

**AGEING WITH A DISABILITY:
THE EXPERIENCE OF
LONG-TERM MALE AMPUTEES**

**Briefing paper prepared for
British Limbless
Ex-Servicemen's Association**

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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, Limb-amputations 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 BLESMA who have contributed to the project. A total of 13 male members have participated following a request for volunteers sent to 40 named individuals. The average age of this group is 71; they have been disabled for between 31 and 50 years, with the average being 46 years.

Following an overview of some of the main background issues to ageing with disability, the views of BLESMA members 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 BLESMA and others. The briefing paper is organised around the following topics:-

- # Concern about ageing and the need for research;
- # The experience of ageing amongst long-term male amputees;
- # Physical and health problems associated with ageing;

- # Health services/health care;
- # Practical/personal support needs.

BACKGROUND ISSUES

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

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

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

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

CONCERN ABOUT AGEING AND THE NEED FOR RESEARCH

The response we have had from people with long-term limb amputations 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 disability 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.

* Several BLESMA members in the study also emphasised the importance of being able to establish links between physical ageing problems and their original impairments in the context of establishing eligibility to benefits and allowances. Most were satisfied that BLESMA have been working effectively in this area; although they still felt that there was a general lack of awareness and sensitivity to the issue amongst the statutory authorities.

* 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 BLESMA to take this further and incorporate members concerns about ageing into their own work.

CONCERN ABOUT AGEING AND THE NEED FOR RESEARCH (Quotes)

"I do think that the medical profession should be looking into these things more. Alright, I know that - if you have a tin leg - you're bound to get problems with arthritis and things like that. I know that mine is to do with my disability because you do put an extra strain on your good leg to compensate - so it's bound to wear out. But, you don't know if there is anything that could have been done to alleviate some of that strain. Maybe there isn't - but if nobody tries to find out, you're never going to know for sure are you. Then there are a lot of grey areas with all of this. There are so many things that you can go wrong when you're older in any case, but nobody seems to be trying to find out what's connected to the disability and what might just be old age. Unless you have some idea, you don't know if there's anything you can do about it - if there's any treatment that they ought to be trying out. You see, if you take this arthritis - which I know nearly everybody gets - if it turns out to be caused by having an artificial limb, or if that speeds it up, which is what I would guess is what happens, then people should be told about it so that they can decide if they ought to be doing anything about it themselves. I mean, perhaps you wouldn't tear about so much when you're younger if you know you're going to suffer for it later - I don't know. Obviously, it's up to the individual - you can't tell people they have to do this that or the other - but, they should be advised of the situation so they can decide for themselves."

"The trouble is that, with a lot of the problems you get when you are older - if enough people are reporting the same sort of problems, then there must be something in it. But, the doctors don't ever listen do they. That's why it's good that you have organisations like BLESMA to push people into taking some notice."

"There was a survey about heart trouble - some University did one. But I don't think anyone took it up. They have established the link for lower limb amputees, but not upper. But, it is the same as far as I can tell. I certainly had these problems because of all the extra strain."

"I was determined to get it established - because I wanted to make sure I could get Constant Attendance Allowance so that the pension would pass to my wife. That was my main concern. It wasn't accepted but I got the CAA anyway on account of the arthritis - so it didn't matter in the end."

"Medical officers - they just don't take enough interest. It's just what they decide is wrong with you and you have to accept it - there isn't very much discussion."

Carer: "Still, it's nice that someone comes round to listen - so you can tell them these things. Because, this is how you can find out a lot of things. Because, a lot of people just don't realise what's going on."

"You see, the state of the country today - it's so lax that it is really unbelievable. I mean, what you've done, and what you've fought for, it's been for nothing. Because - the way you're treated - you're treated as if you were an outcast really. Other people - foreigners are getting better treatment than what I'll ever get. I mean, I don't begrudge them - don't think that - because, I don't blame them, I blame the Government. If anybody can get anything out of this Government, I say good luck to them - because, I can't and, what they know, I'd like to know about too so I could get it. But, I don't."

"Well, people might say it's just because they're too old. But, I think the thing is that - an Englishman, he's got his own way of going about it - he just don't seem to want to bother. Because, I think he knows that if he do say anything, he's only wasting his time anyway."

THE EXPERIENCE OF AGEING AMONGST LONG-TERM MALE AMPUTEES

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

Some of the main issues identified are summarised below.

- * Many of the people we contacted felt that their needs, and even their existence, have been overlooked.
- * Because of the invisibility of disability (particularly earlier in their lives), many older disabled people feel very isolated and unable to get anyone to understand their anxieties about ageing. For some, participating in the study had been the first opportunity to discuss this for maybe 20 years or more.
- * People's perceptions of, and attitudes towards ageing cannot be understood without reference to previous life experiences. As the experience of disability will have been a major feature of the lives of all of the people participating in this study, it is not surprising that this frames their personal responses to ageing.
- * This is illustrated by people's level of satisfaction with the quality of life. The findings indicate that, ageing is typically associated with a 'downturn' in people's level of satisfaction after they had been disabled for between 20 and 30 years. Also, this appears to be closely associated with the onset of the ageing process. About half of the people in the study reported that their satisfaction with the quality of life had risen again over time as they accommodated themselves to the physical and personal changes experienced with ageing. Others, however, remained dissatisfied.
- * There are numerous factors which influence how older disabled people view the quality of their lives. First, some people feel that the effects of the ageing process itself are like the onset of a 'second disability'. In other words, they likened the impact on their lives to the kind of experiences they had when they first became disabled. Indeed, for some who had never really considered themselves to be disabled before, the main impact of ageing had been that they now recognised their disability for the first time in their lives. Other people felt that, while they had always found the physical consequences of their impairments difficult to cope with, the additional effects of ageing had made the situation much worse.
- * For some people, this heightened awareness of disability had been a gradual or even insidious process. Often, however, the process had been triggered by a particular problem or crisis like the death of a partner, being forced to take early retirement, or a sudden or accelerated downturn in an individual's 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.
- * 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. In the case of ex-servicemen, there is often the added dimension that - given the circumstances in which they became disabled - they feel fortunate to have survived. On the other hand, some were bitter or disillusioned about the fact that they seemed to have been forgotten.
- * 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.

* 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 EXPERIENCE OF AGEING AMONGST LONG-TERM MALE AMPUTEES (Quotes)

(1. Early experiences)

"It's been so long now, that you just have to put up with it. It was only a couple of weeks before the end of the War in any case - but that's the way it goes. I mean, I know you can talk about the pension - but I know what I'd sooner have. I mean, all the money in the world aint no good to me without my health and strength."

"I understand why you might want to look at what happens when you get ageing and disability coming together. But, I don't think you can really understand someone's attitude to being disabled unless you look at what they were before - what their situation was like before they even got a disability. I've never let my disability beat me. In fact, I don't even think about it most of the time now. You see, to me, getting a disability in the first place was the biggest change there's ever been in my life. It completely changed everything at the time because I had my heart set on being a musician and obviously - without an arm - that all went out the window just like that. But, after the initial shock - which didn't last all that long in any case - I just decided that I had to forget it and get on with my life. After all, I had my whole life ahead of me. So, after I'd made that decision, all the rest of it didn't matter - so I can't really say that I've changed one way or the other."

"In any case, I think you can spend too much time talking about someone's disability - especially if, as in my case, it doesn't really matter to them all that much in the first place. It's all a bit boring frankly, isn't it. So much of this is to do with the attitude of the individual. If you keep thinking about what you can't do, then you never teach yourself what you can do - you never find out what the possibilities are. I think that too many people still have this attitude and it only makes people feel more disabled than they really are."

"Really, I'm lucky to have lived like I've lived - to get to 71. I mean, when I got done I thought to myself - well, that's it. I always remember, when I was a kid, I see a man on a little skateboard pushing himself along with no legs. And I thought to myself - I nearly took a Luger to my head to blow my brains out. I was only 19 when I got called up - so that's the sort of thing that goes through your mind. You think to yourself - when you see that man on a board pushing himself along, you think to yourself - I couldn't do that. You don't think about artificial legs and things like that. You just think to yourself - cor blimey, how am I going to go through life like that. So, you think - I'm going to pop myself of - and that's it. But the thing is, you don't realise until you see these people that are worse off than what you are - it makes life seem a lot better than what it did before. So, that's the way I look at it now - there's always somebody else worse off than me."

"When you were in the PoW camp - you used to think about all the things you were going to do when you got out - if you got out. But, that's the thing you see - you never knew if you were going to make it home. So when you did, you're always thankful for that and, everything that's happened since is a bonus in a way. I think that stays with you - it does tend to make you just be grateful for whatever you get out of life."

"It's not true that ordinary people were all wonderfully optimistic when the war was finished. Many of us didn't know what to expect - but we knew it wasn't necessarily going to be easy. But, I think we have the right to expect more than we've had in return for what we did for this country."

"I was a driver - I was driving big artics. I just blocked it out because, they used to tell you - when you're disabled - you can't get a job. So, I just never told them. I mean, a few times I nearly got killed and I can't remember how many times I fell over - I used to fall over on the ice and snow. But now, I can't even walk round the corner - I've just had enough. I used to go out to work in pain - in agony. And I used to think - what do you have to do just to make a living? But, all them years, it gets on top of you. I mean, I was pleased with what I was doing because it meant I could do a days work and I was quite pleased with myself for doing that. I was in agony - but I done it."

"I was a machinist before the war - but they wouldn't let me go back to that because it was too dangerous. So, I went to this rehabilitation workshop instead. I was just dismantling bits of electrical equipment and chucking them in a box - that was it. Well, I stuck it for about 3 weeks - I was bored stiff. I said to the manager - you'll have to try and find me something else or I'm afraid I'll have to have to ask for my cards. I didn't want to but, it wasn't any good to me - I had to think of my future. Anyway, he came back and asked if I fancied pushing a pen. I'd never touched a pen in my life, but I thought I may as well give it a go. So they gave me a job in the

engineering shop as a clerk. That went on for a few years and it was alright - no problems. Then they said they wanted to give me a new posting and I had to go to Scotland. I said - there's no way I'm going to Scotland - I was living in London and I had the wife and my son there. So then they said - well, there is another post in Wales. It's just not on is it - I couldn't believe they'd treat someone like that. I mean, I've never asked for any special dispensation. I just ask to be on an equal footing with everyone else. But that really got to me - being pushed around like that. Before that I always said that we're not disabled - just incapacitated. But I turned round and said - what a way to treat someone who fought for their country. I'd never flogged my disability 'til then."

"I was lucky, because I had my amputation done in Denmark. So, I did have six months rehabilitation before I was discharged - I wouldn't have had that if I'd been sent straight back because they hardly ever bothered with any rehabilitation here. I think it does make a tremendous difference - I would never be as fit as I am now if I hadn't had that. But, although it was very good on the physical side - there wasn't any help at all with finding a job or training or anything like that. I think that's still a problem even today. The standard of rehabilitation for disabled people in this country is very poor - very poor. I mean, there are supposed to be resettlement officers - but, you show be someone who's actually ever found them to be any use. And, the employers are supposed to take so many disabled into their jobs - but they don't - and the government don't ever check up on them. In fact, the government departments probably have the worst record of all."

"The thing about rehabilitation - it is so important - because, if you're going to make your way in life, you need to be able to explore all the options that might be available so that you can be as independent as you possibly can be. That's where I missed out because - alright, I have fought my way up and I have been very independent - but, you think how much easier it would have been with a little bit of help and advice at the beginning. And, what about all those who can't do it for themselves - it affects them for the rest of their lives, it affects their confidence."

"I wasn't told anything - I had to find out for myself. A bit more help with getting a job would have been a good thing. When I came out of the army they said - oh, you'll be alright, you'll have a job for life. Well, I did get a job but it didn't last long - I was made redundant in 1945."

"There was no help finding a job. They didn't want to know. You're just finished as far as they were concerned - you just have to find your own way. There was no chance of a house or anything like that. No, in my opinion you're very badly treated. You were just sent out and that's it. It still causes a lot of bitterness - there was no help at all."

"I do think rehabilitation is very important. It can affect you for the rest of your life."

(2. Later experiences)

"It's a very slow process - it gradually creeps up on you. You deteriorate as you get older and it seems to be speed up all the time. Especially at the age we are now - I'm 70 and I can't do what I did when I was 60 even. I can't climb stairs anymore - which is causing me a lot of problems obviously - and I can't do the garden anymore, which really grieves me, seeing it go to pot like that. I can't get in the bath anymore - well, I can, but I can't get out again. Something like that though - it seems to suddenly hit you. One day you can do it and then you suddenly find you can't. And it does get to you a bit obviously - I cried the first time I realised I couldn't get out of the bath - that's how it got to me. But it's not really specific things that you can pin down - it's just the wear and tear on the limbs. Basically, that aside, I'm actually very fit. I've never been in hospital or anything, and I hardly ever need to bother my doctor - it's just this wearing out. The only specific thing I've got is cervical arthritis because I never use the arm, that's what that is obviously."

"The doctor - if I wanted him - he'd be over here like a shot. But, like I say, there's not a lot they can do. But, you do get in such a state that you could top yourself. The pain - it's so consistent, that it just don't seem to give up. It knocks you down - like, when the grandchildren come over it's too much, it does take you down a bit - because, you aint got time to think about anything else when you've got this (pain)."

Wife: "He does get to the state where he just bursts out crying -when he's had enough."

"I get very depressed."

Wife: "He gets ever so depressed. You've got to keep something going all the time - to keep his mind going - you know what I mean?"

"It's just the last 10 years - I can be sitting here, and all of a sudden, the tears just come down my face. You know, if you just sit here all day, sometimes you do get down. I mean, I'm not a miserable bloke - but that's how it gets you sometimes."

"I worry about if anything went wrong with the house. I worry that - if I go - that the house is paid for, so I don't leave her (wife) no debt. You know what I mean - that's the only thing that worries me. I mean, I don't worry over myself - I never have done."

Researcher: Do you think that there's anything that could help with your depression, or do you think that it's something that you just have to put up with?

"I don't think anyone could do anything. It's just that it's in your own mind, and I don't think anyone could do nothing about it really. You just have to get it out of your system. Once I've had that cry then it gets it out of you, then you're alright. So that's what I do."

"The only thing that would really do it as far as my independence is concerned, is if I ended up in a wheelchair. That's the only thing that would really worry me - I just don't see how I could be independent if that happened. Alright, you know that you're going to gradually deteriorate - I've known that right from the start, and I accept it. But, there's a big difference between having to struggle to do things, and not being able to do them at all. I suppose if that did ever happen, I would have to go into a home or something - but I hope it never comes to that."

"When you've been disabled for 40 years you do become very independently minded. Lets face it, you wouldn't survive that long if you didn't - obviously. So, I suppose you would perhaps be more reluctant to give up any independence if you were ever in that position. But, fortunately, you also tend to become a little more adaptable when you are older so I suppose you can put up with a certain amount of change if you had to - I'm not sure."

I am a very independent sort of bloke. I suppose that I don't really want all that much but, the way I feel about it, you like to know that there is a little bit of help if you need it."

"I've always taken a very philosophical attitude about that (disability), because I know that I'm one of the lucky ones. The blokes who really lost out are the ones we left behind under the sand - all they had to show

was a wooden cross sticking out of the ground. So, you never get down about it because you always think to yourself - 'that could so easily have been me'. But, the funny thing is that the way I feel about it has just got better and better over the years because I never let it get in my way. I knew right at the start I had to motivate myself to make something out of my life - because, you can be sure as hell that no-one was going to do it for you - and that's the way I've always gone on. So, even now that I'm deteriorating the way I am, I still never let that get me down. It's as if the two things sort of go in opposite directions. Physically you are going downhill - and fast - but, mentally, you get stronger and more determined. That's been my experience, but you'll probably find that a lot of people will tell you much the same."

"I do get frustrated because I can't do what I know I should be able to - what I used to - especially since I retired."

"Well, I don't bear no malice over it. I mean, it's the people under the ground who never come back - they're the ones. So, I don't bear no malice or nothing like that. I was called up to do these things, and I was just one of the unfortunate ones. But, I'm not unfortunate really - I'm one of the lucky ones. Because, as I say, the others never came back. I mean, you do get a different outlook on life. Like - I like to go swimming. But, you think to yourself - if I was to dive in the pool, you know, with one leg and all that - you feel out of place. I mean, all them things you can't do - but that's just how it goes. All you're left with really, is the pain - and that, you've just got to put up with."

"I think, personally, that, if you are disabled you always go flat out to prove that you can do anything anyone else can do. You don't want to ever admit defeat. It's an ego thing I suppose - well, it is with me anyhow. So, in a way, I've never considered myself to be disabled. But, if you're asking how well I think I've coped, I'd say I've been pretty successful at it."

"Of course there are things I can't do as much of as I'd like. So getting older does effect you in that way. But, I wouldn't say it bothers me particularly - I'm still very positive about life, I'm pretty fit for my age - I can't complain at all really."

"Sometimes you get frustrated. Everything takes so much longer."

"The only thing that really set me back was losing my dear wife. But, even then, there is always a positive side because you find out how much people are prepared to rally round and support you. I am very lucky because I have such good friends and they helped me get through that. But, the things is that, you have to remember that you've have to help yourself first. If you do that, and people see that you are making the effort, then they will help you along. I've always gone out of my way to help other people and I think, if you do that, it does pay off for you because the friends you've made aren't usually going to turn you away if you need anything, or when something happens to set you back - that's the way it's always been."

"I don't have any difficulty motivating myself to keep everything going - even though it is a lot more of a strain than it used to be. I have to do it - not only for myself, but mostly for my wife. She was always so supportive in my life and I feel I owe it to her to keep everything the way it was when she was alive. For example, when I have visitors they always remark how spotless this place is and they wonder how I manage to keep it like this. But the thing is that, that's how (my wife) always kept the house and so I want to make sure that it doesn't slide - I'd feel as if I was letting her down if I ever did that."

"I retired when I was 59 on medical grounds. I stuck it out for as long as I could - I worked for 47 years - but it was getting too much. It was the finest days work I ever done though - I don't find time drags or anything."

"I could have retired when I was 60, but I decided to stay on a bit longer until I got too tired. After three years I thought I'd had enough - especially with having to get out in the cold winter mornings."

"I've always had the attitude that - you work for as long as you can. The only time I ever went to the doctors was when I went to Roehampton (limb fitting centre). Anyway, I think a lot of people on state benefits are much worse off because of it. I don't just mean the money itself - I mean, it makes for a sort of dependence attitude if you know what I'm saying. There's no incentive. So, I've never really had much help and haven't asked for any either. The only thing really was that, I had to get a bath seat and some hand grips because that was getting a bit tricky. There wasn't any problem though. We saw the social services woman and they came the next day - simple as that. I think a lot of it is the attitude you have towards these people. If you are antagonistic they're

probably a bit less inclined to help you out. I don't know, but I've never had any problems."

"I can't do as much gardening as I'd like to ideally - that's because I get too out of breath and have to sit down and rest every few minutes. But, fortunately, most of my hobbies have always been indoors - I love listening to music and I'm very interested in photography - I'm never happier than when I'm pottering around in the house."

"I still have a couple of lady friends, so that's obviously going alright. Actually, there is one woman in particular who you could say I am serious about. I did propose marriage not so long ago, but she wants to just stay friends at the moment - which suits me fine."

"I don't go out a lot - that is out of choice. Although, we do have a local social club here and I can always pop over there if I feel like it - we do that occasionally."

"I enjoyed working, but I always wanted to be able to spend more time sailing and doing all the other things that you enjoy doing just for yourself. So, when I retired, it gave me much more freedom than before."

"I always have plenty to do. In fact, I'm even busier these days than when I was working."

"I love gardening but it's out of the question now. It's just too much for me - the same as with the decorating and all the odd jobs about the house - I just can't do them. It's age as well as disability. So, nowadays, I do a lot of reading - I can always find things to do."

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 long-term amputees. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and disability 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 disability, 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 amputees who participated in the study 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 have a higher prevalence amongst this group which should be highlighted for further investigation. For example, arthritis and other rheumatic problems, coronary disease, increased pain, circulation problems, spondylosis, asthma, spasms, ulcers, headaches/dizzy spells, and problems with shoulder, arms or hands were more likely to be reported by long-term amputees.
- * On the other hand, there were some problems which have a lower prevalence, or are even non-existent amongst this group. These include problems with vision, decreased energy levels, osteoporosis, problems with weight gain, and limb deformity.
- * 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 disability 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 have had bad back trouble in the last 3 or 4 years. It does affect getting in and out of bed - and when you're having a bath. So, sometimes my wife has to help me - and with dressing some of the time as well. But, we manage very well at the moment - I shouldn't think we need any extra help just yet."

"I definitely feel the cold a lot more. I think it's the tablets - the angina tablets - because they do thin the blood out."

"I had problems with my lungs, and my shoulders originally. With my shoulders, it's got worse now because I have arthritis in the shoulder, but I also have it in my good shoulder. With the breathing problems as well, it has affected my walking very badly - I'd say it's been especially bad the last 10 years. I could have had an operation they said but, it's not for me at this age. You don't want to have to start learning to walk again - not now."

"I've had insomnia for many years now. But, I've taken so many tablets - they just don't work anymore."

"I have worn out physically - definitely. But, a lot of that is to do with work. You see, if you walk with a stick, nobody will give you a job. So, for all those years I used to get by without it, so, naturally, you wear out much quicker because of that. In the end, I had to start using a stick when I was 60 but I really should have been doing that 10 or 15 years before - that's when it started to get really bad."

"I have had problems with my good leg - arthritis and allsorts. The doc suggested I had an operation, but I don't think too much of that idea. If anything went wrong, if anything happened at all, I'd be completely stuck - so, I won't take the risk."

"You go round the doctors and they keep giving you tablets, but they don't do any good. I have pain killers but

they don't make no difference - they do wear off - they do no good for me really. I get about 2 hours kip a night, if I'm lucky, because of the pain - it just don't go away."

Carer: "You can't moan. He just has to put up with it - and with his age as well - he is 71."

"Dressing myself is the other thing - I just don't have the movement in my arm any more with the arthritis."

"It's no good keep going round to your doctor, because they can't do nothing. I mean, I have been on the point of suicide - it got so bad - that's how it got in the end (pain). The pain was so bad - you can't describe it really. It's horrific really - mind you, there's not a lot you can do about it."

Researcher: Did you talk to your welfare officer about seeing a specialist?

"I did - I did go and see the Neurosurgeon. I was in there a week, and I came out with a collar. It's no good going back there because they can't do nothing. He just said - your spine's worn out, but if you still get the pains, come back. There's not a lot I can do, he said. But, what's the good of that. If they can't do nothing, what's the good of going back? You're only wasting their time and your own. It's a waste of time."

"I have osteo arthritis - in my good arm. The other thing I have is this spondylosis. It's the weight and the extra strain - because you're always doing everything with one arm. You're making one do all the work of two."

"I consider myself very fortunate. I had a guillotine - straight off. The amputation I had was very good and so I haven't had as many problems as I might have done."

"My heart attack was brought on by all the strain of walking about on an artificial limb for all those years - I know that for a fact, and it's been accepted now. But, you have to fight, fight all the time when this sort of thing occurs. I did my own research and turned up this paper which proved that heart attacks are caused by the amputation. It was from America - someone had gone into it all and proved it and now, I think it is generally accepted that that's what happens. Of course it makes a big difference because I was reassessed from 40% to 80% after that. And, because of that, it also means I can get the mobility supplement and unemployment which I didn't get before."

"There isn't any doubt that having a long-term disability must mean that the ageing process is going to be accelerated. If you ask me, I'd say it's not just speeded up, it's more like an exponential change. I mean, I have rheumatism and all the various aches and pains that you get. But, when you put it all together, you can bet your life it's going to be a lot worse than if you didn't already have a disability to contend with."

"I know that you will get parts of the body wearing out as you get older - there's not very much you can do about that. But, I'm not sure that it's always easy to tell what you would have had anyway and what might be to do with having an artificial limb. On the other hand, there are some things which I know for a fact are connected to that. I've got spondylosis in my upper arm and right across my shoulders for a start. That, I have been told is to do with the strain I've put on the arm. I've also got a bit of that - what do they call it - a slight curvature at the top of my spine. That must have something to do with it as well."

"As you get older it (pain) definitely gets a lot worse. Also, I had a duodenal ulcer. I presume that was caused through the army - with all the strain and mucking about and all that. I've only got a quarter of a stomach, and as I say, my spine's nearly gone completely - and I've got one leg off. So, really, I'm just like a spare part unit."

"You see, you get all these phantom pains in your leg. As you get older, that's getting more severe anyway - now, they're more sharper pains than what they were before. But, the doctors don't seem to know much about it - so that's how you go on."

TABLE 1: PHYSICAL PROBLEMS/CHANGES EXPERIENCED WITH AGEING

Proportion reporting problem/change (%)	Amputees	Total sample
Arthritis/Rheumatic problems	85	29
Difficulties with walking	58	40
Decreasing agility/mobility	58	51
Heart problems/angina	42	12
Increased pain	42	27
Problems with circulation	33	12
Problems with shoulders, arms or hands	25	18
Spondylosis	25	4
Asthma/breathing problems	17	10
Spasms/spasticity	17	5
Ulcers	17	2
Headaches/dizzy spells	17	2
Drug dependency/side effects	8	12
Problems with vision	8	22
Fractures/dislocations	8	9
Viral infections	8	3
Changes in energy levels	8	27
Stroke(s)	8	5
Bladder or kidney infections	8	7
High/low blood pressure	8	7
Respiratory problems	8	11
Contractures/muscle wastage	8	6
Scoliosis	8	2
Brittle bones (osteoporosis)	0	5
Problems with transfers/turns	0	7
Proportion reporting problem/change (%)	Amputees	Total sample

Problems with hearing	0	6
Weight gain/loss	0	21
Muscular atrophy	0	3
Thyroid problems	0	3
Pressure sores	0	1
Limb deformity	0	7
Balance/co-ordination	0	4
Speech/communication problems	0	5
Edema (swelling of joints/limbs)	0	4
Incontinence	0	3
Epilepsy	0	1
Other(s)	25	13

IMPLICATIONS FOR USE OF HEALTH SERVICES/HEALTH CARE PROVISION

The experiences reported to us suggest that the provision of health care for long-term limb amputees 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 sensitivity amongst doctors on medical boards and tribunals. Again, this was related to concerns about the lack of understanding about long-term disability discussed earlier.
- * Some members felt that there is a lack of routine check-ups for long-term limb amputees, and that this aspect of long-term health care has declined over recent years. In particular, some felt that the standard of care in limb-fitting centres had declined since re-organisation, while others felt that it had been considerably improved. A few also talked about the reluctance of some older amputees to try new limbs and/or other aids which have been developed in recent years. This echoes accounts from elsewhere, and suggests that there may be scope for more work on helping older members to deal with their anxieties and concerns about new technology.
- * 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 limb amputations, and very little understanding about the long-term effects of disability amongst the medical profession as a whole.
- * 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 their original impairments; 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.

HEALTH SERVICES/HEALTH CARE (Quotes)

"One thing that does annoy me is all this fuss you have to put up with when you go to these medical boards. The way they treat you is shocking, it really is. They treat you as if you were a scrounger or something and they try to catch you out on the slightest thing. I think the whole system for medical boards needs to be changed. You need to get rid of all these stuffy colonels and majors for a start and get in a considerate and compassionate doctor instead. Also, I think it is very important that - if you do have to have an assessment - you should have a disabled person there to make some sort of judgement because, when you go now, they don't have a clue what it's really like - so how they can they judge anything. I had this when I went to get assessed for my mobility supplement. When they'd finished, this stupid major said - 'just hop over there and pick up your leg now, there's a good chap'. I was livid. I turned round to him and said - 'you bloody well get over there and pick it up for me, and don't you ever talk to me like that again - we're not in the army now.' I mean, that's the way they treat you - it's just not on is it."

"The doctors they have on the tribunals are better than they used to be - there is more understanding now I think. But, I don't like the system they have because they are always trying to trick you - to catch you out. Like, they have the meeting up two flights of stairs or something - you turn up there, you find out where it is, and you go in and they say - Oh, how did you get up here then? You know, they try and catch you out. But, you don't think of these things. If you're smart, you'd turn up and tell them - I couldn't possibly get up the stairs, could you send someone down to help me. But, you see, when you have that, people have to try and make themselves seem like they're helpless or something otherwise you can lose out. You get penalised for being honest and just trying to get on with it."

"I think, since they've re-organised the limb fitting service after the McColl report, it really has improved tremendously. The limbs they can give you now are just fantastic because they are using new technology which we just didn't have before. I know that some people are reluctant to try out a lot of the new limbs because they don't want to change after all those years, but they don't know what they're missing out on, really they don't. I know when I first had my new leg fitted, it scared the life out of me because I just couldn't believe I was ever going to be able to walk on a thing like that. I told the prosthetist that it just wouldn't work but he persuaded me to try it anyway and I had to admit he was right and I was wrong - it was marvellous - and, not only that, it

was cosmetically acceptable which was unheard of before. So now, after 40 years, I can go out in summer wearing shorts which I've never been able to do before."

"I think the trouble with a lot of the old ex-servicemen is that, they just don't want to try anything new. Also, I suppose the worry a lot of people have is that the spares for the old limbs are going to be run down - because it just isn't economical to make them in the quantities they want now. So, I suppose they think that they had better hang on to what they've got. But, it's a shame that they take that attitude because - with the technology they have now - the limbs are so much better. I mean, if you'd told me 10 or 15 years ago that I could have a carbon and plastic leg that you just slip on and stays on without any strapping or anything like that, I would have thought it was some kind of joke - it just didn't seem possible."

"The limb fitting service has improved to some degree, but not all that much. I know they do their best but - after the war and up to about 1960, you had good fitters who had grown up with the job and come through with us. Now, it's all theory and not enough practical experience. But I do think that some of the problems are due to the modern technology they have in limb fitting - it's all part of the same thing really. What I mean is that, these propylene (ie. plastic/rubber) limbs - they are good I know, but there's too much standardisation. When you had the metal sockets, if a limb didn't fit just right you could get a hammer and knock it into the right shape to fit. You don't have so much of that now, so I suppose the flexibility has gone out of the way the newer fitters work because of that. But, the biggest problem I've found is that they sometimes don't take the care over repairs and overhauls that they used to. I've had to change my fitters because of that actually, after I got my spare back and it hadn't even been checked after a service. It's just not on is it. It's a crime sending a limb out which hasn't been checked when peoples' lives depend on it."

"Since the MaColl report, the (limb fitting) service has started to change quite considerably. But, whether it's changed for the better is another matter. The ideas in MaColl were great - an ideal service in many ways - but they haven't been properly implemented. The contractors are too concerned about their own profits and there is the danger that people will sometimes end up getting what the suppliers want to give them, rather than what they actually need. That might be good for the suppliers - but it doesn't do anything to help disabled people. It's not an exact science in any case - fitting a limb - everyone's different. So, you can't standardise it in any way - you have to keep it on a personal basis."

"I suppose there could be more in the way of looking at new types of limbs - especially all the strapping and everything, because that's what causes a lot of the problems. I mean, my arm - this one hasn't been redesigned since 1945."

"Personally, I think the limb fitting service has improved tremendously since the Macoll report. It's certainly a lot more efficient because, now you can get in without any hanging about - in the past, you could go there at 9 o'clock in the morning and hang around til 4 just waiting to be seen to. And, of course, the other thing is that you have a choice of about six contractors now - so if you don't like one, you can always try one of the others. There's still room for improvement though. The main drawback is that the service isn't as personalised as it used to be. Before, you always had the same fitter - he was your fitter and he knew you and you knew him. Now, you might see three or four different blokes every time you go. So you have to spend a lot of time messing about explaining what you want and everything. When it was more personalised, you didn't have to worry about that because you knew your fitter and you had more confidence in what they were doing - especially if you ran into any problems. So, I suppose there is that element missing because you don't feel as secure as before. But, there's no reason I can see why they couldn't arrange it so that you had the same fitter - at least most of the time."

"I think the (limb fitting) service is very good. The only thing I suppose is that it's not so personalised any more. I don't think they show as much interest as they perhaps used to."

"I used to go to Roehampton but they send me down to Gillingham now. It's not too bad. You used to have fitters who were in the same boat as you. They had the same sort of experiences and that probably made the service better. The chaps these days don't have the same kind of experience but, on the other hand, they've got much better legs these days - so that's a big improvement. The only problems are silly little things. Like, when you go down there, they make you wait around for 40 minutes or an hour - there's no need for that. The other thing is stump socks - that really is a bit of a pain. You used to have these nice thick woollen ones, but the ones they have now are so flimsy they just wear out and you get pressure sores and allsorts. I've been to work with skin hanging off and weeping sores before now. You just have to put up with it but I do think it's a bit mean."

"Where you used to go up there to get your socks - now, you have to make an appointment. It's been privatised now - you even have to pay to park - that's at the Limb Fitting Centre."

Wife: "The last time he went they put an old strap on his leg - his leg fell off in (town) it's terrible isn't it."

"If you want anything doing down there now - it's impossible. It's a shambles - nobody knows what they're doing. It used to be lovely. If you went down there, if you were in pain or anything - you used to walk straight into that hospital and they'd see you right away. I used to go to Roehampton, but when they opened Harold Wood they transferred me there. It is nearer for me - but I think you used to get a better leg made when it was at Roehampton. The one I used to have from there was a lot more comfortable. I remember one time we went (Harold Wood), I came out of there and I could hardly walk. I said - what's wrong with this leg? They'd only gone and put on two left feet. Two left feet - I don't believe it. And, socks - honestly - I get through about 3 pairs of socks a week. The toes on that thing are so sharp they just keep tearing the socks. I think I'm going to have the toes chopped off because I can't afford to keep paying out for these socks."

Researcher: Would you like to change the leg?

"I have changed it - this is the new one. I wish I still had my old one but - when I went up there - they told me they were going to scrap it because it was condemned. I said - I don't want it condemned, it's comfortable. But, they just said - it's got to be scrapped - it's out of date. I don't think the service is as good as what it used to be - it's all young boys now, and they don't really know a lot do they. You see, when it was at Roehampton - you used to have one fitter, and that was your fitter. He was the only man you would see. So you see, when you were fitted with an artificial leg - he used to have a bit of black chalk, and he used to mark it on the sock. Then, you'd walk up and down for an hour to find out if it was rubbing. They don't do nothing like that now. If it hurts - they just shave a bit off. But, how do they know where it hurts. So, I've had abscesses on the back and all sorts."

"I think you should be able to go up to somewhere like Harold Wood at least every 6 months. You see, now, they don't send for you like they used to. You just have to take yourself up there and hope for the best. In the past, if I had any problems I'd just go up there and say - can I see the doctor. But now, you can't get in there unless you make an appointment. So, that's not so good because - if your leg's hurting and you're in pain - you want to get it seen to straight away."

"I used to get a regular check-up at Roehampton, but I haven't been called down there for years now. Personally, I'm not all that bothered because I don't really need to go but it would be a good idea if they did call you up so that you could go if you wanted to."

"The other thing I would say about the limb fitting - they could do more to keep people up to date on the new technology. They don't tell you enough about all the new developments, so people don't always know if there might be improvements which could do them some good. That's another reason why it would be useful to have more regular visits, because you don't always know what's available."

"No - but it would be a good idea to have a regular check from your GP - they know you best."

"I've had 5 operations on my ear. I've been from one hospital to another - but they couldn't find out what it was. I've been going backwards and forwards for 10 years before they found out what it was - can you believe it. But, with this new one (Consultant), it took just one sitting and it was cleared up in a fortnight."

"I think they could do something to get the waiting lists down. My wife was waiting 2 years for a hip replacement. We went private in the end because she was in so much pain."

"My GP has said that they are doing these check-ups for the over 75's. I haven't had one yet but I am going to. She said I would be able to have one every year if I want it. Yes, I'm very satisfied with my GP. She's very interested in my situation - she's what you need with a doctor."

"I hardly ever go to my doctor, but he wouldn't be much use if I did really. I did go to have my blood pressure checked a couple of times but I don't bother now. I did go once though when I was having difficulty with my hearing. I told him I wanted to go to the military hospital and he said - you are ex-services then are you? I mean, he didn't even know about that - he should have known from my notes, but he had to ask. So, that shows

how much interest he was taking doesn't it."

"My old GP was very good but the one I've got now is not so good. I had to change because the surgery was too far to walk since I've had this angina, that was the main problem."

"It does make you wonder when you hear about all these chaps having heart problems and all this arthritis and everything. I think a lot of that might well be down to pushing people to do too much when they're younger - or even, when they're older as well. It was the same with me walking for all those years without a stick. Mind you, I didn't really have much choice if I wanted to work. I mean, alright, I know it's their right. If someone wants to try and walk then that's up to them. But, if they're forcing people - making people walk all the time when it might not be the best thing for them in the long run - I'm not so sure if that's the right approach."

"The only place I know of where they seem to have the right approach (to rehabilitation) is the Churchill centre - down at Maidstone. You see, the idea they have down there is that, they don't just look at what you can do physically - they do a complete assessment and go everything you can do, and what you want to do. I think that sort of thing is very important. It's especially a good idea for older people because they might need to find new ways of walking, or help with doing other things they might be having problems with. But, with ordinary doctors, I think they often try and force things on people. You know, they say - you must do it this way, and if you don't, that's just tough. But, the way they do it at the Churchill is much better because they try and see what people actually want to do and try and fit in with that. That's the sort of place that ought to be involved with what you're doing - I think they'd be very interested."

"Oh yeah (check-ups) - it would be a really good idea. I think that's a really good idea. I mean, if it's something that would get you out of pain - I don't care how far I have to travel."

PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING

Like many other groups within the ageing population, people with long-term limb amputations 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 limb amputees 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 BLESMA and other voluntary organisations to act as 'information brokers'.
- * Unlike most other groups of older disabled people, however, BLESMA members do have access to their own residential homes, or other supported housing for ex-service men and women. Although most would still wish to avoid moving into any form of home, they were at least confident that there would be somewhere they could go if they needed to.
- * Some older people 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 local and national disability organisations.
- * There are also problems with claiming benefits and some individuals reported having experienced difficulties in establishing their entitlement to benefits such as Attendance 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 or additional allowances on their war pensions. 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 disability discussed earlier.
- * Regarding welfare services provided specifically for ex-servicemen. Almost all of those interviewed were satisfied with the support they had received from BLESMA over the years. There were noticeably more criticisms, however, about the War Pensions Welfare Service, which several people felt had declined considerably and no longer provided the continuity of support which they had relied on in the past.

PRACTICAL AND PERSONAL SUPPORT NEEDS (Quotes)

(1. Personal and domestic assistance)

"My wife can't really walk very far at all now - so, I sometimes have to give her a little help around the house or doing a bit of shopping. But, we're both very independent and we wouldn't want any outside help - we'll be

able to manage as we are."

Wife: "It's nice for you to come to have a talk to us like this - it's nice to know that someone's taking an interest. But, I think that a Welfare Officer should come here every so often to see how you're getting on - but they don't. I think they should come round once or twice a year - but you don't see no-one. You used to get a visit from the War Pensions Welfare Officer - but they stopped that, they don't do that anymore. Although, you can get them if you ring up and say you are in trouble - they will come down."

"There aren't any good samaritans now. We were lucky that there was a young bloke down the road. He said - if you want anything, just give me a knock. But, you can't keep on pestering them can you - you can't impose on these people all the time. Well, I'm not going to do it anyway. In the end, the house just gets run down because you can't afford it. And, you've got so much on your mind - it does get you down."

"The government now - they keep going on about everything being cost effective. It's all very well - I mean, there's no point wasting the public's money, I agree with that - but, you can't very well run services like some big industrial corporation. It's just not possible to cost everything out like so many spare parts - not when it's people's lives you're talking about. No, it's all about the quality of life - and how do you cost that? I'm not saying you shouldn't look at how the money is being spent, but that should not be the main assessment. First of all, you have to ask whether a service is improving the quality of someone's life - that has to be the number one consideration."

"If the government are serious about wanting to improve the lives of disabled people then there has to be signs of some genuine commitment, which I don't really think we've seen too much of so far. Maybe with all the changes that are coming through now things will get better - we'll just have to wait and see. But, I can see why some people might be cynical - especially when they say they're going to give people more choices. There aren't that many choices - all that we have seen is that there are more and more nursing homes opening up. Maybe that's what they mean by giving more choice - I don't know."

"I think it would be good if you could get some help with the garden and repairs on the house and that sort of thing because, if you can't manage to do it yourself anymore, it all goes to pot - which is a shame. Maybe there are some voluntary helpers or something like that - but really it should be organised through the council, so people know where to go if they need that sort of help."

"The only thing that does worry me is what I would do if my wife wasn't here. I wouldn't be able to manage on my own."

Researcher: Have you thought about what you might like to do if you found yourself in that position?

"No. I worry about it sometimes, but I haven't made any plans. I suppose I prefer to think about it at the time - there's no point just now."

"I don't really know what other help I might need later on - it depends how long you live I suppose. The garden would be one thing - that's for sure. We already have to have help with that and so, if we moved somewhere else with a garden, it's a sure bet we'd need some help sooner or later. The only other thing I can think of straight off is - maybe later on a hoist. Mind you, I have heard some people have to wait a pretty long time to get them from the social services. I don't know if I'd like to do that - I might have to pay for it myself if they made you wait too long."

"I've always been able to look after myself without any problems at all. I don't see why that should change, but if it did I think the best thing would be to employ someone to give me a hand with whatever I needed. I think it's much better to stay at home, because then you have everything the way you want it. Probably the only thing that would change that would be if I ever ended up in a wheelchair, simply because I would have to have the whole place re-designed so I could get around. That would probably be impractical - but I hope I don't ever have to worry about that."

"Getting in the bath is probably the only real problem. That is getting pretty tricky now. My wife does help me some of the time. But it depends - some days I can just about manage, but other days it's more or less impossible, or at least it's pretty dangerous to try it - I have fallen a couple of times."

"You could say it's about an hour and a half a day altogether. But, it's all the little bits of help you need. Like, I might just want my wife to help me put my coat on if I wanted to pop out - things like that. It's hard to say exactly how much help you'd need like that - it depends on what you're doing."

"If it got to that stage I would have somebody coming in - yes, definitely."

Carer: "If anything happened to me - if he was left on his own -then he would definitely have to have something like that."

Researcher: If you were in that situation, would you prefer to have somebody from an agency like Crossroads, or the Council - or would you prefer to get someone yourself?

"Get someone ourself - definitely. But, I wouldn't be able to afford a lot anyway - that's the only problem. The thing is, when you're doing something like that, you've got to be very careful who you see and who you let in the house. Even if it's a private contract. I mean, I would never let them in the house until I know them properly"

"Whatever way you look at it, there are always going to be problems. There are a lot of pros and cons you've got to way up. But, it would still be much better than relying on the Council. I've got no time for the Council."

"Having your own helpers would be a good idea. I would be prepared to pay - but it's a question of being able to afford it. If I ever had anything like that, I think I'd prefer a woman - they can handle things better."

"I suppose I'd think about having someone come in - it's not a bad idea in theory. But, it depends on the person really. Some of them want to be involved and I don't know if I'd really want that. If it's just a question of someone coming in when you need them and then going again - that would probably be alright."

Carer: "That woman who just came in - she lives up the road. Now, she is very good. If I'm in trouble in the night or anything, I've only got to phone her and her and her husband will be over here like a shot. That woman would do anything. But neighbours -the neighbours wouldn't help you"

"Oh yes, I'm very happy with that - we get on very well with all our neighbours. It's like a little community round here. But, of course, a lot of them are in the same position as I am - so I don't know that they would be able to do very much although I rarely ask for anything in any case."

Researcher: Are there any other local services you'd like to use which you don't use at the moment?

"Well, there's not a lot round here is there. I don't know no local services. The only thing we got round here is that Dial-A-Ride - I don't even know what that is - that's something to do with the handicapped isn't it?"

"It's a much better arrangement than having a council one (home help). She's very reliable."

NOTE: Above respondent has a private domestic helper.

"We did ask to see someone from the council - a Social Worker - last year. But, we're still waiting for them to come down."

Researcher: Do you have much contact with the War Pensions Welfare Officer?

"You don't see them so much these days - they don't really come down to see you unless you ring up and say you're in trouble. But, I think - the thing with the welfare services - they're running them down and, to be quite honest, I think they're just waiting for us to die off. You see, there's not a lot of us left now and the few of us what are left are just the lucky ones. But, like I just said, they just don't care - they are just waiting for you to peg out."

Carer: "I do everything like that for him (getting in and out of bed). It's OK at the moment, but when I get older it will be a problem. But, as I say, at the moment I'm OK - I can look after him."

"When I went up to the civic centre about getting a rebate - they said well, you get the pension. I said - you

must be joking. OK, you have my legs and I'll have your job. He apologised and I said - I should think you should an' all."

(2. Aids and adaptations)

"I have tried one of these new rubber limbs from Germany. £800 it cost me - but I can't use it. It just doesn't fit right and - sweating - you sweat so much in one of those things, I just couldn't get on with it."

Wife: "It's a really sore point that is - I keep going on at him to take it back, but he won't listen. I think, if it doesn't suit you they should change it or give you the money back."

"They won't give us the money back - just forget it, it's done now."

"I think the new limbs they are making now are marvellous. I know some people aren't so keen - it's down to the disposition of the individual isn't it. The new limb they gave me has been tremendous - it's given me so much more freedom of movement."

"Having some longer (bath) rails might help a little I suppose, but it doesn't really solve the problem because - it's the deterioration in shoulder power - if you can't push yourself up, then a rail doesn't make much difference."

Wife: "When we had the bathroom done, the council said - we'll give you 90% and you pay the rest. Well, then he phoned up and said - I'm sorry, I've made a mistake, we can only give you 70%. So, we had to find £600. Anyway, we got on to BLESMA and BLESMA give us £250. And, we got on to (SAFFA), and they gave us £250. So, that helped us out - otherwise we would have really been in trouble."

"With things like decorating - it's so much harder to do it when you get older. So, if you can't get someone to help you out as a favour, you have to pay - which is what we do. But, the thing that really annoys me is that these houses - the housing association bought them for the war disabled, but they haven't done anything about the upkeep. Now, they say they're going to put the rents up in line with council rents - but, will they pay for any repairs? Will they hell. These houses were great when we first moved in, but, over the years, they've gone down badly. This house needs decorating again and there are a lot of repairs which need looking at. It's very drafty and we just can't afford to do it ourselves. I mean, if they were going to put the rents up and do something about these repairs it would be alright - but they're not prepared to do any of that."

"Recently I have applied to the social services to get a rail for the steps outside the front door. I've been waiting five years now since I first asked about it and now they've said it will be another 3 months at least. The thing is that, they say that comes under the leisure committee, not social services - it doesn't make a lot of sense does it. Anyway, that's that. I think I'm going to want to get a rail for the toilet as well, so I'll probably have to wait for that too."

"Telephones - they're a lifeline. That's something that should be available to all older people. You have to have some way of getting help if you need it."

"The social services have provided a hand rail and the bath seat. As I say, I need to get some bath rails off them now as well. They have been good - I've got faith in them if I need them."

(3. Transport needs)

"I lease my car on the motability. That's been really good - it's improved a lot since they first started. I couldn't afford to have a car without it."

"I used to do all my own car repairs out there on the kerb. I couldn't do that now - no way. But, I have Motability now - I used to have a Ministry car - but I think the Motability is an excellent scheme. Really, I can't

understand why anyone wouldn't want leasing - it makes life so much easier."

"It's vital to have a car. That's the only thing that makes it possible to live here - we'd never be able to get out anywhere without the car."

(4. Housing needs)

"All the houses on this estate are for disabled - so we're our own little community and most of us all get on very well. Not that we live in each other's pockets or anything - but everybody helps each other out if it's needed."

"I can't climb the stairs now and so we are going to have to move as soon as we can get something fixed up. I have applied to the council for a place in sheltered accommodation. They sent us to view the first place they had but it put me right off. For a start, there wasn't enough room to swing a cat in there. There wasn't even enough room for one person let alone the two of us. Actually, I'm pretty sure it was only meant for one, but they were just trying to fob us off that it was meant for two - I was thoroughly disgusted with the place in any case. It was very badly designed all the way through. It just didn't make any sense for someone who has a problem with mobility - I reckon you'd have even less mobility in one of them flats. Then, I can't get in the bath so I need a shower - all they had was a communal shower - I ask you. And the toilet would have been far too low - if I got on that thing, I wouldn't get up again. I did ask about whether I could get a shower put in if we did move there, and get it fitted out so that it would be a bit easier to get around, but they said no to that as well. On top of all that, I didn't think too much of the warden either. She didn't seem at all interested and you could see that they didn't do much checking up or nothing - which defeats the object in any case."

"Having seen the council place, I think I'm going to have to look for something else. It's tricky anyway because, they only offer you three places and then that's it. So, you think to yourself - the other ones might turn out to be even worse, so maybe I should take it - so you're sort of forced into it a bit. No. my ideal choice now would be one of the Lord Roberts Workshops bungalows. They've got some nice ones on the Isle Of Wight - two bedrooms too - so that may be a better bet altogether. We are going to look into now and see what the chances are. This is a problem though isn't it - you have to dig and probe to find out what's available. Apart from taking up a lot of time, it can be a pretty hit and miss affair whether you actually find what you're after. I think that there should be somewhere you could go for this sort of thing - it should come from the social services, they should be doing that. But, the trouble with the social services is that - if it's not on their books, it doesn't exist. They don't really bother to find out about what else might be on offer."

"We bought this bungalow - where I have the boat. If it was up to me, I'd much sooner go and live down there - I much prefer the country to living in a town. But, we can't do that you see, because of my wife - she couldn't possibly manage down there because she needs to be near to the shops and everything else. It would be too cut off for her, so we couldn't sell up and move permanently."

"I won't move - not at my age. The only reason I could think of why we would ever want to move is that - my family aren't from round here - it might be nice to live a little closer. But, we can't afford to move anyway - it's best if we stay here."

"We've put in for accommodation with the British Legion. They've got some bungalows (British Legion Village at Maidstone) and one of those would be just right. Either that, or sheltered accommodation - they've got some places as well. The upkeep for this place is getting a bit much - it's quite high here. And, the garden as well - it's far too big for us to manage now."

"I'd try and get a place in sheltered accommodation or maybe at one of the BLESMA homes - they're really comfortable there and you've got everything you need. You see, now, my wife has to help me in and out of the bath so I'd have to have someone to do that. The other thing is help in the night. I mean, if I have to go to the toilet in the middle of the night I might not make it unless I've got someone to help. I suppose I'd stay here to start with and see how I got on but, if it wasn't working out, I'd just as easily move."

"Of course a lot depends on my wife. If anything ever happened to her, I think I would go to Crieff (BLESMA home). It would be much simpler that trying to stop on at home - even if you had helpers coming in. I mean, you are so well looked after there - it's as good as any 4 star hotel. We've been going for 12 years now because we

like it so much, so I know the place well. The only other thing is the children, but you don't want to go putting on them, so that's not really on. No, Crieff would definitely be the best bet for me."

"With residential homes - you're confined. I'm an outdoor man by nature - it wouldn't suit me at all. With flats - it's the same. It's not for me. If anything happened to my wife and I was desperate I could go into a service home. But, I wouldn't like that - it's too regimented for me."

"You say that most older people don't want to go into a residential home. I'm sure that's right - at least they don't if they can see an acceptable alternative. But, you know, it also depends a lot on what type of home it is and who runs it. Now, BLESMA have two wonderful homes and you are very well looked after there. I think you'll find that most of the men - although there are a few women there now as well - wouldn't be anything like as keen to go there if it was run by some private concern, and if it wasn't specifically for ex-services. They feel comfortable there because they know that it's their home and it's run by their own people. So, I think that has a lot to do with it. But, if you look at the situation for other groups of people who don't have their own organisations looking out for them, I can understand why they wouldn't be so keen, because the standard of care in a lot of the nursing homes around now leaves a lot to be desired by all accounts. But, I think that the future for places like the BLESMA homes is limited because the population is dwindling. Even now, they don't have enough people to fill the places they have. That's why they offer holidays - just to use up the empty places. But, the trouble is that the DHSS are moving other people - not ex-services - in there now. Alright, I understand that they have to go somewhere, and if there are spare places they may as well be used. But, it is a bit of a shame because then the homes lose the special atmosphere they've always had."

"If I had to, I'd go into a residential home. But I'd rather not if I could avoid it. I've been to the BLESMA homes for meetings and functions. They're very good but I think I'd find it very depressing to be there all the time because - if you have a place full of disabled people - you get caught up with people talking about their disabilities all the time - things like that. It's not much fun is it."

"Having a bungalow - it's invaluable if you can't get about so easily. That's why we moved here. We decided life would be easier in a bungalow - especially for my wife."

(5. Financial needs/War Pensions)

"Financially I'm well off - there's no worries there. In fact, with the two pensions and all the allowances I get with the War Pension, I'd say we're better off now than at any time in our lives."

We had to buy the house. We were getting a rent rebate and then -all of a sudden - they stuck our rent up ,50 overnight. You see, what they done - they took my war pension in with my other pension, and they put them two together. Now, to me, that's wrong. They've always said that the war pensions would never be stopped on any account. But - they've done it in this council. So, I've lost about ,25 a week."

Carer: "Believe me - he gets a pension, but it's hard to live -it's hard just to scrape through. I mean, we don't have no luxuries. We don't get no clothes. As a matter of fact, we get our clothes given to us."

I can't climb ladders now - so I can't do the guttering. I mean, I can't keep paying out ,400 to do the guttering. But, you can't get no help anywhere. Things like that, are what you need, you can't get them. I had to give the garage up, because of the poll tax - I just can't afford it."

Carer: "The council should help. I mean, I do a lot of things here. I mean, I strip walls and everything. And, when you're getting old - I'm 70 now - it does get too much for you. I mean, he tries his best - but we can't afford to keep paying out for people to do it."

Researcher: Do you think the council, or somebody like that, should offer a service to help with things like that - with the repairs and decorating?

"Yes, that would be a good idea - as long as they don't charge too much. You see, some council's might do that but - here - they're absolutely useless. I mean, you go up there, and they just don't want to know they can insult

you right and left - that's what you get."

"We're managing OK - we're still able to save a little."

"We were getting a rent rebate first of all. Then, all of a sudden out of the blue we got a letter saying we've got to pay ,56 a fortnight. That's about all you've got - it came as the biggest shock of our life. That's when they stopped my pension -they said they'd take it off my pension. So you can imagine the state we're in can't you? We don't get a penny - we don't get a penny off of nobody. This thing that you're supposed to get rebates - it's a load of rubbish."

Wife: "You know, I wrote 3 letters to Brian Gould - you know the MP. I said - I was under the impression you were supposed to help the disabled and the old age pensioners. But, I said, to my mind you just look after yourselves."

"We get almost ,200. But, that's for 2 of us mind. By the time you've paid your mortgage, your water rates, your insurance, your gas, your electricity - by the time you've finished all that, believe me there's not a lot left over - we got about ,30 a week to live on, and that's it. That's with attendance allowance, mobility allowance, my pension, and her old age pension - everything together - it's not a lot."

Researcher: Do you think the amount of money you've got to pay out has gone up over the years?

"Oh yeah - definitely. I mean, I don't spend a lot because I aint got it to spend. I was better off 10 years ago than what I am today. The money has never been a lot - but it's the cost of living that's gone up so much. I was working up until I was 58 - then they closed the firm. Before that, I'd always worked - I didn't have no disabled badge or nothing like that. It was her (wife) who went and got that. But, that was only after I'd retired."

"The pension you get just doesn't keep up with the cost of living. It's lousy really - we only just get by. If you ask me how much I think we need - I'll tell you, I think it should be ,150 a week. I mean, if you go to these foreign countries - like Germany and that - that's what they're getting. I mean, I've got a friend what lives in Belgium and his pension's about ,200 a week plus their old age pension. It is hard to live here - when we do our shopping, you have to look at every ha'penny you know. And, we don't buy no clothes - if you have any money, it all has to go on the house. With the lack of money - there's a lot of things you have to go without. I mean, there's things what I'd like to have done to the house if I had the money to spend on it - but you can't do it."

Wife: "My daughter has helped us out. But, you can't expect them to keep doing it - not when they've got 3 kids - I can't keep asking her."

"It was only when I was reassessed after my heart attack that I found out about mobility supplement and unemployability. All those years I could have been claiming the allowances - but no-one ever told me that. You see, before I went into service I was a fully qualified mechanical engineer and after the war, of course, I couldn't go back to the same work. So, now I find out that I could have had unemployability supplement and the Reduced Earnings allowance because of that - but I missed out because nobody ever told me that, either at the time or any time since then. Still, I don't ever bother about it now because it's done and there's no sense moaning about it. But, it makes you realise what you've missed out on. I do think they should be more on the ball when it comes to telling people what they're entitled to - but they don't do that."

"I retired when I was 63 - I'm 70 now. I had a duodenal ulcer and so I went out on health grounds. Financially, it's the best thing that ever happened to me because, if I'd stayed on till I was 65 I would have just got the old age pension. But, they told me at BLESMA that I should go before a medical board because I was going out on health grounds. So, I did that and I got 100% pension. That's worked out quite well except that, I also found out I could have been getting that pension for years. I'd never had a medical before then you see. When I told them (at BLESMA) they were amazed. Still, it's too late now."

"The pension is very good but, really, it's come at the wrong time of life. It's not that I don't need the money - I do. But, I can tell you, I could have used it much more when I was younger - you know, when you're starting up a family and all this sort of thing. But, I just didn't get any help in those days."

"I was on 60% when I first came out. So, all that time, they were doing me out of 40% - all them years. When I

first went to the medical board, they said there was no change. When I got on to BLESMA, and they sent a letter straight away and I got another letter back saying I'd got the 100%. So, why couldn't they have done that in the first place?"

Note: Above respondent developed osteoporosis in the spine as a result of wear and tear caused by the original amputation. But, was not reassessed at 100% until 30 years after the onset of his original impairment.

"And, another thing. I mean, we've all done our bit for the country - but, you take the Falklands - their pensions are double mine is. But, they served about 4 months in the Falklands and I done nearly 6 years in the army - and what do I get - ,60 a week. They're getting ,140 and ,150 a week - so where do you go from there? You see, it's two different payments - but why should there be. The other thing - which BLESMA have been fighting for - is the pensions for the widows. I mean, if anything happened to me, I think my pension should still go to her until she dies - but it don't. That's the sort of thing that these people should try bring up. I mean, if I go, my wife will get about 30 odd pound a week - what's the good of that? So, that's a thing - if you could get round to that in your interviews and your report. When a person dies, and he's on a pension, the pension should keep on until the wife dies. If it's not the full pension - at least half of it, so that at least she's getting something to keep her going. Why can't the Government do something like that - I think that these sort of things should be brought forward so that - the few years they've got left to live - they can enjoy in comfort and not have to scrape and scrounge like you do have to. So, this is a good thing what you're doing - if you could get something like that published."

Wife: "It's not just the money because - with all the work that we've done for the Government at home for all these years - it's a small sum to pay. So, like he says, this is the good thing that you're doing. I mean, I know we can speak for ourselves - but if you've got so many people saying the same things, then you know they're not lying or nothing like that."

"The main complaint I have isn't about the pension itself - it's that you get taxed on it and you're not supposed to. The other thing that does bother me - you probably heard this from a lot of people - the widows - there's so many anomalies about pensions for war widows. You take my wife - she's had to cope all these years and she doesn't get any help - it's not fair. But, if they would only produce some clear guidelines on who can get a widow's pension and who can't then at least you'd know where you stand."

"This business with the Falklands really put my back up as well. Those men were only out there for a few weeks - we were fighting for six years in the second world war. But look at the amounts they got - it's just not right. But, the worst part of it all, I think, is the way they've created two tiers of war widows now. That is shocking - such an insult. All those widows gave up everything they had and that's how they get treated. It's unbelievable really. And then, if you think about those whose husbands are still alive - think of all the work they've put in over all those years looking after their husbands, and think of all the money they've saved for the government by doing that. Alright, some of them will get a pension if their husbands go before them. But, that's only if they can establish that they died as result of their war disabilities - and that isn't as easy as it sounds and they may well have to fight to get it. But - the others - they're going to miss out all together, and that's hardly fair is it."

"That was the biggest insult going. I wanted to work but they wanted to give you work that you wouldn't give to a kid - and I wasn't having any of that. That's an insult. They don't look after the disabled - not one bit. I wrote to the council - and they want ,400 to do that run in and ramp at the front. I haven't got ,400 to do that. I can't get a penny - I don't get a penny off nobody. Everything I've got, I've had to work for. I've had nothing off of the State - I've had nothing at all. I mean, I'm a very independent sort of bloke - I would like a bit of help now and again if I need it."

"My wife gets this Mobility Allowance now, although we only found out about that quite by accident. My welfare officer (War Pensions) came on a visit one day and she said - I couldn't help noticing that your wife is having difficulty walking, are you claiming for Mobility? Well, I didn't even know what it was then, so she gave us the form and said to take it along to our doctor. So, she went to see the doctor and he told her he'd fill it in as soon as she walked in practically. He said - it's obvious you should be getting it Mrs. xxxx, so that was that. But, you see, we only found out about that my chance - she could have been claiming it for years, but we just didn't know."

"It's just about enough to cover my expenses - yes." (ie. Mobility Allowance)

(6. General views about BLESMA)

"If you ask me, the problem with the ex-services organisations is, they're just too close to the establishment for comfort. They always seem very reluctant to rock the boat in any way in case they upset any of their friends in the civil service or the government. But, when you look at the sort of people running them, it's not surprising is it. They're all majors and colonels - they are actually part of the establishment themselves, and I think that most of them are completely out of touch with how disabled servicemen feel and the sort of problems we have."

"I'll tell you one thing that makes a difference when you're talking about war pensioners. I'm an RAF man myself and I've always thought that there are differences between us RAF and the army pensioners. The RAF men are more gentlemanly, but the army and navy types always seem to me to be whinging and irascible. So, I think you'll find that the ones who are always complaining are more likely to be from the army. The RAF and the army never get on you know - well, in my experience they have never got on."

"I think that self-help is very important. You take an organisation like BLESMA. Now, BLESMA really looks after its own people and that only started really because no-one else was doing anything. The government made very little provision in the early days and you look how much things have improved from the First World War, to the Second World War, and then you look at what the chaps who came back from the Falklands are getting - tremendous improvements - and you wouldn't of had any of that if it wasn't for people like BLESMA pushing the government all the time. Still, it's a shame in a way that it takes a war to make them sit up and take notice - I hope we never have to see that again. I know because I've been through it, and I think war is madness, I really do. So, self-help is a lot of the answer - and you also have to help yourself. I was lucky enough to get a good education after the war because I went out and got a training grant, otherwise I would never have been able to do that. That has made a tremendous difference to my life, because I was able to get a fairly good job."

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 BLESMA should respond. Rather, we have simply pointed out some of the most important practical implications and highlighted the key issues which older disabled people themselves are most concerned about.

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

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Appendix A: Details of project participants

Breakdown of impairments (by gender)

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

Appendix A: Details of project participants

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Current age by gender and race (interview sample)

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

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

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

Appendix B: Dissemination materials produced

Publications arising from the research

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

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

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

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

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

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

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

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

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

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

Main project report

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

ISBN 0 900822 04 X

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

Briefing papers

Appendix B: Dissemination materials produced

`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 male 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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