

## **AGEING WITH DIABETES - PRELIMINARY FINDINGS**

Gerry Zarb, Thames Polytechnic - February 1991

INTRODUCTION: The preliminary findings on ageing with diabetes are from a wider study on ageing with disability. The study is examining the experiences of people with a wide variety of long-term (defined as 20 plus years) physical disabilities or disabling illnesses who are now also experiencing the ageing process. These include the following;- Diabetes; Polio; Multiple Sclerosis; Scoliosis; Parkinsons Disease; Amputations; Arthritis.

The survey is an independent enquiry funded by the Joseph Rowntree Foundation and will lead to the publication of a major report directed at policy makers, service professionals and voluntary organisations. The report will aim to increase awareness of how people who are ageing with a disability view their own needs, and what kind of support services they would like to see developed. We hope this will also lead to improvements in service provision.

We are also keen that issues raised by the study should be made available to and discussed with the relevant voluntary organisations whose members have volunteered to participate in the research so that they can utilise this information in their own work.

This document contains a selection of quotes from members of the British Diabetic Association who have contacted the project in response to the request for volunteers in the September 1990 issue of 'Balance'. These quotes have been organised under the following broad headings which reflect the issues most commonly raised by members;-

Concern about ageing/Need for research;

Physical and health problems associated with ageing;

The introduction of human insulin;

Health services/health care;

Practical/personal support needs;

Each section contains a summary of the main issues raised and (where appropriate) the possible implications for BDA and others. This is followed by a selection of members quotes, from which the reader may obviously draw further conclusions and insights based on their specific interests in the material.

THE RESPONDENTS: To date we have been contacted by 72 members of BDA; 6 of these have already been interviewed, either in person or by telephone, and it is hoped to complete interviews with a total of around 25. Of the remainder, some have already sent written or taped accounts of their experiences; extracts from these have been included with the other data contained in this document. Altogether accounts (some short, some very detailed) have been received from a total of 54 out of the 72 people who originally contacted us. The average age of these respondents is 63, with the youngest being 40 and the oldest

aged 86. They have had diabetes (insulin dependent) for between 23 and 62 years, with the average being 39 years. (This includes 6 respondents who have had diabetes for over 50 years, 3 of whom we know are Nabarro medal holders). 53% are men and 47% women.

## CONCERN ABOUT AGEING\NEED FOR RESEARCH

The large response we have had from people with long-term diabetes indicates the considerable concern about ageing and the need for more research of this kind. As the selection of quotes under this heading from members illustrates, there are several dimensions to this concern:-

\* Many 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 diabetes itself and/or long-term use of insulin.

\* Even where people have not yet experienced any significant problems, some are anxious about what may happen when they are older. Those who have other diabetics in the family are, not surprisingly, anxious that their relatives might avoid the problems they have experienced; others are simply concerned for the sake of future generations of diabetics.

\* Whilst medical research is obviously important, many people clearly feel that there has been a marked lack of attention paid to the long-term implications of living with diabetes in terms of quality of life issues and practical/personal support needs. As the quotes highlight, some people 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. Whilst the study will hopefully be able to meet some of these expectations, there is a clear need for organisations like BDA to take this further and incorporate members' concerns into their own work.

## CONCERN ABOUT AGEING\NEED FOR RESEARCH (QUOTES)

"I have read with great interest of your survey, and would very much like to help in whatever way I can - for far too long I have felt this particular aspect of research has been neglected." (ID 248)

"I'm scared to death of what's going to happen to me. I'm living by the skin of my teeth - I really am." (ID 174)

"I have had diabetes for 30 years. Also one of my sisters has had it 35 years and my brother 27 years. We all are experiencing the ageing process and are apprehensive of the future. Our father had diabetes for 43 years, and when he died he had lost most of his sight and had had both legs amputated below the knee. So, naturally we wonder what the future holds for us." (ID 280)

"I have been an insulin dependent diabetic since 1961 and am now aged 36. I have seen many changes in diabetic care over the years and am aware of the complications I may be prone to in future years." (ID 240)

"There's too much emphasis on simply researching the causes of diabetes. I'm not saying that isn't important, but there's not enough attention being paid to long term treatment and support. I'm at a stage now where no-one has ever trod before. For example, I'm worried about the possibility of blindness. I have had laser treatment but - the thing nobody seems able to tell me - is about the possibility of regression and what I can do about that for myself to control the situation. It's important that these things are looked into thoroughly because, it's only been started in the last 5 or 6 years, and nobody knows about the possible long term effects." (ID 254)

"Some of the doctors at the main diabetic hospital I attend (Addenbrookes) have never heard of some of the complications people are getting with diabetes. Or, at least, they have never heard of them in the past. In the last few years they do seem to be more aware, but I don't think they know enough about why these things are happening. I mean, the most difficult question is whether or not it's due to more ageing diabetics experiencing a wider variety of problems, or whether these are also down to human insulin." (ID 254)

"I think it's very important to have a study like this because, in the past, even when there has been research no-one ever seems to have bothered to find out how people with diabetes really feel about their lives and all the little ways it can effect you. You need to put the research in a wider context, so I think it's very good that you are trying to do that. It's no good if these researchers come along and don't listen to what people are telling them. So many of them are blinkered in my opinion - they don't open themselves up to their subject." (ID 254)

"I should be happy to participate in order to assist fellow diabetics and others. I am 66 years old and have been an insulin dependent diabetic for 27 years. I have been fortunate so far in escaping some of the unpleasant secondary effects - all the more reason to assist." (ID 112)

"I've had uncontrolled diabetes for the last 15 years - possibly longer. A couple of years ago I had gangrene in my foot which had to be amputated. I was in hospital for 8 months. Now, it's completely finished me - my life is over. I'm dreading the future - I'm taking no chances. I don't go anywhere - I no longer enjoy life." (ID 089)

"I would be pleased to help you in your survey, as it would be of great interest to me as well as yourself." (ID 167)

"My wife and I have long been anxious to reveal my history to someone to whom the knowledge would be of use, but until now without success. I would be most willing to take part in your survey, especially as our son has now been diagnosed and I am anxious he should not have my problems. So, best wishes to your project, I hope I can help." (ID 198)

"Obviously, the medical profession should be trying to find out more about these things (ageing). But, the thing is that it's hard to know who is going to do it - nobody seems to show very much interest." (ID094)

## 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. arthritis) 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 number of problems/changes which seem to be related much more specifically to long-term diabetes. As mentioned earlier, several people felt that there is a need for more work on separating out the consequences of ageing and diabetes 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 diabetes, it will be difficult for the medical profession to develop appropriate medical interventions. Out of the 54 people who have given relevant information to date, 51 have specified one or more physical problems/changes, whilst 3 people reported that they have not experienced any. A breakdown is given below:-

PROBLEM/CHANGE	PERCENTAGE (Base = 54)
Blindness	19%
Problems with eyesight (not blindness)	19%
Arthritis	17%
Coronary failure	13%
Reduced mobility	13%
Over/under active thyroid	11%
Hypoglycaemia	11%
Unstable diabetes	10%
Peripheral neuropathy	8%
Kidney disease	8%
Carpal Tunnel Syndrome/Ulnar Nerve Compression	6%
Circulatory problems	6%
Reduced energy levels/fatigue	6%
Angina	6%
Amputations	6%
No physical/health problems	6%

OTHERS (All less than 5%):- Anaemia; Hearing problems; Blocked arteries; Muscular Dystrophy; Myanthenia Gravis; Viral infections; High blood pressure; Skin damage; Communication disorders; Sciatica; Stroke

\* As might have been expected, the two most common physical problems experienced are impaired vision and blindness. The availability of laser treatment in the last 10 years may well help to reduce the incidence of blindness amongst diabetics in the future. At the same time, those who have had this treatment have reported mixed experiences (see section on health care) which suggests this may not be a universal solution.

\* Whilst it would be unwise to draw anything other than very tentative conclusions from a sample of this size, there are a number of problems/changes which appear to be closely associated with diabetes which should be highlighted for further investigation. For example, over 10% of this sample reported experiencing the onset of hypoglycaemia, or an increase in severity of hypoglycaemia in older

age; a similar proportion reported that their diabetes had become more unstable or 'brittle' when they were older. People who have reported such changes usually feel that not enough is known about why this occurs and what, if anything, they can do about it.

\* Over 10% have also reported experiencing over or under active thyroid conditions which may be worth further investigation. It should also be noted that this appears to be a particular problem for women in their 40's rather than for men (although not exclusively so).

\* The incidence of Peripheral Neuropathy, Ulnar Nerve Compression and limb amputations are also perhaps slightly higher than might be expected amongst the general ageing population (although, as mentioned earlier, it will be very difficult to establish whether or not there is any link with diabetes itself without detailed clinical research).

\* Some of the most common problems/changes reported are also very prevalent amongst the general ageing population (eg. arthritis, coronary problems and reduced mobility). As the quotes from respondents illustrate, however, the effects of these when combined with pre-existing diabetes related conditions are often cumulative, and can have significant consequences for the quality of individuals lives. There are also implications for the provision of practical support which are discussed further below.

#### PHYSICAL CHANGES/PROBLEMS EXPERIENCED WITH AGEING (QUOTES)

"I have been a diabetic since 1945. I have all my limbs, arthritis, poor feet, and need glasses. I am recovering from a very mild stroke from last July, from which my right arm and shoulder are getting more mobile." (ID 236)

"I am 70 years old, have been an insulin dependent diabetic for 40 years. I also have angina, sciatica, an underactive thyroid, and have had two heart attacks." (ID 227)

"I have had diabetes for 23 years. I have developed osteo arthritis, which the doctors have told me is the ageing process. I have this in my wrists and feet. As I have got older, the effects of the diabetes have got worse." (ID 115)

"It's like driving a car with the handbrake on. It's a hidden illness, but it is a depressing and a complex illness - and it gets worse the longer you go on. It's really messing me up. ... I still find it very difficult to cope, but it's much harder now that I'm 50. You talk about the quality of life - it's getting poorer all the time." (ID 162)

"I am having turns more than I used to. I don't get any warning at all. My diabetes is getting - how can I put it - it's getting more brittle." (ID 162)

"The big problem I've had recently is with this Sharko joint. Now, there hasn't been any prevalence of this amongst diabetics up until the last 5 or 6 years. I think it's been caused by the change to

Human Insulin - but that's only my opinion. There should be research on why these changes happen." (ID 254)

"You ask about the effects of ageing with diabetes. These, in my experience, are briefly as follows:-

1) Difficulty in healing any minor cut. Eye infections like conjunctivitis, even with the appropriate medicament, remain extremely obstinate. Also, ear boils. One has periods when one is much more vulnerable, inexplicably, to anything - even if generally very healthy, which I am.

2) No feeling whatsoever, and total unawareness of hypoglycaemia developing.

3) An inability to get my words in order before I speak, and a certain hesitant slowness - coordination is lacking. I get over this by thinking out exactly what I want, then saying so briefly, or eating a Dextrosol tablet (3) beforehand.

4) A lack of feeling in the right foot, and numbness, even when actively walking. This does not occur all the time however. An intermittent lack of feeling from the chest to the legs at times making for an uncoordinated, disjointed sense.

5) A much greater sensitivity to certain foods, such as red meat. (I have never been able to eat pork without sickness - because it is too fatty).

6) More need for longer periods of sleep. General slowing down, and less stamina. However, I am active physically - provided I stop at times for a rest.

7) Even on holiday when I'm doing nothing I tend to become hypoglycaemic in spite of following all the classic basic rules. This is becoming more marked." (ID 248)

"There is one noticeable change I've had with ageing. I had an operation on my thyroid gland which, at that time, was overactive. Then, when I was about 40, it reversed itself and now the thyroid is underactive. I think this is a problem for diabetics - particularly for women, because I've heard of quite a few women having this problem. So, I think it would be useful if there was some kind of investigation into why something like that should happen." (ID 093)

"In 1981 (20 years after onset\age 49) problems with an overactive thyroid gland smote me, and following treatment with radioactive iodine, needed thyroxine therapy. During 1982 diabetic retinopathy made frequent laser treatment necessary and I lost the use of my right eye. In 1983 I had to take early retirement on the grounds of ill health - plagued by hypoglycaemia which continues to this day - it's very brittle. In 1985 my vision was restored following an operation at Moorfield's." (ID 158)

"I am aged almost 65 and have had diabetes for almost 30 years. I

have been on insulin all that time - first on one injection a day, then two mixed doses. For the past 5 years I have had an insulin pump. Despite great care I have always suffered from severe hypos and long periods on unconsciousness as I never get any warning of low blood sugar. I also suffer from a very rare type of muscular dystrophy - Myotonia Congenita - which is made much worse by being cold, so the two complaints do not help each other. Recently I have also had arthritis." (ID 168)

"Although I am only 40 I have suffered from diabetes for 28 years. In addition to this I am a registered blind person, despite three years of extensive laser treatment and a vitrectomy operation earlier this year. I also have kidney failure and am at present receiving dialysis treatment under St. Bartholomew's hospital (CAPD). I am on the waiting list for a kidney transplant and am also taking medication for a hypothyroid condition. I am fairly restricted as far as travel is concerned, and I have been forced to take early retirement." (ID 171)

"I have had diabetes for 31 years and am 52 years of age. I have found that in my case, it is not so much the problems of the original complaint but the other disorders which seem to come with ageing with diabetes - such as failing eyesight, fluid on the lungs, liver function tests not being correct, etc." (ID 178)

"When I started with diabetes at the age of 15, I was determined to prove that diabetics could do anything that non-diabetics could, and that it would be no handicap. Over 32 years later, after a series of laser treatment, I have realised that diabetes does rule ones life, and increasingly so as one ages. I would be only too pleased to further research if I can." (ID 180)

"I am a 62 year old diabetic. I also suffer with Diabetic Peripheral Neuropathy in my feet and legs, and also have arthritis and high blood pressure. I am unable to work." (ID 191)

"During the last 20 years I have progressed through blindness; renal malfunction - awaiting CAPD; vascular damage - now inoperable because a heart condition makes me unsuitable for anaesthetic unless vital; neuropathy - faltering mobility - an unbalanced stance - nocturnal diarrhoea; neurological disorders - have not got the knowledge to distance these from neuropathy but have included carpel tunnel compression and ulnar nerve compression; and as though that were not enough I have now developed impaired hearing and perhaps tinnitus." (ID 198)

"I am 70 now - my interests through the medium of radio, are sport and current affairs. The winter is a problem to me - my normal temperature is one or two degrees below average. Neuropathy has effected my muscles - first noticeable as palsy in the hands - making anything needing use of grip very difficult. As a result of the operations on my arms at the National Hospital for Nervous Diseases (Ulnar Transposition and Carpel Tunnel Decongestion) reactions are not always as I expect and this makes me appear clumsy and can make me impatient with myself. Walking is a problem due to vascular and neuropathic conditions and blindness." (ID 198)

"After the menopause when I was 50, I developed eye trouble and had

cataracts removed from both eyes. The complication of glycochaemia started in both eyes after this and then I had a severe detached retina which resulted in blindness in my left eye. The right eye which was always the weaker of the two became blind as well. I also have rubiosis. I was registered blind in 1981. I have been on Meltroxin tablets for the past 4 or 5 years because of an underactive thyroid. I had a slight fall in 1984 which resulted in a double break and a pin was inserted a year or so later. I've also had a coronary since then. A few years later, in a fall, I fractured my pelvis and damaged my shoulders and ribs. Now, I have a very brittle diabetes and my main complaint is tiredness and feeling weak." (ID 211)

"I got severe pains in my legs on rising in the mornings. Going up or down stairs became problematic and I used my bottom instead. I also discovered that I was suffering from angina. Also, eye problems started to occur - but, thank goodness for laser beam treatment. By this time the leg problems were very much worse, but I still managed to walk a short distance. I'm now getting severe problems with hands and arms, and virtually unable to walk, have had operations for frozen shoulder, trapped nerve in the elbow - which needed the nerve moving to another part of the elbow, Carpel Tunnel Syndrome in both hands, and now have very bent fingers. Some days I can hardly hold a pen or fasten buttons etc. but, I am very pleased to say that my eyesight has remained fairly steady." (ID 137)

"I have always been diagnosed as brittle and although I take the Novo II and Ultrataved I cannot balance my night/morning blood. I have had laser treatment on one eye and of late, my consultant has discovered protein in the urine. Two years ago (22 years after onset\age 32) it was found that my thyroid gland no longer works, and a few months ago, that I have anaemia. Not bad at the age of 34. I feel like a chemists shop these days!" (ID 136)

"My husband - has been an insulin dependent diabetic for 49 years. Over the years he has had numerous problems. At the age of 21 he lived in the local hospital, coming home only at weekends. When the diabetes was stabilised, other problems arose. He was admitted to hospital 7 times with chest trouble. Then, he has undergone 3 operations on his eyes - first cataracts, then for a detached retina. This was unsuccessful, and he now goes for laser treatment to stop him losing the sight of his left eye. In 1984 (43 years after onset) he suffered a heart attack. Then, in 1985, cardiac arrest after an operation. In 1987 he had his left kidney removed which was badly diseased. Over the years his health has steadily got worse, and he uses a wheelchair to get about now. He suffers bad circulation in the legs, and his hands are badly swollen and he is unable to straighten his fingers." (ID 154)

"I was obliged to come off shift work in order to remain diabetically stable (24 years after onset). Medically, I was operated on for a twisted colon in 1983 (28 years after onset), and suffered a very slight heart attack two years later. I have mild Atheroma, and have suffered from depression. My eyesight is declining but I am assured that this is a result of age rather than diabetes." (ID 153)

## HUMAN INSULIN

The change from bovine and porcine to human insulin has been a major issue for many long-term diabetics, the majority of whom have reported a number of problems which clearly demand further investigation. For the BDA, there is likely to be an increasing demand from members for advice and information about this issue, as well as for support for individuals who have experienced serious side effects which - as far as they are concerned - are a direct result of the change to human insulin. For the pharmaceutical companies supplying insulins and the medical profession, the main implications of the experiences reported would seem to be that there is an urgent need for further testing of human insulin on a wider range of users, and more research on possible side effects. The most commonly reported experiences and views on the use of human insulin are summarised as follows:-

\* A large proportion of members who have contacted us have reported that, since changing to human insulin, they no longer have any warning of hypos. Some also reported that they now take longer to come out of hypos. Apart from the obvious distress and anxiety which this can cause, some people were also very concerned that this can actually be life threatening if attacks occur during sleep and/or if individuals are on their own when they lose consciousness.

\* Apart from change in the onset of hypos, several people reported experiencing various more general side effects (some serious) since changing to human insulin (eg. energy loss; impaired vision; nausea; intestinal disorders). Again, members feel that there should be more research on the causes of such problems in order to establish if, and in what way, they are connected to the use of human insulin, and what remedial/preventative action may be possible.

\* Several people are also concerned that they are rarely warned of any possible side effects of human insulin (although a few had received such warnings). A few individuals also suggested that both the medical profession and BDA have in fact known about the problems experienced by long-term diabetics for some time, but have been reluctant to pass this information on.

\* Some respondents pointed out that, older people may be much more prone to the problems experienced with human insulin than younger people, as their bodies were already adjusted to the insulins they had been taking for 30 or 40 - hence, the negative reaction following the change to human insulin.

\* A few people have now reverted back to bovine or porcine insulin (some at their own expense); unfortunately, there are also others who wanted to do so, but reported that their doctors would not agree to this.

\* Clearly, many members feel that human insulin should have been tested much more thoroughly - particularly on long-term diabetics - before it became so widely prescribed. More generally, several members feel that there should be wider consultation with insulin users when any such changes in treatment and control are contemplated.

## HUMAN INSULIN (QUOTES)

"I began having problems obtaining the type of insulin I required, so I returned to my GP. Another doctor in the practice advised me to visit the local hospital and see another diabetic specialist. He examined me at the hospital and put me on to Human Actrophane insulin 100cc which I am still using at the present time, taking a dosage of 36 units per day. He (the specialist) warned me I might have problems with this insulin but so far I have not encountered any." (ID 261)

"I feel it would help if manufacturers of insulin would advertise the fact more widely if any type of insulin is being taken off the market. After all, insulin is the life line for many diabetics like myself. When one finds certain types of insulin cannot be obtained it certainly does not make life any easier to bear, I can vouch for that." (ID 261)

"I was an outpatient at the old Addenbrookes hospital and had a 12 monthly check-up at their clinic. I was still stable and the registrar (the specialist was on holiday) decided I should switch from soluble bovine to zinc protomaine insulin and thus, only take one injection a day. That night I took my shot and the following day I travelled to London for a meeting and, at 11am, I collapsed and was taken to hospital by ambulance. I came out of hypo four hours later and my wife informed my doctor of this. The doctor nearly blew up and reported her comments to the specialist who in turn was livid and dismissed his registrar. His statement at that time to my GP was - nobody with any sense would alter a treatment on any patient who had been stable for so many years. This is the very practical reason why I have fought for so long against a drastic changeover from soluble bovine or porcine insulins to these diabolical human insulins, which are I have no doubt perfectly alright for later diabetics - up to five years - but not for diabetics who have been dependent for over 25 years and whose systems cannot and will not accept the shock of a complete change. ... to have to now be reduced to a semi-cabbage because of some chemist's desire to change and make a name for himself, and for the pharmaceutical companies to make a fortune out of other people's misery is just not on. When I was on soluble insulin, I hypoed but had warning enough to stop it getting out of hand. In 47 years of working in industry I did not have one day off through diabetes, but in the last 6 years I have blacked out whilst driving, in trains, in restaurants, in stores, even at a wedding - all without one minutes warning. The first one was five weeks after the changeover and was the first time in 45 years my wife had to call out a doctor to me as she could not bring me round. It took me three days to get over that one. Since then I've had five sessions in hospital. Major surgery to remove a growth from my stomach - the surgeon said it was insulin induced. I've also had three heart attacks and now have a pacemaker fitted. I can only walk a maximum of 100 yards with difficulty. I no longer drive, and do not dine out for fear of embarrassing my family and friends. So, life is not pleasant. Thank God I still have an active mind and still get a kick out of life, but it's not a lot of fun for my family." (ID 174)

" The main problem is - no feeling whatsoever and total unawareness of hypoglycaemia developing. I can be walking around with a blood

sugar of 2.9 or less and then collapse. I can't count how many times my husband and others have helped me. For example, recently, my husband brought me round with glucose during our evening meal, and I had no idea anything untoward had happened. Four such attacks occurred that evening. It is like a telephone line which has been blocked with white cotton wool. Sometimes, after a good hour, I realise what might be happening, reach for glucose and some carbohydrate, and get myself out of the attack - but the brain has had what has been described, I believe, as a white out." (ID 248)

"I have been a diabetic since 1947 - nearly 43 years. My age is 71. I must say that I had a bad time this year. The new human insulin is not the same - you get no warning for a hypo or coma. The last one I had - my husband was on hand, but for two days after I felt very tired." (ID 273)

"The human insulin - it's not been tested enough. I've changed back, because of the problems I had with it." (ID 272)

"I only started having hypos since I've changed to human insulin. There's a much more rapid onset, it takes longer to get out of them, and they are deeper than any hypos I've had before. It's very worrying. Some people might be dying in the night because of going into a coma and not coming out of it again. There have been 5 cases already and I think the number will only increase because it's such a recent development. There really is an urgent need to look into this for everyone's sake." (ID 254)

"The introduction of U100 and then Human Insulin have caused problems. I feel they have 'critical' times, and hypos are more sudden and severe." (ID 117)

"At long last someone is doing something to bring to light the plight to which so many insulin dependent diabetics have been brought down to. Also, at last one of the dailies is taking it up. The Daily Mirror brought out into the open what is happening to so many long term diabetics by use of these damnable human insulins I was handed a copy of this article and rang the BDA who rang me back and told me that they had been inundated with calls since publication. I was also told that - well at long last you have been proved right. It's taken me 6 or 7 years of battle and aggro with the NHS, the DHS, hospitals, specialists and doctors, so it's a little satisfaction - but too late for me. But, maybe some other poor devils will not have to suffer as we have had to through lack of thought, consultation and care." (ID 174)

"Whilst my remarks may seem in some respects bitter - these are my own personal feelings regarding the treatment meted out to me (us) over the past years. I'm far from alone in this as you will have seen following the write up on diabetics in the Daily Mirror. If the BDA would only be honest with you. You would be surprised at the complaints they have received for years now from long term dependent diabetics regarding their treatment at the hands of the authorities and specialists." (ID 174)

"My last hypo was 5 years ago, having gone to bed showing a blood sugar of 9. I knew when I returned home that I was lucky to be alive, and was sure that, had I been sleeping alone I would not still be

alive. So, every night before going to bed I ensure that my blood sugar is 11. Another point which may be of interest is the lack of warning about my need of sugar. Before I went on to human insulin, I used to get a sudden sharp headache, everything would blur and my hands would shake. Now, there's nothing." (ID 189)

"Until 1987 my diabetes was reasonably well controlled by Daonil, Metformin and diet. In 1987 it was discovered that Daonil was not the best control for elderly diabetics and human Monotard was prescribed with drastic results leading to hospitalisation. I was more confident on Daonil." (ID 198)

"My husband has been suffering with diabetes for the past 25 years. For many a year, whilst he was on the animal insulin, he was an extremely fit diabetic. This was stated by the doctors who cared for him. The eye specialist said he had wonderful eyes. Since the arrival of human insulin - Actraphane - he has not been the same. He is now suffering from arthritis, detached retina of both eyes, and intestinal problems which has caused bleeding and severe sickness. As an addition, his tinnitus has got worse. We are, of course, well aware that age may have some bearing on these problems (he is 65 years of age). No doubt the long period he has suffered with diabetes has a lot to do with these complaints, and of course his diabetes gets out of control when he is unwell. In fact, he had to retire 12 months before time because of his illnesses." (ID 221)

"I get low sugar very often. But, with human insulin which I take now, I perhaps don't always know beforehand - so I have to be more careful." (ID 216)

"During the last 5 years my life has been a living hell. It all comes back to this so called wonder insulin - this human insulin. It may be alright for younger people, but older people like me are suffering unnecessarily. You see, new diabetics don't suffer the side effects, but the older ones do. I've been 58 years on soluble bovine insulin - when your body has been used to that for so long, it doesn't take kindly to the change." (ID 174)

"I just can't use the human insulin - or if I do, I'm going to have to suffer for it. I have so much trouble getting the old bovine insulin though. I can still get it some of the time, but I can only get it on a licence - which costs me ,16 a week." (ID 174)

"I have coped fairly well all these years, except I didn't seem to keep well on human insulin, but I am now back on animal insulin." (ID 177)

"Over the years I have of course experienced hypos at various times. In the beginning they were easily recognisable with the sweating etc. ... Now (after human insulin) I find that the onset of hypos is less easy to recognise. (ID 220)

"The new insulin is different. The main thing I've noticed is that, now, if you get any reaction you get no warning like you used to. I wouldn't say it's any better than the pork and beef insulin because - (a) the reaction you get, and (b) I'm not even sure if it actually works. I don't think it's too clever. Since I've changed, the attacks have become more unpredictable. You used to always get some signs.

Now, you don't get any warning." (ID094)

"I don't know why they changed (to human insulin). I'm not saying it's dangerous, because I don't know that - but I don't think it's been tested enough. It's no better than before anyway - that's certain - so, why change?" (ID 162)

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

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

\* Some people reported having to attend upto 5 different clinics (one individual was currently attending 10 separate clinics) for various medical/health problems and conditions they had experienced. Others (particularly those living away from large towns) complained about the lack of specialist clinics for diabetics. These problems suggest there is a case to be made for the rationalisation of out-patient services for diabetics so that people can get access to specialist support, without the fragmentation which appears to occur currently.

\* Both the numbers of different clinics some people are attending, and the fact that some people have to travel long distances to obtain specialist advice, obviously have implications for transport. A few people were concerned about the extra expense incurred through having to attend so many different clinics and some (without cars) reported finding it difficult to travel long distances to get to specialist clinics.

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

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

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

\* Eight respondents reported having had laser treatment. Of these, 5 felt that this had improved their eyesight, or prevented any further deterioration; the remaining 3 were less than satisfied with the treatment. As the majority of those who had had this treatment were very pleased with the improvement in their eyesight, it would seem to be desirable for laser treatment to be made as widely available as possible. At the same time, it the treatment will obviously not be successful or appropriate in all cases, and other methods for dealing

with the problems of impaired vision/blindness commonly experienced by long-term diabetics will still need to be prioritised. It should also be noted that, two individuals reported having been refused laser treatment on the grounds that they were 'too old', which they felt to be discriminatory.

#### USE OF HEALTH SERVICES\HEALTH CARE PROVISION (QUOTES)

"My condition necessitates attendance at a General Eye Clinic, a Contact Lens Clinic, Low Visual Aid Clinic - but these are decreasingly useful as my sight deteriorates, Diabetic Clinic, Vascular Clinic, Renal Clinic, Diabetic Retinopathy Clinic. Also, Neurologist, Chiropody and Audiology. So, you see, I am kept busy. It would help if hospital visits could be centralised. Ambulance transport is very difficult but patients attending as many as 10 clinics for one condition can hardly be expected to be able to pay for taxis for all the visits." (ID 198)

"The one problem I feel which could be eased somewhat is the fact that the medical fraternity should stop having diabetics constantly going back and forth to hospital for check-ups. This causes quite a bit of anxiety and, therefore, illness I feel. Let them rely on help from their own GP's should any difficulties occur, then they can be referred to the hospital consultants. I'm sure many diabetics are constantly in a state of worry and apprehension due to having to attend at outpatients clinics. This will not help their condition I'm certain." (ID 261)

"In March '83, I had a hip replacement which was successful in so much as the sciatic nerve was damaged - it was Sciatic Nerve Palsy, the leg and foot were paralysed and I had no feeling. Now, I can get around with two sticks. In 1984 and 1985 I had ulcers - one to each heel - there was a lack of proper hospital treatment." (ID 266)

"Really - diabetics are a lost race in this country. The treatment we get is completely ghastly. The doctors don't seem to care if we live or die." (ID 174)

"I've really suffered at the hands of the medical profession. They just don't seem to listen - they ignore the fact that every diabetic is different. My specialist was aghast at the treatment I was getting." (ID 174)

"I am under the doctor at the diabetic clinic (local hospital) but see the doctor only every 6 months. Everything else I have to do for myself." (ID 273)

"The blood glucose level sensor which I need is not available on the NHS. So, I have to pay for that myself (cost ,62)." (ID 272)

"The consultants - they don't do anything. You can't get access to your medical notes or X-rays - I've tried. So, if they don't tell you anything, you're completely in the dark. The medical profession - especially the younger doctors - don't really understand much about diabetes. Things are moving forward, but not fast enough. There's no real treatment - except insulin and diet - for diabetes." (ID 254)

"It's important to have confidence in your doctors. They need to be able to relate more - to show some empathy with their diabetic patients. With most of them, they don't seem to show any appreciation of what living with diabetes can be like." (ID 254)

"It is important to give laser treatment to older people. I can't understand why anyone should be refused simply because a doctor thinks they're too old. I mean, alright, it won't improve someone's eyesight but it will stop further deterioration." (ID 254)

"I've been trying for years to get a decent pair of orthopaedic boots. I told the chap at the hospital what I wanted, but he didn't take very much notice. So, in the end, I've got this pair of boots - they're ,400 a pair, and I can't use them. Again, it's the same thing - the doctor's wouldn't listen. They just say - we know best. There's no thought at all for the needs of the individual." (ID 254)

"I go to the chiropodists, but I only get an appointment every 8 weeks. I would really like to be able to visit more often." (ID 254)

"I have my check-ups at Addenbrookes, but I'm not very impressed. They just talk to you for a few minutes and test your blood pressure - that's all." (ID 254)

"I've been having laser treatment on this eye at Barts. I go in once a year for a test and I do have a check-up every 6 months. But, nowadays you only see the doctor for 5 minutes. He just says how are you? Are you alright? - Yes, no, that's it. You used to have blood tests and all sorts of checks - but it's all gone now. My specialist said that they just can't afford to do it now." (ID094)

"I think the laser treatment has been very good. But, I have heard of some older people who've been refused because, when you're 75 or something, they say you're too old to have laser treatment." (ID094)

"I would prefer to have my check-ups at the local hospital - yes. It would be much easier than having to travel up to London. But, I just don't trust them. They don't seem to know anything about diabetes and - if there's anything wrong - they just send you back to your GP." (ID094)

"My thoughts on ageing and on diabetes are similar - a nuisance, but I try to let it interfere as little as possible. I hope the NHS manages to maintain a reasonable service so that I can have a check-up once in a while." (ID 114)

"I am 69 and have been diabetic for 37 years. I was badly wounded in 1944 and have several other injuries since then. In 1989 I had a slight stroke. Generally I am well balanced but I find human insulin seems to cause hypos without warning. My consultant says it is my age and, although reverting to Porcine insulin would seem to suit me better, would not help. I would appreciate your advice." (ID 132)

"Over the years I have kept fairly good control with, now and again, ups and downs. I now attend a clinic once a year. This is an excellent new clinic. (Bertram Diabetes Centre at West Norwich Hospital). Over the years my appointments at the clinic have decreased from monthly, to two monthly, three monthly, and now six

monthly intervals. My criticism of clinics has been that one sees so many different doctors - I have not seen the consultant for years. If one sees the same doctor more than twice then one is lucky. In this way they know very little about one, if one is married or single, where one works or what one does. Some, although one has been diabetic for years and years tend to treat one as just diagnosed. For instance, a few years ago my diet was increased by 10 grammes. I was instructed to see the dietician to do this. This was at 12.30. I found her office - she was gone for lunch and would be back at 2 o'clock. My car was already on a two hour limited parking. I had to transfer my car to the park, go into the city for lunch, and then back again to the hospital again. All this for 10 grammes." (ID 220)

"Regarding long term health problems - half the specialists in my own case are useless, and I no longer attend a diabetic clinic. One instance - when I reported for a check-up I told my specialist that I had hypoed 10 times in 14 days. He then referred me to a psychiatrist - who's cuckoo? I told my GP of this and he said it's the stock answer when they don't know the answer to a problem. I was also told by another doctor that I was lucky not to be in a wheelchair and, by another, that I was - too old and a diabetic. Maybe this answers your question about the attitudes of the medical profession." (ID 174)

"In 1971 (42 years after onset/age 51), I became impotent almost overnight. I went to my GP whose only reaction was to ask me how old I was, and to say that at this age it was to be expected and to be thankful for what I had had. On my next appointment at the clinic I informed the doctor I was a bit off balance at the time and all he said was - we will have to get you OK again, and then we will see about that. Another three months and the next time it was another doctor, with a young nurse standing at his side. This time I did not mention my problem because of her presence. Three more months, and another doctor. This time I had written it down and handed my note to him after he had finished. He handed it back to me with - nothing we can do about that - written on it, that was that. Now, in spite of continued frustration, I had to accept it. In 1982, after reading an article on the subject, I wrote to the Diabetic Association of which I was now a member. I was put in touch with a clinic - this turned out to be a family planning clinic. On my first appointment, the doctor who I was supposed to see was on holiday and I saw a lady doctor from (another) clinic. I then attended the other clinic several times, getting nowhere. Although my wife attended with me she was not invited in to also see the doctor. I was then asked if I wished to attend further. I took the hint, and terminated my appointments. Just over a year ago, a lady doctor at the diabetic clinic asked me about this subject, and I told her of my experience. She was the first person in all those years who was willing to discuss this subject - too late." (ID 220)

"It's not too clever with the GP not knowing anything about diabetes. Doctors should go on courses for this sort of thing. I mean, someone like me knows more about it than they do - but, they should know. ... The first time I had a bad attack, my GP wouldn't come out. Luckily the ambulance woman - we had to call an ambulance in the end - she knew what to do and she got me to come round. But he (GP) didn't want to know - it's disgusting." (ID094)

"I know that a lot of diabetics do have problems with their eyesight.

But, personally, I think that has a lot to do with their diet. People don't always eat the right things because - you don't get the right kind of information from the hospitals - they just don't know. That's something that could definitely be improved because - especially for the young ones - I don't know where they can go to get information about this kind of thing" (ID094)

## PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING

Like many other groups within the ageing population, diabetics 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, blindness etc.); 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 diabetics 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 a small proportion of cases, personal care support.

\* 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. A few expressed concern about the possibility of having to enter institutional care if they could not obtain appropriate support at home. Some people also highlighted difficulties in obtaining information on alternative living options which may be available. Whilst statutory agencies should be providing such information, they often fail to do this so there is a potential role for BDA and other voluntary organisations to act as 'information brokers'.

\* Some older diabetics 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 diabetes. Some people have also highlighted a need for practical support to carers and back-up for informal helpers; several 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 BDA.

\* There are also problems with claiming benefits and some individuals reported having experienced considerable difficulties in establishing their entitlement to benefits such as Attendance Allowance and Mobility Allowance. Delays of several months are not uncommon and one or two people reported struggling over several years in order to establish eligibility to benefits. Whilst 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 diabetes discussed earlier.

\* Some individuals specifically mentioned the need for local self-help groups which would give members the opportunity to discuss matters of mutual concern, and learn from each others experiences. This was most often discussed in relation to the need for practical information on matters such as diet and benefits, but also in the context of mutual support in discussing anxieties about health matters and ageing in general. A few people felt that BDA had a role to play in facilitating the development of such local groups. This suggestion also reflects a wider issue which the study has highlighted, not just for people with diabetes but many other groups also; people who have lived for 20 plus years with a disability or disabling illness have a vast amount of collective experience which can be an extremely useful resource to others. At present, however, these resources are not being fully utilised; the further development of local groups would go some way to rectifying this.

\* A small number of members in the study specifically identified a need for counselling (preferably peer counselling with other long-term diabetics). This could also be facilitated through the further development of self-help groups discussed above.

#### PRACTICAL AND PERSONAL SUPPORT NEEDS ASSOCIATED WITH AGEING (QUOTES)

"At that time (1984) I was working full time - which I have done since 1944. Now I only work part-time, 3 mornings per week, having been told to slow down due to my age, because I also have to care for my 92 year old mother and am therefore subject to stress as well as take care of my own health. I am 63 years old and have plenty of energy for my age. I enjoy my work but am finding it a bit more difficult to cope recently with mother as well." (ID 261)

"I have been an insulin dependent diabetic for 50 years. I was in the army from September '39 to February '41, when discharged with diabetes - for which a pension was only granted in 1988! After an appeal tribunal in 1942 for a pension - this was disallowed so applied again in 1987, when it was granted." (ID 266)

"It's a vicious circle you get into - because I haven't been able to get up for 8 months, I've now got very bad blisters because I've tried to start walking about again. This is what happens, you see - one thing just leads to another. I don't think there really is anything that can help me now - there's no hope. I really think I might die soon." (ID 089)

"I live by myself, am registered disabled, and no longer able to drive. I have a large garden which I expect to feed me - it does. I use an Aidcall alarm system which summons help when needed and automatically if the repeat button is not cancelled. I also have a home help for one hour per week and all my neighbours come when Aidcall asks them to investigate the situation." (ID 158)

"I became a widow last November and went to New Zealand as I have two sons living there and they thought it would be better to be with them. I stayed there two months but got very homesick and came back

to England homeless. So, I am now in a warden control flat - something I always dreaded, but I suppose it is the best thing that could have happened. I am not helpless and I am still a very independent woman." (ID 177)

"I have been a bit put out by the advice they (BDA) give you. If you ask them, they tend to just say - you seem to be in control, just get on with it and you'll be alright. That's not really enough is it. They don't give you enough advice about diet and things like that - I think they could do more." (ID094)

"I live alone in a flat with a warden between 9 and 5, but weekends and holidays are without cover." (ID 168)

"I have not had any experience personally of residential needs - only as a regular visitor to two in Buckinghamshire as part of a support team. Personally I was aghast at the treatment and conditions I encountered on these visits and just hope to God I never finish up in one. Why don't the services treat the patients as human beings and not as units. These people mainly lead a useful life and put something into the community, so it's not too much to let them finish their days in dignity and comfort. Older and disabled persons' carers suffer as much and sometimes more than the patient and, in turn, need help - both financial, to let them get a rest, and someone to at least let them know they are there if needed. We haven't all got families to rely on and very few of us want to be a burden to our children who have their own needs." (ID 174)

"We cope with difficulty and with little help. It was purely by accident that I found out I was eligible to claim for attendance allowance. This I did, and it took me 17 months and two medicals and God knows how many phone calls to London, Blackpool, my MP, the Health Minister to get it. I'm independent and have an active mind and would not give in. But, how many other people have given up. We keep reading in the papers of the ,9 million per year of unclaimed benefits - the above will tell you why it's unclaimed. It is also a fact that no doctor will tell a patient that they can claim anything at all, and during my spells in hospital I was never visited by, or put in touch with, the DHS for any benefits whether financial or aids. It is also a fact that the DHS are not allowed to offer you assistance and it is only when you contact them that they can guide you as to what to do. How are people expected to know this. Every hospital patient should be told if they are eligible for benefit, and long term patients by their doctor or nurse." (ID174)

"What would help? - someone to talk to about my inner feelings would be very useful because talking to family is not the ideal solution. Counselling is at the moment not on offer and friends have troubles of their own." (ID 198)

"As my wife and I go into our 70's support will be needed - home help, district nurse, and day centre. Also, I would appreciate some form of recreation or interest as I am mentally alert. I would like help in taking responsibility for my own quality of life. At the moment I rely on (my wife) to research, suggest what she is willing and able to cope with in the way of survival, outings and holidays. I would like to be in the position to take more charge of our day to

day living and future plans. An otherwise helpful social worker thought it morbid to need to know what is on offer in the event of me being the survivor, or indeed left alone to cope while (my wife) was in hospital - for however short a period. We assured her it was 'a need to know' in order to get on and enjoy life until such a contingency arose." (ID 198)

"It (diabetes) doesn't effect me physically - but, I do worry about what I might do when I'm older. I can't be left alone at night because, you are always worried about the possibility of having an attack. So, if I was on my own that would be a problem - you can't rely on your neighbours to come and check you during the night like your husband would - so I don't know who would do that. It's quite possible I'd have to move somewhere else when I'm older." (ID094)

"Whatever happens, I think it is quite likely I will end up moving from here at some time in the future - yes. For a start, the facilities here are not very good - you are a bit isolated and totally dependent on having a car or being able to drive. It wouldn't be much use for an older person who couldn't get around so easily. I don't know exactly where we would go. It certainly wouldn't be a home - no way. I could have a flat but I'd feel too confined in a flat - especially not having a garden. Wherever it is, it would have to be near to the shops because - if I was on my own say - I don't have any family who could do shopping for me. " (ID094)

"I applied for a private car allowance through the health service. After a very long time finding the correct department I was successful - although, this has now been changed over to Motability. ... I would very much like to see more understanding from the Social Services for long term diabetics. The usual comments from staff are - oh my Ma, or my Aunt, is a diabetic, they don't have these problems - it must be something else. They just don't appreciate what can and often does happen to the long term diabetic. To keep our independence and mobility is very much important. A letter sent to Mrs. Thatcher and Mrs. Edwina Curry has helped us get some of the much needed equipment on prescription but, still more aids are needed for many of us. Nothing would please me more than to be able to go out to work and earn the money to buy this sophisticated equipment." (ID 137)

"I am 34 years of age and have lived with diabetes since the age of 10. As a teenager, I found it difficult to come to terms with and always felt hemmed in. Other diabetics were always telling me how well they coped and of their constant well balanced blood sugars. To this day, I feel that all diabetics, from the teenagers on, need a doctor/friend who can listen." (ID 136)

"I am 82 years old and have been diabetic for just over 50 years on insulin - two injections per day, until a year ago when I was put on the new human insulin which is one injection per day. I live in a private home for the elderly now and find it difficult to vary my diet. I have had, for the past 16 months, a very bitter metallic taste in my mouth. Everything I eat or drink is the same - even water. My doctor cannot help me, if only you could I would be so grateful." (ID 176)

"Ageing in itself is a hard enough struggle - but with the added handicap of diabetes, this does not make things any better. I live alone, do blood monitoring, do all my own housework, and help other people. All my diabetic life I have done two injections a day and I am very active so far. My fear is to have to end up in a nursing home or rest home where the staff have little knowledge of diabetes. After caring for oneself all your life with blood monitoring etc., to be looked after by people with little knowledge of the complaint is quite frightening." (ID 175)

"This stinking rotten government - when will they stop treating us like we were beggars or something. We are entitled to our money, but you have to fight to get it all the time. It's the same with phones - we can't get help with getting a phone, but phones are a necessity for someone like me - not a luxury. It's so hard just to survive when you're disabled - people treat you like you are a pisstaker" (ID 162)

"The fight I had to get my Attendance Allowance. I had to wait 6 months for a decision. I think they hope you'll just give up and go away. They make it so difficult. I'm not saying it's easy for anyone, but is harder for diabetics because - you're up one minute and down the next. So what they are comparing you to, I don't know. Anyway, I got it in the end, but that hurdle seemed like 40,000 feet at the time." (ID 162)

"How do I view my own needs? A weekly meeting place locally with other diabetics to discuss how others are fairing. (ID 236)

"The problem, I think, with the BDA is that, there's not enough active diabetics in the organisation. And, there's too much focus on fund raising - that should be a side issue." (ID 254)

"They (BDA) should be doing more to bring people together, so that they can learn from each other and get some mutual support." (ID 254)

"It's a race against time. I could wake up tomorrow morning and I'll be completely blind - it could easily happen just like that. So, I have to just try and get everything sorted out and get some help before my time runs out - because I don't know what I would do otherwise. I think I'd probably end up giving in and calling it a day." (ID 173)

"All I get is one hours home help a week, but what I need is someone here every day - at least for a couple of hours. I want to try and find someone myself but it's so difficult to know where to go for advice. It's the same with the benefits. I heard about this Invalid Carer benefit (ie. ICA) and I was thinking that - if I can get that, I could use the money to get some help. But, I don't know who to ask - I was hoping you might be able to advise me." (ID 173)

Note: Above respondent put in touch with local DIAL for advice on claiming ICA.

**NOTES ON BRITISH DIABETICS ASSOCIATION'S RESPONSE TO BRIEFING PAPER  
'AGEING WITH DIABETES - PRELIMINARY FINDINGS' (February 1991)**

The briefing paper was circulated to Dr. Moira Murphy, Head of Research at BDA. A meeting was held in February between Gerry Zarb, Dr. Murphy and other BDA staff from the Welfare and Information Departments. The main points raised at the meeting are detailed below, together with a summary of the action BDA are taking or considering in response to the findings.

1. FINDINGS ON SIDE EFFECTS OF HUMAN INSULIN REPORTED BY LONG-TERM DIABETICS: BDA stressed that this has become a very contentious issue and were slightly sensitive about how the findings are to be presented. In particular, they stressed that the findings should be placed in historical context. Firstly, around the time Human Insulin was introduced (early 1980's), there were also significant changes in control regimes for diabetics and, consequently, in the advice given by both BDA and doctors about how diabetics should control their blood sugar levels. It is not known, therefore, whether the problems being reported by many diabetics are due to these changes, human insulin, a combination of both, or other factors. Secondly, BDA have been researching these problems for the past five years; the comments from respondents in our study would suggest that BDA members are not aware enough of the work BDA are doing. Thirdly, the 'official' BDA line on the Human Insulin issue is that, the link between increased hypos and human insulin has neither been proved or discounted by existing research (although they did agree that the warnings given of possible side-effects are often inadequate). In view of the above, BDA will consider ways of raising awareness of their research activity, and reassuring members that the problems are being taken seriously. One specific proposal was to collate and publish a summary of existing research in a non-academic format and they will be looking into this in the near future.

2. CONCERNS ABOUT AGEING AND THE NEED FOR RESEARCH: BDA have been aware of the concerns about ageing for some time and have carried articles on the subject in their newsletter; they accepted, however, that older diabetics concerns are not being adequately addressed and asked for advice on how they might best deal with this, particularly as the number of enquiries they have received on this subject has been increasing noticeably. The possibility of BDA producing a series of pamphlets on ageing related issues was discussed. These would be based on the kind of concerns expressed in the JRF study and would focus on practical advice and information which would help older diabetics to deal with problems which may arise with ageing. BDA will be preparing some drafts incorporating findings from the study as well as their own research. GZ will be liaising with them in this.

BDA also pointed out that, upto 10 to 15 years ago, they did have a policy of not informing members about possible ageing problems because it was felt that this would cause unnecessary distress. However, this was no longer seen as appropriate as members have a right to such information so that they can make their own decisions about any changes they may wish to make in their lives. This is also borne out by the findings from the JRF study.

BDA agreed that more research on the physical/medical consequences of ageing was required. For example, some of the problems which respondents attribute to Human Insulin may have occurred anyway with ageing, but there is insufficient research to know.

A question was raised over the representativeness of our sample in terms of health status; GZ explained that, given the sample was self-selected, it is almost inevitable that people who have not had any problems (and therefore feel they have nothing to report) may be under-represented. At the same time, the large numbers involved and the consistency of the experiences reported indicate that the problems reported are both widespread and genuine. Also, that the study was not meant to be a rigorous clinical trial, and medical researchers should be following up these issues for themselves.

BDA asked for any further data on neurological problems/changes reported in the study. Neurological complications associated with ageing are not as immediately recognisable as some of the more 'dramatic' changes reported (eg. increased hypos). They are concerned that there may be an increasing incidence of neurological complications in older age which has not yet been fully recognised. Also asked if the JRF data allows for analysis of whether physical problems/changes are more highly correlated with age, or length of time since onset. GZ will be carrying out this kind of analysis for all the main disability groups and will report back at a later date.

3. HEALTH CARE: BDA asked about findings on respondents point of contact/referral with the health services. GZ reported that this seems to be mainly with GPs (which corresponds with BDA's own observations). In conjunction with the findings on the lack of specialist knowledge about long-term diabetes, this raises a concern about the quality of health care support in the future when GPs will be expected to take on even more responsibility for check ups, advice etc.. BDA already have a programme of training sessions for health professionals, and will now be considering targeting GPs.

BDA accept that, in general, health care advice to long term diabetics is often inadequate, although the situation is improving. Also, they recognise that they have a role to play in keeping health professionals informed so that they can respond to people's needs. Responding to the criticism raised by some respondents that BDA are too close to the medical establishment, they accept this was true in the past but BDA has tried to change this and take on a more proactive campaigning role.

BDA expressed concern that - even though advice about diabetes itself may be improving - advice and support to older diabetics about general ageing problems (eg. impotence) is still very poor. Their own Welfare service has been hearing of the same kind of problems for many years.

Regarding the need for specialist check-ups, BDA were not aware that this was a major issue and did not feel there was a particularly high demand for check ups. However, when it was explained that most people just want to know that the support is there if/when needed, this finding made more sense in terms of BDA's own dealings with members.

4. PERSONAL/PRACTICAL SUPPORT NEEDS: BDA were very interested in the framework of the 'supportive environment' model used in the study. In particular the principle that, knowledge about the right kind of support being available was often the most important factor influencing the security of support provision. This idea was felt to be very consistent with BDA's own dealing with members across a range of support needs from benefits advice to counselling. For example, a recent training session run by BDA's Welfare service highlighted the need for people to have an emergency phone number for on-call support; also, that District Nurses were resistant to the idea of incorporating this in their own services.

The principles of the supportive environment model were also seen as consistent with respondents desire for more information on what problems they may experience with ageing and what, if anything, they can do for themselves; similarly, the desire to know what services are available if/when needed and information on living options.

It is interesting that BDA's own experience suggests that subjective security is the most important factor in creating a supportive environment for older diabetics. Dr. Murphy reported that their main overall conclusion from applying their own observations to the findings in the briefing paper was that, a large number of people do not feel that enough attention is being paid to their concerns and needs. This is reflected in BDA recognising that there is clearly scope for increasing their advice and information services through dissemination, pamphlets, training sessions etc.. GZ commented that, whilst this is a very positive response, people will also want practical support (eg. benefits, transport, home helps etc...). BDA agreed that equal emphasis should be placed on lobbying for community services which are responsive to older diabetics needs.

On specific support services, BDA questioned whether large numbers of older diabetics would require personal care assistance. GZ commented that, whilst the proportion may be lower than amongst some other groups in the ageing population, there is likely to be an increasing number experiencing mobility problems and blindness which suggests the potential for a significant demand for personal care support.

Regarding benefits and pensions, BDA have observed an increased demand for advice from older members. It was felt that, because physical disability will often not be an issue until they are older, many diabetics will not be as familiar with the benefits system as some other groups in the study (although it was recognised that obtaining information on benefits is never easy for anyone). BDA have been trying to address this issue by - a) regularly publishing benefit information in their newsletter, and b) referring enquiries to relevant organisations (eg. DIAL. RADAR). The drawback with a) is that people tend not read the information or take it in until/unless they have a specific query. It is only when they do that they will seek advice. The main problem with b) was seen to be that people often want actual help with making claims as well as information. Whilst some other organisations can help with this (eg. CABs), people will often want to go to a familiar source - ie. their own organisation. BDA recognised that there is a potential advocacy role for them in this area, but were concerned that their welfare

department does not have the expertise to provide a specialist welfare rights service. Also, that many enquiries would ideally require face to face contact which means that a national head office may not be the best contact point. The possibility of facilitating the development of local self-help groups with training of volunteer workers was discussed as one way of dealing with this. BDA questioned whether volunteer members would have sufficient time and knowledge to provide welfare rights support. GZ commented that other organisations (eg. British Limbless Ex-Servicemens Association) have built up a national network of volunteer welfare rights workers; also, many local DIAls are staffed by disabled volunteers. This would suggest that, whilst by no means easy, the task would not be impossible. What would be needed would be for BDA and others to develop facilitating services which would enable volunteers to build up the required knowledge. Agreed to discuss this further at a future meeting.

The issue of self-help groups was further discussed in relation to the findings reported in the briefing paper. Some respondents highlighted the need for more local groups to provide mutual support over a range of issues. BDA already have around 400 local branches and have already started a programme of training and supporting members to set up self-help groups. Again, this is an area where members are not being made aware enough of developments already taking place; although, problems of transport for older people, geographical location, and the wide age range of the membership were also suggested as constraining factors on the participation in self-help groups.

Gerry Zarb, March 1991