have the choice, and I'm sure they sometimes get stuck living in homes which aren't really suitable - they just haven't got the money to get out of it."*

*"We did specifically choose a bungalow when we last moved which I suppose, in a way, was because we had half a mind on what I might be like later on. We plan on staying here though. You don't think too far ahead - I have to plan my life for today. In any case, this place is very convenient and we're lucky to live somewhere with such a pleasant aspect (overlooking the sea)."*

*Husband: "After the children were grown up we thought it would be better to move. We had a three bedroom place and, apart from his not being able to get up the stairs all the time, it didn't make sense having all that space anyway. So we came here and the council got us in this place which is much better. It's all completely level as you can see, so there's no problems there - no, we like it here, it was the right thing to do."*

*Respondent: "Our son did find us this bungalow in Milton Keynes. It was a lovely place and he was going to help us move and everything. But, I've lived round here all my life - so, what would I want to go to Milton Keynes for. We had a week to think about it, but I couldn't go so we left it."*

*"You must be prepared to move when you need to. In our situation - we had the perfect retirement home. But, it was perfect for an able bodied couple - so we had to look for somewhere else to live. We needed a bungalow. We knew that. We had to do quite a lot of searching to find the right place. Everything had to be checked out - what kind of area it was, the size of the doors, whether there were any steps - everything. We went around quite a bit before we eventually found this place. It is small - much smaller than we were used to - but, it's more manageable. Now that we've done it, I think it was definitely the right move. It's no good waiting until you're really disabled before you do anything about it."*

*"I think I will be staying here now - unless they take me out in a box. But, if for any reason I can't stay here I would go to a private nursing home. There's one not very far from here which I have visited. It's small - about 8 or 9 people - and the staff are very caring. Obviously, you prefer to stay at home - but somewhere like that would be a fairly sensible choice if you did have to move. The only trouble is that, you need to have all the information, which is pretty difficult. It's pot luck really with picking a home. A lot of them seem fine when you get the glossy brochures - but you don't really know until you're actually living there."*

*"I'm the only disabled person here. I think they must have had a bit of a fit when they saw me come in in a wheelchair. But nobody takes much notice now - they just get used to seeing you."*

*"I suspect part of the problem is that most of these homes are privately run now. Maybe if there was more of a mix with the county council homes as well, it might be easier to get in. But, I don't really know - I don't even know where to ask."*

*"I haven't heard about anything like that before, no. It sounds marvellous (ie having own flats with personal assistance) but I think finding someone compatible would be the main problem. I'm sure I would try it if I had to, but some people are impossible to get along with aren't they. Anyway, apart from that you get used to your own company - being on your own - you get to like it after a while. I'm not sure if I could get used to having someone else around really. Maybe I would consider it - if I couldn't walk at all, I might."*

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

*Wife: "He does get the Attendance Allowance - but we really had a fight over that. The first doctor they sent round, he wasn't too hopeful. Then, as he was getting up to go, he turned round to my husband and said - 'just keep it up, I've seen far worse cases than you'. I said to him - 'don't you dare speak to my husband like that, and don't ever come to this house again'. He's no right going round saying things like that. So, we got another doctor in the end and he told us it would be alright as soon as he got here. He said more or less straight out - 'I don't think you've got anything to worry about'. So, we got it in the end, but I was really angry about the way we were treated at the time."*

*Respondent: "The DHSS - they don't do a thing to tell people what they can get. So, if you don't know who to ask, you've had it. I mean, there may be other benefits that I should be getting that I don't know about - do you know?"*

*Wife: "No, that's right. You see, there is this carer's allowance I heard something about but I don't know if I should be getting that - I haven't really had time to go into it. Anyway, even if you do get some extra, they probably only take something else off of you. That's what happened when we got the Attendance Allowance because, after that, they started charging us extra for the home help - we weren't paying anything before."*

*"It is very difficult to find out about your benefits. Someone mentioned to me that the severe disability premium was going up. Well, I hadn't heard anything about this so I rang the local social security office. The woman there said - yes, but if you'd rung yesterday - that was a Sunday - I would have told you you were ineligible. It was because of my age or something - I didn't really understand what she meant, but I didn't bother after that. I get mobility allowance as well. That's another thing - I only found out about that from my cousin. Nobody ever tells you about what you're supposed to claim."*

*"I have certainly got less since I retired. But then again I don't spend nearly as much now because I don't have a home to keep."*

*Husband: "We're lucky that I get a pension from my old job, otherwise I don't know how we would get by. The state pension - there's no way you can live on that. If you have the extra costs that we've had, then it would be just about impossible. Its like being able to buy the van. If we didn't have that we wouldn't be able to get out of the house at all."*

*Husband: "But, the thing that really gets me is that, if you have any money at all - it doesn't have to be that much - then you can't get any help. That's why the social services said I'd have to pay for the bathroom, but they don't take into account the fact that you need what little you have to try and maintain some kind of quality of life. It seems to me they expect you to live in poverty."*

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

*"When we first moved here - at the beginning, I felt so isolated. But, the local support groups (MS) are very good - you soon fit in."*

*"The local Disablement Association here is very good. They organise a lot of socials and that sort of thing. I don't go to so many now, but my wife goes to all the meetings. It's good because, with them being so active kind of thing, there's always people around she can ask if there's anything we need to know about. It's not just people with MS - I think that's good to because you get to hear about what all these other people are up to. It's probably more useful like that. But, the local MS group are very good to, so we are very lucky to have the two."*

*"You have to have the self-perseverance to make sure you get the help you need. With a lot of the old darlings, they just don't know what help there is and nobody ever tells them - that's the trouble really. If you speak up, you can get the things you need. But some don't know where to go to ask, so they're stuck aren't they."*

*"It would be a good idea if they (Multiple Sclerosis Society) did more to get people's ideas together so they can share what they know between them. I know there's a need for that sort of thing because, I put a letter in the newsletter about my diet, and after that I had literally dozens of phone calls from other people wanting to know more about it. ARMS are very much better with that sort of thing - they put out a lot of information."*

*"I go to most of the meetings of the local MS group. They are nearly all young ones but I don't mind that. As I always say - I've come as a sort of example to you younger ones."*

## **THE NEXT STEP**

In highlighting the needs and experiences of people who are ageing with a disability, we have not tried to be particularly prescriptive about how organisations like the Multiple Sclerosis 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
Freidreichs 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

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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

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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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