

99. David M.

(1) Tell me about your background.

Well, I come from Scotland; born in Fife, and raised there. I was a fairly sickly child, because I had what was known as acidosis of the stomach - couldn't keep anything down. But I grew out of that when I was twelve, and I took a job, before going to school, running rolls around places, round houses, and this sort of thing. Left school at fourteen. Went to work for the National Coal Board, so I've been down all the pits in the east coast of Scotland; did that for four and a half years. Then left that and went into the Merchant Navy. First trip on a ship was almost my last, because, oh, I get seasick every time I go; I feel like Nelson. But it got easier, because I then went on oil tankers, and that was running up where the war is going on at the moment, between Iraq and Iran, Kuwait, places like that, and back to the continent, or down to South America. Did that for two years, then was going to get married, and didn't. And so, between flight and flight, I tend to flight, and off I went to India, where I became a tea planter. And I was there for just over three years, and I met my wife there. My wife comes from India. She was teaching up in Darjeeling, I was working on the foothills, the plateau. And we met at a large annual general meeting. One thing led to another, and we ended up getting married in Delhi. They didn't particularly care for me marrying my wife, because my wife's an Anglo-Indian, and, as time goes on in India, so does the feelings of... not the people there, but our own people. It's interesting that when the East India Company went there, they encouraged the soldiers and the people to marry Indians, so that they could get on with the people better. But as it went on, if you married someone from that country, they didn't like you. So, I packed it in after three and a half years, and brought my wife back here. And did a few weeks in Brighton General Hospital, working in the laundry; did about six weeks there, while I waited to see if I would be accepted as a prison officer, which I was. And I was a prison officer for ten years, and then I became a prison governor. And I spent thirty five years in the prison department, retiring when I was sixty. And that's basically my life.

Can I give a few dates: What year did you get married, what year did you return to England, and what year did you join the prison service?

We returned in 1966, October the tenth, 1966.

Having got married when?

A few weeks earlier: August the twenty seventh, in Delhi. And then we spent two months going round the north of India, seeing where Patsy went to school, and this sort of thing. We had to go and see the Taj Mahal, because that was in an area that was away from where either of us actually worked. And so, we came back here in 1966. I started at Lewes prison in Sussex. We lived in a flat in Brighton for a couple of years, before I moved into a quarter. My son was born in 1968, and my daughter was born in 1970.

(2) Tell me about your wife's diagnosis with diabetes.

Well, as I say, we got married in 1966, and spent our time bringing up the children, going to our various parents and relations for holidays, and this sort of thing, at the time. Twenty years later, she was discovered to be diabetic. But that wasn't easy, because... We knew it was diabetes: her grandmother had it, and lost both her legs; her uncle had it, and lost some of his toes; her mother had it - she was a late onset, the mother - and five years before she died, she died of a small scratch that she'd got on her shin, getting into a taxi in Brighton, that developed into ulcers all over her legs, and this sort of thing. So, when Patsy... we went on holiday to place called Andalo, in the Italian Alps, and she'd been drinking an awful lot. And I took one of these long carrier bags with fifty six bottles of juice, and this sort of thing, which was gone in about three days. And she was very, very thirsty; drinking a lot of water. And that would be 1985. We came back here, and her eyes were bothering her. She'd been to the doctor two or three times, in Wallingford, and he said "no, no, it's not diabetes, it's not diabetes". She says "well, could you take some urine and see if that's it?" "No, I don't think you've got diabetes", and this sort of thing. Anyway, when we went to the optician; she said "you've got a bit of trouble at the back of your eyes. You've got veins that are beginning to break up". And she said "are you diabetic?" And my wife said "no, he tells me I'm not, but my whole family history is full of diabetes". And she says "well, I'm going to write a letter, here and now", and she did, in front of us, and she says "give that to your doctor". So, we gave him the letter, he took a test, and he came back and he said "ah, you're going to be diabetic". He says "you've had it", he says, "but that's not too bad, because you get free prescriptions". And I thought that was a little cavalier of him, having told us for some time that she wasn't. And that was in 1985. About a few months later, she had a tachycardic attack. We'd been out one day with one of our dogs, to get it mated across in Benson, and on the way back she had this dizzy turn. And I thought "oh, your blood sugar's dropped", and told the kids to get some sweets from the front of the car. I said - I'd just bought some steak - I said "get this down you, you'll be okay". But my son panicked, and I'm glad he did panic. He went into the hall and he phoned the doctor, because the next thing I knew, this lady doctor was at the door, on a Sunday afternoon, and she says "I understand someone's ill". "Oh", I said, "come inside. Who called you?" you know, and it was my son. And Patsy was lying in a chair, and she knelt down beside her, put the stethoscope on, looked at me, and says "do you drive?" I said "yes". She says "well, rather than calling an ambulance at this time on a Sunday afternoon, if you can just get a bag of stuff ready and take her to the Radcliffe hospital, because her heart is beating. It's not life-threatening, but it can't go on like this". And within forty minutes, I got her into the Radcliffe, and she was surrounded by students, because it's a teaching hospital. And she had all the stuff put round her chest, and all the rest of it. And it came up on a monitor at 259, you know, and they kept her in, and gave her injections through a cannula in her arm, to bring her down.

- (3) And the next day, when I came in to see her, she was just drifting off there, and I'm standing at the end of the bed thinking "what are we doing

with our lives?” You know, our kids were getting up. And she came out on the Thursday, and on the Saturday we were on the Island of Korčula, off Yugoslavia. And I thought “this is fantastic, this is what I need to do now”, you know, and just keep travelling. And we liked it so much that we went back to Pula, in the October, and we were going to... on a trip to... By this time, she’s on a diet. They’re not giving her any tablets, but were treating it with diet. And we were going off on a trip to Tito’s island, and we were held up for about an hour before we could get the ferry. And we never got the ferry, because, although we’d taken an apple and some biscuits, and this sort of thing, she started to fade. And the fading took the effect of, she just went grey and cold, and, funnily enough, didn’t want to eat. And a gentleman on the bus, who was also diabetic, sat her down and gave her some sugar that he had in his pocket. And we stayed there; we never got to the island. I took her to a restaurant and got her some spaghetti, and this sort of thing. And it went up and down like that for a couple of years. The next year we went to Morocco, and I’d got to the stage where I can tell that she needed something, you know. I remember, one day, I left her in a carpet shop, and she’s sitting there, she goes terribly quiet, and I could see it in her face. So, I went running around the souks to get bread and cheese, and got her over that. And after that, they put her on tablets, and she stayed on tablets until she had a stroke, on January the eleventh, ’99. We’d been to Miami for New Year, came back on the fifth of January, and she had a stroke on the ninth of January... on the eleventh of January. And that ended up with nine weeks back in the Radcliffe... well, back in the Infirmary, which is closed now.

- (4) Before we move on to life after your wife’s stroke, can you talk about life with diabetes before her stroke, in 1999?

Well, life with diabetes in the early stages, which was, as I said, diet, and I used to take her urine samples, and check them with the key-card, sort of thing: that wasn’t too bad. As I say, the family had a history of it, so we tried to keep the weight down, as much as possible. From photographs, you can see what we were both like when we got married; we were both extremely thin. She started losing weight, just before she was diagnosed. We’d had the children by then. And she went through a period where she was slightly depressed, because I got promoted and moved up to here. And she had done... her education things were done in 1963. She became a teacher, and that was when the English system turned over to the Scottish system, from a two year teacher training course to a three year teacher training course. So, when she arrived here, they wouldn’t accept her qualifications. And so, while the children were growing up, and I was working in Lewes Prison, she went back to college and university, and got herself a BED; did a mature students’ course, and had got a nice job in Brighton. And then I got promoted. I came up here, and, of course, at that time - that was about 1975 - they were only accepting people from Westminster College, and this sort of thing. And she felt a little downhearted, so she had a period

where she really was fairly depressed. But we worked our way through that, and eventually she got a contract, and then worked in the school down here for twenty years, while I then went to other places to work. But we managed. The diabetes is not something that, in the early stages, seems to worry anybody. But it's an insidious sort of thing; it creeps up on you. And there are so many side effects, that when she had her stroke, that really turns the world upside down, you know. And that's when she went on insulin, when she was in hospital.

But still before we get on to the stroke, you talked as though you were quite involved: you know, you took her urine samples, or you both tried to keep her weight down.

Yes. Of course, it was almost continual arguments, at times. I was as guilty as she was. We decided that we would travel, and we have done a lot of travelling. And, of course, you go to Italy, you go to America, you go to other countries, Egypt, and this sort of thing, you can't help but keep trying different foods, and that sort of thing. And, as I say, as long as we were controlling it, even after she went onto the tablets, we seemed to think everything was going fine. Deep down inside, you worry when the next stage is going to come, but, for that early period, I'm sure a lot of people in this country have got diabetes, and they just haven't been diagnosed with it.

- (5) And they think there's nothing wrong with them. But it's a creeping disease. As I say, her grandmother ended up having both legs removed, her uncle had his large toe, and I don't know if he had the one next, and her mother was just covered with ulcers that they couldn't cure. They just couldn't get rid of them, so she's sitting with her legs up for almost five years, you know. And so, my advice would... If you feel there is something wrong, get yourself checked out. But we've come a long way in twenty years, and I think that's the most thing...

You mentioned that on two early trips, after she was diagnosed, you noticed the signs. Is that usually the case?

Oh yes, that was very obvious. She just went silent... she didn't even want to eat. You're almost forcing spaghetti into her, or forcing her to eat bread, and I'm saying "you have to eat it". "I don't really like it", you know. "Eat it", you know, and that sort of thing.

Would you usually notice the signs before she did?

Yes, because what happened was that some of the tablets she went on took her sugar level down very fast. And you do notice the pallor in the face, and the sort of quietness. And, as I say, you look sideways, and you think "I need to be doing something here, we need to get out of this shop, we need to get her to eat". A sandwich was no good, she needed a full meal. As I say, people will carry biscuits and that with them, but if their blood sugar goes too down - and we're talking about blood sugars of two and three - it's a meal you need to boost you back up again. And it's like watching a blow-up doll come to life, you know,

just beginning to feel better within themselves.

- (6) But you were still at work, at first, so what happened when you weren't around?

I was here; I was very lucky. It was 1987. I stayed here, in Wallingford, for twelve years. I worked at the local Borstal, between Henley and Wallingford, and I did split shifts, so I was always back here in the afternoons - nearly always, unless there was any meetings to go on - because the time that you could see the lads were in the evenings. I used to do my interviews and boards, and this, with them in the evenings, when they were back in the wing. You didn't want to stop them working during the day. So, at one o'clock, I'd come home here, and I'd be home when the kids came home. And so, that lasted for twelve years. It was in 1987 that I went down to the Cotswolds, and then I was down there for just over five years. Then I came back up and worked in Grendon - I don't know if you know, that's a psychiatric prison - and so I bought a little cottage on the M40, because that was... And my wife moved into Didcot, here, because the school was just down the road. But no, we stayed in Wallingford for twelve years. And, of course, nothing happened, until '99. So, I was very fortunate, and I think the kids were very fortunate that I was always home for meals. Even as an officer: the shift patterns, and I lived in a quarter, which meant I could be home for breakfast, dinner and tea, more or less. Even if I did a double shift, I was home.

Did you choose that way of life because of your wife's diabetes?

No. I suppose I've... I chose it, because it was twenty years, we were married, before she had the diabetes, so that didn't even come into the equation. I needed to have some security; I'm having children, and want some security. And if I hadn't had children, I probably would have left the service much earlier. But I was raised in what was known as the corporation poorhouse, up in Scotland. My father was a caretaker there, and they had a men's wing and a women's wing, and I was four when I went there. So, I've always been in the caring thing. Same when I was in India; you look after the people that work for you. Each estate is like a little town on its own; you have your own little hospital, your own bazaar. You make sure that people have got enough - apart from money, which they don't get a lot of money - but you make sure that they get things like bamboo and thatch, and this sort of thing, for their house, and for their children. And they get medicines for the children. So, I suppose I've always been in the caring sort of profession. So, even when I retired, as I say, I wrote a letter back saying that "well, I suppose I've spent about fifty years in the caring profession, I'm just doing it again" you know. But that's... it wasn't because I knew that she was going to get diabetes.

- (7) Now, you mentioned the date, the eleventh of January, 1999, when your wife had a stroke. The very fact that you remember that date suggests it was a very important marker.

Oh, there is no doubt about that, really. We didn't know how much it would be, when she was originally in hospital, until... And I was known in the hospital,

because she'd gone to the same place to get her eyes done, and this sort of thing. I used to go in on the morning, on my way to work: get her up, get her dressed, this sort of thing. Come back in the evening, and do the opposite: get her back into bed, and this sort of thing. And you suddenly realise that this is going to be the rest of your life, in many ways. And then, of course, now, as it's progressed, she's on something like eighteen tablets a day. And with all the privatisation of the medicines, and this sort of thing, you start off with orange pills, and then they suddenly turn yellow, different shapes, they become capsules, and become such and such. There is no way that my wife could make up dossett boxes every week, with the amount and with the type of tablets. I let her keep two tablets that she takes with meals, and this sort of thing. And even these, she keeps saying "is this a Metformin? Is this a Dipyridamole? Is this...?" you know, because they change their shapes, and this sort of thing. And I just don't understand how elderly people get on with all these things, you know. I break my nails, half the time, getting them out of their packaging, you know! But...

Did the problems with her eyes begin before her stroke?

Yes, they... She had a cataract, and she had the first cataract done in the left eye in September '98. And then off we went to our New Year in Miami, and knowing full well that... by that time, we knew that Mr Elston, the consultant, had come to see her, and said "I will do the right eye myself in February". But, of course, in February, she's now in Ward 17. So, he came up to Ward 17, and saw the consultant that was dealing with stroke. And he says "I think we can do it," he says. "If you can stop giving her aspirin for a couple of days" he says, "'cause I don't want to go in there and find blood all over the place". She was getting aspirin, now, because there's nothing much else you can do with a stroke, except thin that blood. And he did it, and it was very nice, until we got to the situation where another doctor saw this debris in her eye, and he decided that he would go with laser treatment. The other two consultants - there was three of them - had an argument, in front of us, about which is the best way to treat this debris that was in the eye. And we arranged for an operation about three or four weeks later. When it came out, she just couldn't see through the right eye, and yet, originally, the eye was perfect, when Mr Elston did it. But that's another part of the history, I suppose. My wife says "sue them, please sue them, do something", you know, because... We went back once,

- (8) because we go back frequently now, and she heard the voice of the woman who did the operation, and she just had a little panic attack. And I had to say to the nurse, I said "is that Miss so-and-so that's doing this?" She said "yes". I said "she won't go in with her". She said "don't worry, we'll arrange for another appointment next week with someone else". She was so worried about... I mean, that doctor had come and told us that she'd made a mistake, that she'd cut a little bit of the membrane behind the eye, but she hoped that it would heal, and it didn't heal. And Mr Elston had to do a vitrectomy on it two weeks later, because the fluid started leaking out of the eye, and the lens had moved ninety degrees. So, two weeks later,

he had her round at seven o'clock in the morning, and did a vitrectomy, which meant putting false gel into the eye. And so, the eyes have been another part of the problem, that's all I can say. She can't see in colour, now. If she's watching the television, unless she's right up against it, she sees mostly in black and white. And, of course, it slows the reflexes down. She can't... the only thing she can tell me on the road, as we're going, is "thirty, fifty, thirty, sixty"; it's the only signs she can read, you know! She can't read where we are, so I'd be lost without my Sat Nav.

And those problems with the eyes were really happening - or the treatment - at the same time as the stroke. And were you still at work?

Yes. When did I retire? 2000... I retired two years later. And I was staying down the Cotswolds, but I came up, or she came down, at the weekends, and this sort of thing. She stayed where my daughter stays now, with my daughter. And we'd meet up at the weekends, and she'd stay with me down there, until the time she said "are we ever going to live together again?" you know. But, no, we managed it. But, as you get older, things get... I've just had to buy a new wheelchair for her, because I found the original wheelchair quite heavy. But I use that one when she goes to the day centre on a Wednesday, at one of the Cheshire homes. I take her over there the Wednesday, and I use the older wheelchair, because it... I don't put the pedals on it for her feet; she uses her legs, because if she doesn't use her legs, they'll waste away. So, I have a walking machine upstairs in the bedroom, and she does a couple of minutes on that. Not very long, but it just keeps the legs moving, because she hasn't got all that much strength in the arms to push the chair any place. But if she can actually walk, and pull the chair along with her feet, then she's fine. And that chair is... lets her feet touch the ground, and so I use both the wheelchairs, at the moment.

(9) Did you retire early because of your wife's health?

No, I was due to retire anyway; I'd had thirty five years, and I was sixty then. And I would have retired early, but she couldn't go back to work. She never went back to work after the stroke. She'd hoped to go back, but with the trouble with her eyes, and then, of course, the trouble with the wheelchair - she couldn't manoeuvre it all that well - she wouldn't have been much good with the children. So, she didn't work. My daughter, you see, has always worked here, and so they lived together, mother and daughter. And my daughter had to get up early, and at eight o'clock at night, she goes to bed. And when I picked her up, she says "I've been in bed at eight o'clock every day this week. She switches the light off, gets me upstairs, and I'm in bed by eight o'clock!" But no, they got on fine for the couple of years they lived together. And everything was a sort of learning process, and even now it is. What is good, I think, is that she goes, on a Wednesday, to the Cheshire homes, because, over there, there's a lot of people a lot worse than she is. And she's able to help, by feeding people who can't move their... with MS, and this sort of thing. And I think it also lets her see that... I think if you don't, you get this... you want self-sympathy, you know, "well, I'm stuck in this chair, and that's it". She has her down days, but

fairly few and far between. I think you've got to keep a sense of humour, keep moving, keep planning for holidays, and this sort of thing, and just do it, you know. And I think that's all I can say to people is: find out what can be done, and then do it, you know; that's all you can do, really.

- (10) Can you talk about the learning process, once you'd begun to look after her full-time yourself?

Well, you learn what she can do, and what she can't do. But that's almost an everyday learning, for about a year, because you don't do necessarily the same things. You start by learning to put bras on, rather than take them off, you know! Earrings, necklaces, trousers; you learn how to dress people. I make sure that her legs, her... because I know the feet are terribly important, and the podiatrist, and the woman that used to treat her mother - the consultant - we've seen her, and she thinks they're still in good condition. I cream them every night, make sure that there's no cuts or bruises, or anything like that. And feeding, you know. I don't have to feed her, but yes, I have to cut the food up, once I've cooked it, and this sort of thing; especially meat, and that. You have to put it into sizeable chunks, because, as I say, she can't actually work both hands at the same time. She now eats like an American; the Americans cut up their food, and eat with a fork, you know, they don't use a knife and fork. But we have friends out in Florida, and they noticed this, that they do. As I say, you occasionally have off days. The medicines: she's had to change recently again. They can bring on things like diarrhoea, and that isn't very pleasant. But, as I say, I've been doing most of it most of my life, so it doesn't really bother me too much. Although my father had stroke after stroke, until he couldn't speak, couldn't eat, this sort of thing. I don't know that I could have done it back in the seventies, and really, my mother had quite a difficult job, with him. But, funnily enough, when it's your own wife, and you've been in these intimate positions before, it kind of comes naturally. And, yes, it's that sort of thing.

- (11) Learning to push a wheelchair: I used to push her into walls, and I still do, sometimes; you push the wheelchair into a wall. Say "wait there, I'm just going over here now", and she says "what am I looking at, then?" you know! And she's very good, because we're nearly all Arians, in this house, and it's much like an Italian house, I think: we shout at one another. But my son is an Arian, I'm an Arian, and Patsy's an Arian. And my daughter should have been, but she's a Pisces. And she's much calmer than both of us, except when she's driving; she gets a bit of road rage, and I think most youngsters do, you know. She won't let me drive her car; I'm too slow for her. But yes, you've just got to allow each other a little bit of space. Patsy's very good. I go to the gym. If you weren't coming this morning, I'd go to the gym for a couple of hours, because that keeps me fit. I mean, if you're not fit, you're not going to be able to push the wheelchair; you're not going to be able to... Mind you, if she falls over, I can't get her up anyway, on my own. We were going off to Majorca, and stayed in my son's house in Banbury. We were getting the plane from Birmingham. They



were away doing a job, him and his wife, and so the house was empty. Got up in the morning, and as we came out of the door, she fell. And do you think I could get her up? Once she's down there, I can't get her up. And so, I had to go next door and say "excuse me, can you come and help my wife up, she's just fallen over?" She did the same in a single bed at her sister's. I'm in one single bed, she's in the other single bed. Suddenly, she rolls over and falls out. Took us fifteen minutes to just get her back into bed again. And it's these little learning situations that you learn the best way to... if you can get them round onto their knees, so she can get something that she can grip on to.

Right, we just paused, then, so that you could help your wife to the toilet. Can you talk about other aspects of caring for your wife?

Yes, getting her to the toilet, here, isn't really any problem, because it's a downstairs toilet, and she has... we have an en suite one upstairs. And I still make her go up the stairs; I just walk behind her in case she falls. But yes, when you're out, and in different countries, even trying to get her into a disabled toilet... Now, America's funny, because they put the disabled toilet right at the far end, so you've got to walk past other toilets - ladies' toilets - to get to there. And they don't like you doing that, you know. So, sometimes you have to ask a woman, could she take her in and take her to the disabled toilet, which is at the other end. Then, in some countries, you go up and there's a lady sitting at the door, and this sort of thing, taking coins, and they won't let you in at all, you know! But, yeah, that's an aspect that we find a little bit difficult. It's not difficult, it's just that... We've got used to it, but I think, in the early days, it's a little bit embarrassing for men to be just wheeling in, and then going into the toilet with your wife, and this sort of thing, because she needs to have the handle put down - they lift up and down, there. And then there's the washing hands, and sometimes places don't have hand driers, and you're looking around for tissues, and that sort of thing. But yes, these are little things that bothered us, in the early days.

(12) Were there any other situations in which you felt embarrassed, in the early days?

Not really; I don't think so. Often she'd get upset with me, or I'd get upset with her, for some reason or other, and she'll say it quite loudly: "I don't want to do that, I want to do this", like, you see. And I'm saying "well, we can't get down there", "well, I want to go down there", like, or "I don't want to go down there". Or I'm trying to get her to go down to somewhere: "I don't want to go down there", you know. And she can be quite stubborn, and I can be quite stubborn. As I say, we're all Arians.

You talked, just now, of sort of making your wife go up the stairs. Can you talk about, kind of, the balance between what your wife can do for herself, and what you do for her?

Apart from cooking, and this sort of thing... She did try to - with only having

the one eye - she did try, one day, to... I have a perching stool over there, which I put over here, this weekend, because this is the first weekend I've been away. This is the first time that I've been away from the house, and my daughter was over here, and... But one time, before, she came through, and she thought "I'll put the kettle on, and pour the tea". She's at the sink, and she's pouring water into the kettle, but she hasn't lifted the lid, and it's pouring all over her hands. If we're in a restaurant, or something, she'll go for the salt. And she's got this problem with distance, and my son, or someone, will take her hand, and pour it over the potatoes - pour the salt over the potatoes - otherwise, she'll pour it over the table. But that's to do with the eyes, and not to do with the stroke, or the diabetes. As I said, prior to the stroke, the diabetes could be managed fairly well.

Do you attribute the stroke to the diabetes?

Oh, I think so. I think, having known, now, as I said - I used the word before - insidious diabetes is. It creeps into your body, and it's working away there while you're unconscious of it. And then, suddenly, you might have a liver failure, or suddenly your eyes go. And there's not many people get out of this life, that has diabetes, that don't have something wrong with them, at the end of the day, you know; something's going to catch up with them. And I don't know what the figures are, I think, but I suspect strokes are one of the more common ones, because that's all to do with blood, blood clotting, this sort of thing. And, of course, it's the keeping the blood sugars level, with insulin or with tablets, or with just a decent diet, that helps. Once the pancreas starts to go, then that, really, is too late. But when you see stage 1 stuff, with children, they just go into it, and you see kids at eight and nine giving themselves their injections, and this sort of thing, and they don't know any better.

- (13) I've always loved... As I always say to people: "if you're feeling down, if you're feeling away, just take a walk through a children's ward in hospital. You'll hear more giggles than crying." And that is... And you see them turned upside down, if they've got trouble with their hips; if they've got emphysema, and they're coughing all over the place. But nevertheless, they're laughing more than they're crying. And I think that's a good way of getting people out of their misery situation.

You said that your wife only gets down sometimes. How do you both keep your spirits up?

I joke a lot. I do, I'm terrible. I've got one of these warped senses of humour. I just have to see something, and, in my head, comes a little cartoon with little bubbles coming out of it, you know. I just think we've gone too far... You know what annoys me more than my wife and her stroke is this nanny state we've got ourselves into, where kids can't just climb trees. I just read in yesterday's paper: a slide that has been there for fifty years has been taken down, and it's not going to be replaced. People keep telling us what to do, and if we don't do it, they're going to fine us, they're going to throw us in prison. And they can't throw us

in prison, because we've never built another prison for the past ten years. And that really annoys me that... And we'll give our children ASBOs. ASBOs are something to be collected like exam papers. When they've got an ASBO, you know, they say "I've got one too", you know, and it doesn't mean anything.

Let's change the subject from the nanny state to the welfare state, and what support that you have had in caring for your wife.

I've been extremely fortunate. In the early days - and I think this is because I was capable of having the time to go in every day to the hospital, over the nine weeks that she was in there, then being able to go to the places where she did her rehabilitation after that, because it took her six months to learn to stand, more or less - I got to know people, and I got to know... So, we got the wheelchairs, we got the riser seats, you know. They came and put risers on our chairs, so as that she... the chair wasn't too low, it was higher up. They gave us a seat for the bath, although that's all gone now, and I've purchased my second wheelchair myself. I've also had to get a new bath thing, because they run out of batteries, and things like that. But from that point of view, I've been extremely fortunate. But then, throughout the past eight years, we haven't had much to do at all, really. A lady came and saw me... Patsy phoned the lady, and the lady says "who's your care manager?" She says "I don't know, I don't think I've seen one", and then, at the other end of the phone, she says, "oh, it's me"! And the next thing, we got a visit from another lady, and they've sent me two hundred and fifty pound to hire a cleaner.

- (14) Because, that's the other aspect of it: little things about the house, in the garden, changing bed sheets. Everything you more or less have to do yourself. As I say, not in the early days - my wife was fine with her diabetes, in the early days - but people have got to recognise that not everybody gets out of this world without a more serious thing happening to them. And you've got to go shopping, you know, you've got to go down there. It gets easier, but it still takes up time; the day runs away with you. And not only does the day run away with you, the weeks run away with you, and suddenly you find you're another two years older. We've got to phone up - she was phoning up last night - to find out how old the children were: were they one year, or two years? We've forgotten when they were born, you know. And the old mind goes a little bit; that can be very irritating.

You mentioned that you'd been away, last weekend, for the first time. Could you do with more respite care?

Not really. There is a nice place here in Didcot, itself - a carers' place - and they send me the pamphlets and that. And then they do things for carers, like taking them on a bus trip, and this sort of thing. But I would be no good on a bus trip with a load of carers I didn't know. My wife has to go with me to enjoy anything. I'd be completely lost, you know. And I think that, sometimes, that's not the respite I'm looking for. Patsy often says "well, go away on holiday by yourself",

and this sort of thing. I said “what would I do on holiday by myself?” you know. Some people can do that, maybe. . . you’ll get lots of people who do that anyway, in normal married life. Women go away on holidays with other women, and the men go away on football weekends, and this sort of thing. But I’ve just never done that. And wherever we’ve gone, we’ve gone together. And I’d be. . . I’d just be. . . The only time we did go away, with my son, was when she went into hospital. We’d already booked a holiday, for the February half-term, to go to San Francisco. Of course, she was lying in hospital. We’d bought the tickets, and my son was coming with us, and Patsy says “will you and Ian go there,” she says, “’cause there’s nothing I can do. I’m lying here, and I don’t know when I’m going to get out”. So, off Ian and I went for a week in San Francisco. And, of course, the nurses, as I say, knew me, so when I phoned in the middle of the night over there, to get the daytime here, they’d go “your husband’s on the phone”. “Well, I’m on the toilet, I can’t come. . .” She says “he’s on the phone from San Francisco”. “I know, but I’m on the toilet”! As if I knew. And yes, Ian and I had a lovely week in San Francisco, and we got lots of ideas of how to deal with his mother by the hills, you know. We thought about linking her to the back of these tram cars that go up these big hills, and then when we get to the top, just taking the link off and letting her go. She could land in Alcatraz, you know! That’s a lovely place. How elderly people work in San Francisco, I don’t know. Half way up hills, I was turning round and walking backwards, ’cause. . .

- (15) You said that you don’t need that kind of respite, of going off on holiday on your own, that often. But is there any help that you could do with?

Yes, I did miss when they stopped the Carer’s Allowance. I think that is the most. . . the worst thing the government could do. And it happens with women at sixty, and it happens with men at sixty five. As soon as they get their. . . They’ve been carers for five, six years, and they’re getting a Carer’s Allowance. Now, it’s not a great deal of money, but it helps. And then, suddenly, you get a pension, which you’ve paid all your life into, because, although I’ve never been to university - except to eat! I’ve been there many times. I used to take university students and Borstal boys camping, and this sort of thing - but no, I’ve never done any of that, you know; I’ve worked. I’ve never been a day out of work in all my life. Wherever I’ve been, I’ve always been in work. I’ve never drawn the dole, because I’ve never been on the dole. And that’s my only claim to fame, is that I can do that. And you pay into a pension. And then, when you get a pension, they call it a benefit, and you can’t have two overlapping benefits. So, they stop the least of the two, which is your Carer’s Allowance. Now, I have an entitlement to a Carer’s Allowance, and so has everybody else. You’re entitled to it, but you won’t get it, unless you’re on death’s doorstep, you know, and you haven’t got really any other money to deal with it. Now, if you’ve worked all your days and you have a pension - like I have a work’s pension - when I got my Carer’s Allowance, they immediately took thirty nine pound more off me in tax. So, I phoned up and said “excuse me”, I said, “I got a Carer’s Allowance,” I said “but on my pension you’re taking thirty-nine pound off.” I said “is this another stealth tax where you pay me forty pound a week, and then take one week back?”

And she says “no, what we do with that is, we add that to your pension - the allowance to your pension - and then we take it off”. I said “does it get taxed? Because my wife’s allowances don’t get taxed; it’s an allowance”. She says “yes, but it gets taxed” - this is a woman in Cardiff. And she says “I don’t really know how old people do with this”, you know, because it is so confusing. They give you it with one hand... Any other allowance that you get, they add that to your work’s pension, and they take it. Then you get your old age pension, five years later, and they chop that off altogether, and they call your pension - your state pension - a benefit. My state pension isn’t a benefit; we’ve worked all our life for that, and so has people. And I just think it is wrong, because every year these people are getting older. There’s people who are absolutely sick; women who can’t hold their husbands up. They’re lifting them from the chair into their beds, and this sort of thing, and they’re getting absolutely nothing for it. And yet, if the stroke, or whatever illness it was, happened five years before they were getting a pension, they were getting an allowance, when they were much younger and fitter. You’re older, and getting sick yourself, and they stop it. It’s not... it’s the people who care for people, in this country, save the country a fortune; a total fortune, they actually save. And I just find that wrong; I do, I find it wrong.

- (16) And I find, I’m sorry, but going to war, so that armament dealers can make a lot of money, or builders are going to make a lot of money after they go and build the places that they’ve bombed out: that is terrible. For me, that is terrible. There was no planning for this war that we’ve got, and they still have no plans. They should have known that, once we get in there, we will repair your water, your electricity, whatever you have, and get you back on track. And here we are, years later, and these people are suffering. And we’re losing people, the Americans are losing people, and so are other countries.

And you’d have liked that money to be spent on carers. Is it a struggle, financially?

I think it is. I think you’re always looking. Because now, the situation today, where the mortgages are going up, gas, electricity are going up, houses are flooded out in different parts of the country that have never been flooded out before. The country, due to stuff beyond our control, is in a bit of a state. But the people who are paying for that... the rich people will never pay for it. The people who are actually paying for it is the twenty two million in the middle who drive to work every day, and have to pay inflated petrol allowances, inflated car taxes, to pay for the twenty five million at the bottom, who are still in so-called education, and a growing elderly population, because we’ve learned so much, in the past ten years, about how to keep people living longer.

Apart from needing more money, is there any practical help that would help you?

Not really; I’m very fortunate. I’ve always had good neighbours, always. And

I think if neighbours looked after themselves more, and didn't argue over a Leylandii tree or six inches of this, but got on with themselves, the nation, again, would be a much better place. We have so many petty squabbles.

What do your neighbours do to help you?

Well, if you take just this weekend, I went, by coach, up to Stockton, up to North Yorkshire. My neighbour was up at half past seven in the morning to take me into Gloucester Green station to get the bus. He drives my car, and he's on my insurance. And if I want to put my daughter on my insurance, it's going to cost me another two hundred and sixteen pound, to drive that car out there, you know, which is a motability car. So, I put his name down there, because, if we go to the airport, he'll drive me to the bus station, and we'll get the bus to Gatwick, and he'll be there when we get back. If I go away, he'll just keep his eye out on the house, this chap across here. We all look at each other's house, and just make sure nothing's happening.

(17) And how do you see the future, for you and for your wife?

If it didn't get any worse, I think we'd get on fine. In the back of my mind, though, is what happened to my father: stroke after stroke, TIAs, this sort of thing, and another bit drops off, you know. He ended up with not being able to speak, with not being able to eat, or do anything. My mother's life totally revolved round taking clothes in, washing clothes, this sort of thing. In a hospital, fifteen miles away from where she was, in 1972, and they took a pound off her pension, and she's having to pay bus fares every day to go in there and help the nurses out. And it was such a relief, I think, when he died. So, I think - and I'm being quite practical here - I can see, within the next ten to fifteen years, euthanasia helping people who get into real difficulties. We have dignity for our animals dying - I watched my last dog being put down - but we don't give our elderly people much dignity. And Mother Teresa, in India: all she did was be beside a person when they died.

But if things went on just as they're doing now, you reckon you could cope?

Yes, yes. Unless something happened to me, you know, then that would cause my wife problems, having to go into a nursing home, or something like that.

How is your own health?

Oh, it's reasonable. I had an angiogram several years ago, and my arteries are a little furred, but that seems okay. My kidneys have a slight abnormality. I may become diabetic myself, who knows? But no, I try to eat reasonably, I go to the gym twice a week, and try to keep fit. And part of that is also a state of mind. You can... the mind is a wonderful thing, if used properly. But it can also get you into a lot of trouble, if you get into states of depression, and things like that, because it seems to take over from your normal bodily functions. But, if you're aware of that, and you say "I'm not going to let this get me down", I think you get on fairly well.