I Ok, well thank you for agreeing to contribute to a narrative to support the education of health care professionals. Perhaps if you could reflect on your Parkinson's, how it started, how it affects you. Particularly talking about your medication you need to take and any experience you may have had taking medication in hospitals.

M Right, well I was, first had problems with riding a motorbike. The problems I had was I changed from being a custom bike where you sat with your feet forward to a sports bike and I was starting to get cramp in my legs and I kept stalling it. So I changed all the bits on the motorbike thinking it was the clutch and then one day I couldn't get my foot out from under the gear lever to change gear so I thought there was something wrong so my wife decided I had to go to see the doctor.

Went to see the doctor and he referred me to a neurologist, and I went in to see him on I think it was June 3rd 2003, and he basically had me walking down the corridor, had a look at me on the thing and says 'I see what the problem is'. When I came back in the office he says 'is your wife with you? Would she like to come in' and that's when I thought 'there's something not right'. so my wife came in, basically sat down, she asked him, he asked her a couple of questions, 'did I have a tremor, this that and the other' and bits and pieces and he just turned round and says 'aye you've got Parkinson's'. Which, I just sort of like looked at him in disbelief, you know it was quite a shock but so like it was basically, 'you've got Parkinson's, we'll have you in the hospital in a couple of weeks to do all the tests and make sure' and within a couple of weeks I was in hospital for like two days where they did all the tests and to make sure that it wasn't something like copper poisoning or, because I used to work in garages before, but I was actually an HGV driver when I was diagnosed.

So went into hospital and had all my tests done and it was basically 'you've got Parkinson's, we'll start you on medication'. And they started me on half a tablet of Selegline, I was on that for about four months and then they upped it to one and then I was on one three times a day and they also introduced Mirapexin over the next couple of years. The problem I had with the Selegline was I'm quite compulsive anyway so I would go and play on the computer for like eight or nine hours, no problem but it was getting too hard with the Selegline, it was disrupting my sleep patterns so that when I would stop on the computer I could be there three days and then it would go, I'd just konk out and I would go to sleep for 12 hours. So they took me off the Selegline and just had me on Mirapexine, I still go on the computer loads but not as much as I used to.

I'm just trying to think which one I went on next. They had me on Mirazapine which was to help me sleep and because I get terrible cramps in my legs, I'm on Quinine. We were on holiday in Crete and we were told about a lady whose aunty had Parkinson's and she had terrible cramps in her legs and she used to drink tonic water, well I don't like tonic water because it's absolutely foul, so the nurse at the Parkinson's Clinic said 'well we can give you sugar-coated tablets 'so you just take the tablets and that keeps my cramps at bay.

Then because of the Mirazapine, I was starting to have violent nightmares but she would start screaming and shouting in the middle of the night, Sandra would just about pooh herself so she would wake me up and when we seen the doctor next time I went on Clonazepam I think it is which is an anti epileptic drug but it stops you having, you don't act out your dreams so that was the next one they put me on and then with the Mirapexine I'm taking, which is nine tablets a day I was having problems with my legs swelling, with the oedema in my legs so they've reduced the medication now down to two Mirapexine, three times a day and I take four Stalevo 100mg whereas I was on 75mg, three a day, now I'm on a 100mg four a day so that tends to level that out a bit. But I'm back at the hospital again next month, or December and they're to have a play around with it again because they're trying to get me on the slow release Mirapexine which doesn't have the oedema effect in your legs.

I don't work now, when I was driving an HGV wagon I found that I was tending to leave my foot on the clutch quite a bit. But the firm I worked for, I had the same wagon all the time so I could work around it and changing gear on my motorbike, I just used my whole leg because I still had my motorbike for a couple of years after I was diagnosed. The, it got to the stage when I got made redundant from the firm I was working for I went back on the agency and I was in different wagons all the time and I couldn't find the righting point on the clutch, my leg would just freeze, so particularly as you lift your leg straight off the clutch and (inaudible – bang it ... under a trailer) or press the clutch back down again and start again and I found it was that stressful that it was getting to the point where it was dangerous so I decided to see my doctor and he was a bit reluctant to sign my medical forms to say that I was unfit to drive a HGV; so we sent the forms in for that and the, I got the letter back from the Ministry of Transport saying that, not the Ministry of Transport, the DVLA saying that they were withdrawing my HGV licence but my car licence and my bike licence would remain the same, which I was quite pleased about 'cos I like my cars.

And I went to see the DEA, the Disability Employment Advisor at the Job Shop and she said they were starting disabled people at which was action for the phone calls for people who had gas leaks or something the matter with their gas supply. So I went and I worked there for a year and then they decided just before we started there that they were shutting it like in a month's time but it went on for a year so before they decided it was going to completely shut and I transferred on to assigning the gas fitters for all the different leaks which I found was quite stressful so I packed in working there and I was advised at the hospital because the stress was affecting my symptoms, to not, like obviously your health was more important than working for a living, so I went on to, I'd already got my disability living allowance for the lower one with care because I couldn't like hold a pan, make a three course meal so I was on that one and as my cramps got worse and my stiffness got worse then we applied for the DLA, the higher rate and I got that and I got the mobility, so we had a little automatic car which we ran about in and my wife was still working so we were looking at, I mean we were having to pay the mortgage, we were having to pay the council tax, pay for the prescriptions and pay for all our other things so we went to see the DEA again and said if my wife stopped working, what would we actually get in benefits? And they wouldn't tell us, they would tell us the other way around, they would say if you were on benefits and you're going to take a job, they would work out if you were going to be better off in the job or not. But they wouldn't work it the other way round if you were out of work and one of you wanted to like stop work to care for somebody, they wouldn't tell you how much you would get.

So luckily my wife's employer turned round and said 'well take a year off, see if it works out; if it doesn't work out then just come back to work as normal and we'll just put somebody in your job temporary' and within two months we literally worked out that we were better off because we didn't have to pay council tax, I didn't have to pay my prescriptions which was like four things a month, we got help with paying the mortgage, so that we didn't have to sell the house and we actually got some income support. With the income support you got all the other benefits included; whereas if you couldn't income support you literally had to pay for everything.

That was up to about three years ago and then since then it's just been going back to the hospital but I actually, I'm the secretary of the local Parkinson's branch. I started out as treasurer and then the year after that somebody else came on as treasurer and I went in as secretary, 'cos we're using a computer all the time, I can like, like I print out all the newsletters, do all the programmes and bits and pieces but I'm finding that's getting a bit hard now so I'm playing with the idea of dropping that next year and letting somebody else take over as the secretary. We organise like Christmas lunches, we organise days out for the members, we have a lot of paperwork now which makes it a lot more stressful because since it became Parkinson's UK, we now have actual paid staff in the North East and they've got certain targets to reach and you'll get a clash of personality between one of the, I mean one of the members on the committee won't like the way something's going because we were told there'd be less

paperwork and I mean now there's more paperwork. We're like, we were just in a branch development meeting and that was like 18 pages of paperwork so the, we've got two or three new members on the committee who are quite articulate and they, they'll turn round 'cos they used to think it was us working ourselves like because we didn't want to do the bits and pieces but they can get, other people can get it across better so you tend to not just have one person taking all the flack.

But, last year I went to the Parkinson's annual general meeting which is the first time I'd been to one. I'd been to one for the YAPPAS which is the Young Parkinson's group in I think it was 2005 or 2006, I'd met a Parkinson's UK worker and he invited us down to the Biannual, they used to have it every two years, they used to have like a general meeting. And my wife went with my and my wife like is horrified by the fact that I've got Parkinson's that's why she's not here today 'cos she'd rather keep it at arm's length, whereas I tend to, if somebody's, like if I'm talking to somebody I'll tell them I've got Parkinson's Disease, it doesn't bother me. And, but when we went to the YAP meet, there was quite a few people that were really bad. And my wife is of the opinion when she looks at people like that, saying well what happens if I'm like in ten years time, how's she going to cope. So she's been to two Parkinson's meetings, the first one was, it was one of the members of the committee's going to dance school and they had all their kids doing the ballet dancing and what have you and I mean it will sound funny but my wife says, we walked in and there was all these girls dancing about in leotards and all these old people sitting there shaking, she says it was like going into a paedophiles' meeting!! So she went to the tombola which was the next one but there was two or three people who were quite bad, I mean they're not with us anymore, and she like tends to look on the negative side, whereas I'll just poddle along my and it doesn't particularly bother me. So she won't go to the meetings now and she'll like, she'll not go to any of the AGMs or anything because there was one of the lads at the YAPMAC meet, he was just curled up in a ball with his legs and everything had gone so stiff and they would come in and put him in a chair and he was literally sat there all day and it like frightened her quite a bit 'cos she looks like more into the future whereas I live more for today.

The, we've got a grandson who, he's just turned four and he keeps me busy all the time so we've just getting him introduced to speedway because I used to ride speedway bikes years and years ago and we've bought him a little motorbike but he's too, he's slightly too small to go on it at the minute so we have to go on with him so it gives us an excuse to be on it. He can be a right worky ticket but it keeps you on your toes.

The latest thing is, I mean when I first got my disability living allowance for mobility we decided because we'd always had old cars, that it would, like it would be nice to have a new car where you didn't have to worry about it breaking down or anything so we bought a Mitsubishi and we had for that three years and it was quite relaxing because you would go for a drive somewhere and we've got a caravan, so it pulled the caravan and you weren't worrying, saying 'what happens if something falls off it or whatever' and at the end of that three year's contract we thought well we've been paying £50 a week for this car, normally it wouldn't cost us that much to run a car, which the cars before we'd had, we didn't have a problem with, so we bought a Renault Scenic and it was low miles so we thought it was low miles and the, we, we ended up putting three tyres on it, getting some repairs done to it and then the timing belt snapped. So we worked out it was costing about £10 a week more to run our own car than run a mobility car so we decided to go for another one and I've just got a little Kia Soul there which is quite nice and we're, they fitted a tail bar for it so it pulls the caravan whereas the car what I had before, I fitted the tow bar in and I found I was having loads of problems and where at one time I would think nothing of wiring in a tow bar and fitting it but I was having problems trying to hold wires with one hand, it couldn't, wouldn't do as it was told and you're trying to solder wires and everything.

So I got quite a bit emotional and upset about that but normally I just get on with things I don't have so much a problem as a lot of people where they can't walk very far, I can, sometimes on a

good day I can walk for miles, bad day, I'm stuck; but other people, their problems are every day so I'm quite lucky in mine's quite slow progressing because I've been diagnosed .... seven years now and I've seen people who were diagnosed later than me and they've actually been wheelchair bound for more than a year now and they've; I mean there was one lad we had who had MSE which is very often diagnosed as Parkinson's disease and he passed away at the beginning of this year but I mean we still see his wife because she's on the committee. He's quite a miss because he was one of our committee members. The, I'm trying to think what else. So I go to the hospital every three months and they twiddle about with my bits and pieces, think like my medication and what have you and what problems am I having and then I'm also involved with quite a few research projects; the PROMS Study, I'm involved in that and I'm on the PPI Panel for DeNdron which is neurological alliance, they deal with a lot of, where they set up the research projects, we get involved with them so that way I'm quite busy with that; my committee paperwork takes up quite a bit 'cos I mean newsletters are usually eight pages, so I have got to design all them and everything for the branch.

But, I'm trying to think what else I can add to that? I mean all the house I did myself when I was first diagnosed, we put the kitchen and everything before I got too bad and we've also adapted the house by that door's wider so if I'm ever in a wheelchair I can get through the whole house. I'm widening the other door because we couldn't get it to open wide enough to actually fit it if we'd, thingied it, because these ones we didn't leave the doors on, we left the doors off to make it easier for me to get round. I'm just trying to think what else. I mean I usually get all the jobs to do but they take us longer, I mean putting the kitchen in took us six weeks where normally it would have took us two weeks. And other bits and pieces like decorating and what have you, I can do if it's on a good day but if it's on a bad day it just gets left. That's it. I mean we will be in the caravan on holidays so I don't have a problem with that. The, we're spoilt for a caravan because my brother just phoned us up one day and said would we like the caravan and we thought it would be some old, tatty thing and well you've seen it outside, it's quite a nice little caravan. So we're, basically we're not tied to going away whether the weather's wet or whatever because the caravan's got heating in and everything and hot water so you don't get stuck for stuff whereas in the old days it was a water pump on the floor and freezing cold water, you had to boil a kettle for everything!

The, I'm just trying to, what else to think, I mean we have meetings every month at the Parkinson's branch so I organise all the, like the speakers or if we're having like a sing-along because we try to have one serious meeting, one light hearted meeting and I like; everybody is on the phone every five minutes, 'I've got something the matter with my computer, can you come and fix it?' so I end up doing that. I've got one to do today and I've got one to do tomorrow. The, one of the little lads who's the vice chair, he was computer phobic before I, I sold him a laptop which my wife had had and when she got her new laptop she was selling the old one, so now he's worse than me for being compulsive on it so he's getting into trouble off his wife, I get into trouble off my wife for spending too long on the computer but since my wife got her laptop she's on it nearly just as much as me now. I mean I'll be upstairs and we'll play scrabble, she'll be down here on her's and I'm upstairs or I'll be sitting with it on, my laptop on my knee and I'll just be like that I mean we play scrabble with people all over the world and I've just had my aunty over from Australia and she, they were over for his new book so I can, now she's back in Australia I can use Skype and I can speak to her and see her at the same time so that's quite good but you've got to stay up in the middle of the night with it being the time difference. I found since I got diagnosed with Parkinson's I didn't drink a lot before but I used to when I was younger, but before I got Parkinson's but since I've had Parkinson's, it doesn't bother me going out for a drink, I'd rather stay at home. But my wife's family are quite supportive, they're always asking how I am and what have you.

(Inaudible) well I see my sister quite a bit because she's a pain in the backside, she's always over wanting something or other and I see my wife's family who just live round the doors more than I see my family 'cos my sister who I get on really well with, she lives in London so I only see her when we go down there; my brother, he lives in Durham so I see him every now and

then usually at funerals or weddings! That's about the only time you ever see the family and my other family, they're like wider family, live down in Leeds and down south so we don't see much of them. I mean I've got another funeral to go to next week so that's an aunt, my dad's sister, so I'll see all the family then and then it's ... I find with the Parkinson's, it plays hell with your emotions, you can go to a funeral and not even know the person and cry your eyes out or you can go to your best friend's funeral and be alright. You can sit and watch something on the telly and get all emotional about it even though it's just a play. So I found that's quite a problem I have with Parkinson's, the, because people look at you like, think you're daft. I mean I don't have that much problem with my speech but some people, somebody in a pub will think they're drunk or they're, or will wonder why they're shaking so much and the thing is, when we go out, we go out with a group of friends, we don't have no problems with anybody wondering, like thinking you're drunk because you either are or you're not.

The, we've got one dog now which my wife takes out all the time, she has quite a few problems so I usually get dragged out to take her for a walk but half the time I'll say 'well I can't be bothered' if my legs are stiff or whatever. I ended up with, not a hernia but it's where the muscle wall splits; so I went to see the doctor because I thought it was a hernia at first and he said 'you've got to lose weight; go and see a physio'. And the physio didn't have a clue when I went to see him, because she says 'you need to lose weight' so I joined the gym, well I found the gym was boring because you was sitting, running on a treadmill or you were, I couldn't do weights because this thing would pop out and then we found out eventually what it was and it's just something which pregnant women get and because I was overweight, the muscles had spread and the thing popped through. There was no, they didn't operate on it and there was no health problems with it so I've now, now I go to the speedway on a Sunday because they race on a Sunday night but we have to cover up the dog track with plastic sheets, and it's, so I give them a hand to help them to do that and I've managed to lose half a stone in the last six months so that's not too bad. I play a lot on the Wii, Wii sports and everything, now the grandson plays on it more than I do but we've found the problems with the Wii was when you put say the step, where you do the step ups on, because with the Parkinson's your leg wouldn't do what it was told to do you would step on the thing, you were supposed to go left then off and like right and then off, your legs would move so you lost the rhythm so that used to get quite annoying. So I stopped using that and then when we got the Wii sport, the Wii fit plus the, it came and you could also alter the tempo so you could go faster or slower so I found that was easier so I can do now like 1,100 step ups in five, is it ten, fifteen minutes. Now, whereas on the other one you would go on for it about two or three minutes and say 'I can't be bothered with this'; same with the hoopla one which is supposed to be good for getting your, the midsection down. You couldn't do that because you couldn't go round and round because you would start, one leg would decide it wasn't going to do something. I find the balance game's good on it because you don't have to move fast, you can just move your body about on the board, that's quite good.

I'm just trying to think what else to put on there.

I don't have a motorbike now, when I got the motability car my wife says we can't have a car and a bike so the bike went; but it was a case of the bike was quite heavy and it was quite a big bike, 800cc and I found that when I was in traffic, you would get stressed because you were weaving through the traffic and everything and cars is coming from all angles, I used to get more problems with my legs, not being able to get my leg off the foot peg and one day I was going to fall off so it was just as well that I sold the bike. And like I say the grandson's got a little motorbike now, he loves it, we have him up the Speedway on a Sunday before the race meetings and he'll, I think he's done more laps than I ever did at Brough Park now. There's a couple of young lads up there and they'll borrow his bike because they fit on his bike, they're a little bit bigger than him so his bike gets quite a good run out. So I'm in the process of building him a proper, miniature speedway bike. So we've got all the (inaudible) and everything, it's just a case of borrowing a welder off somebody and welding it altogether in the right shape, the right size for him.

But I keep myself busy, if I'm not doing something on the computer, I'm either in the garage messing about or making something or other because I've still got all my tools and everything from when I used to be a fitter. I don't know whether I got Parkinson's through all the chemicals we were involved in, I mean you used to think nothing of eating your sandwiches with manky, black, dirty hands covered in oil. I worked down the pits when I was younger which was, you were eating half your sandwich with coal dust. The chemicals in the, like car, I used to be a car mechanic and a bus fitter and you were like working with oils, fuels and you'd think nothing. You would get covered in oil and you would just work through to the end of the day and then get a shower when you went home. So I don't know if that had something to do with my Parkinson's? I mean there's a lot of research now where they think it starts in your stomach, the problems, and then it gradually migrates up. Because from, since I've been diagnosed, I mean I basically know more than the average person now knows about Parkinson's because I've looked at everything. I've done a couple of articles for the YAP magazine when it used to be out, one about riding a motorcycle and Parkinson's and how you can convert it to a trike so you don't have to put your feet down and the other one was starting at the beginning of when I first got diagnosed, was the ups and downs. I had a lot of problems with insurance companies. Then, just by accident I found out that I could claim on the critical illness insurance that I'd taken out on the mortgage when we moved into this house and it was only because I was on the insurance company's website and I happened to be reading the bits and pieces when messing about on the computer and it came, Alzheimer's Disease if diagnosed before the age of 65 and then along came Parkinson's if you were diagnosed before the age of 65. So we went to see the estate agent who we bought the house through and he hummed and haahed and he says 'well if they say no, they say no and what have you' so he didn't seem to be doing anything so we took over it ourselves to do it and we sent all the forms off and everything, the letters from the doctors and what have you and gave them permission to contact the doctors and I got a letter back saying 'our medical panel have like looked at your case notes blah, blah we don't think you have a definite diagnosis of Parkinson's Disease; what you have is early onset Parkinsonism Syndrome'. So at the time I'd only just started going to the Parkinson's, which was the Parkinson's Disease Society then for the meetings and I was speaking to the chair then and she said 'when you go to the hospital', which was like a fortnight later, 'take the letter with you and show it to the doctor. So I went down and I was like seeing one of the professor's associates and he says, I says 'well I've got this letter from the thingy saying I haven't got Parkinson's, I've got such 'n such'. So he says 'leave it with me, I'll go and see' the doctor. So the doctor came in and he says 'insurance companies! There's my contact details, tell them to write to me'. So two weeks later I got a cheque for £20,000 through the post so that sorted that out! I then, when I stopped driving the wagons, my driving licence was insured through the union so they decided I wasn't using my driving licence at the time I was diagnosed; so I says 'well I was working driving 44 tons artics; what was I using my driving licence for ... paperweights?' So they gave in and I got £7,500 off them so that made life a bit easier. We went to Egypt for our 25th anniversary two years ago, three years ago now and the difference when you are out there because of the heat, was your Parkinson's symptoms were halved, it was the same when we went to Crete and it was hot. Because of the heat, I don't know what it is, it's something because the cold doesn't like Parkinson's, we had less problems when the temperature was high than what it was you came back here and you went, because you don't shiver, you actually shake with your Parkinson's and you're freezing cold; but I don't know. Is there anything else I can add to that?

I Well if you could just talk about your medication, how important it is for you and if you've ever had experience in needing to take medication while in hospital.

M Well I've never actually been in hospital since I was in getting diagnosed so I haven't had a problem with that. The only like problems I've had with my medication was the Selegeline affecting my sleep patterns; then the Mirapexine I with my swollen legs. There's a lot of people have problems with Stalevo but I've never had any problems with Stalevo, it just turns your pee bright orange so you can tell if somebody's on it when you go to the loo. The Metazapine I don't take all the time because I know if I'm going to go to bed, I'll go to bed; other times if I

think I've got to stop, I'll take my medication before I go to bed, I'll be on the computer within half an hour it's a case of you've just got to go to bed because you're going to fall over. If I don't take my medication, like if I'm doing something, like say working on the car when we had our own car, the, you would know because you think, like your hands just would stop working so it was time to go and take your pills. But I mean I've got a pill timer and everything but I never ever take them on time because I'm supposed to take one at nine o'clock but I'm usually not out of bed at nine o'clock in the morning. The problems I had, the nightmares were controlled by the Clonazepam I think it is? So that's caused that and I haven't got that problem anymore so we're just waiting now to see if when they changes us on to the slow release Mirapexin, if it stops my ankles swelling 'cos when I reduced it to two tablets three times a day, one ankle decided it was going to go down but the other one hasn't and you've just got to bump your leg and it actually breaks the skin, normally you would just like 'oh it's just felt as though I just scraped it' and never had any problems but with the, with your oedema) legs if you say bang it on the corner of the bed or something it will actually cut and break the skin. My quinine works great for stopping the cramps. I've also got other things which the physiotherapists have told us to do, like bend your toes back over and wrap something through your toes but with the quinine I haven't actually had to do that. I'm just trying to think what else.

I used to, when I was on the Selegiline, I could just fall asleep anywhere, I mean it just depends if I'm a bit tired I can still do that but it's nowhere near as bad as it was. The, I'm just trying to think what else, I don't take any others, so I've gotmyMirapexin which is two three times a day; myStalevos, 100mg four times a day; me, on a night time I take one Metazapine, one quinine to stop the cramps and then the Klemazapine I think it is, which stops the nightmares and that's basically all the pills that I take at the moment. And like I'll go next, in the next couple of months when I'm back at the hospital they'll probably change something and try something else as well. So we'll just see 'cos like each time you go they change it, try and tweak it a little bit 'cos like I say everybody's different, nobody has the same medication. 'cos people come up to me and say 'well, how do I take this one?' I say 'well it's no good asking me 'cos you need to speak to somebody medically trained, not me'.

M The other people that I know who have had problems is like where people who are on patches, having trouble like concentrating; my concentration's shot to pieces, I mean I'll flit from one thing to another. I'll go out in the garage to do something and I'll come in five minutes later to ask my wife what I went out there for! But I don't know, I've always been, my short term memory's always been crap anyway. like you'll be out in the garage and you'll come in for something and it's gone and you think 'what the hell did I ...' (inaudible) go back to the garage and you stand out in the garage and then 'ah I know what it was I came in for'; you walk back in, you've forgotten again. So that's a problem with the Parkinson's. The, when I first started on the tablets you get quite paranoid, I still do, I'll go for something and I can't find it, so 'where the hell has my wife put that now?' and it's, you hunt all over the place, I mean I've put padlocks on things and thought 'where the hell have I put the keys'; I've hunted the house for the keys. I've left my keys in shops. I mean I was at my friend's car shop the other week, my wife had to go up on the Monday and my keys were sitting on the counter. I'm just trying to think what else; the problems I've had.

I don't have any problem when I drive, like I've always been the same when I drive slow I don't concentrate, if I drive quite fast I concentrate so but I don't nowhere near as concentrate as much as I used to. I mean I've like raced cars, rallied cars, raced motorbikes and never had no problems with concentration like that but as soon as I start going slow I start to wander about which is pain with the caravan on because you're sat at 55, 60 miles an hour with the caravan on but you're that busy looking to make sure nobody's, like wagons are overtaking you or anything. You tend to concentrate more that way. I'm just trying to think what else.

I mean the first thing my daughter said when my wife told her that I'd been diagnosed, which was, you know it was at her 18th birthday party, the, two weeks before I was diagnosed and people were coming up and saying 'why're you not getting up and dancing?' Well you couldn't move in time with the rhythm of the music because one side wouldn't go, so that was a bit embarrassing. But the first thing she said when I got diagnosed, I mean she's, 2003 so she'll be 17, was 'is he going to die' (laughter) and she says 'no, no it's not as bad as that'.

And some of the things we looked at when we were waiting to go to the hospital to get diagnosed was, we've got you know like a disks??? free on the magazines and it was such 'n such medical adviser and this that and the other so we were putting all the things in and it keep coming up with motor neurone disease which I thought was not very nice; but obviously when we went to the hospital then we were told it was Parkinson's, the one thing that really bugged me was, you weren't told where you could go to get help or find out about Parkinson's disease, it was just this 'there's the door, come back in six months and we'll see you in six months'. Now that's been a problem with 99% of people, it's one of the bugbears that when we were going to the PPI panel with DeNdron that we don't get told 'oh there's a Parkinson's disease society, they have all the information for everything and they've got, you know 600 leaflets you can get' and you'll get somebody new comes to the Parkinson's and they'll say 'well they just told me I had Parkinson's and that's it' and you think 'well that's the way it is' I can understand why because talking to other people, they've said 'well they'd rather give you a diagnosis of Parkinson's disease than something like motor neurone disease or something else' so it's, I suppose it's more of a relief but the thing is, if they give you a load of information, you would just put it in the bin. But if they just says 'well this is a contact number for if you want to speak to somebody who's got Parkinson's or is involved with somebody who's got Parkinson's or like cares for somebody with Parkinson's' they can get what their take is on the disease. So that's why when, now when new people come to the Parkinson's I'll say to them 'if you need to know anything, my phone number's there so you can either phone me up or you can phone the thing up or you can phone the help line' but the help line is down in London so it's basically somebody just listening to what you've got to say, they can't really like one to one with you where we can at the Parkinson's, at meetings.

I know all about deep brain stimulation, we've had a nurse in talking about that and I've had three friends at the Parkinson's who had it done. one had problems, he got infected so they had to take the electrodes out and put new ones in. another lad was really bad and then he was quite good once he'd had the deep brain stimulation done but now he's starting to drop off again, he doesn't come to meetings anymore now because he's quite bad. And there was a woman who, she was keen golfer but she's stopped playing golf because of her Parkinson's, she had the deep brain stimulation done and now she's got a handicap of eight on the side of the, like on the golf side but the thing is with the drugs and that, that are coming through, you'll go to these like seminars which we've just been to one in Glasgow with the congress and you find out that it's taken like ten years for a drug to be developed so there's drugs that are being developed like now; we're not going to see them for another ten years and then you're going to have to fight with your neurologist and what have you to try and get them. Whereas at one time the neurologist just wouldn't tell you about them, now you find out about them, you go and see your neurologist and say 'well what about this one' and it's a new drug so they don't want to give you it because they're not sure if it's been tested enough or; so now they have a thing which is like shared responsibility whereas you share the responsibility of, because if the drug's going to give you cancer but they don't know about it yet, then you could turn round and say 'well you used to prescribe me this drug and it's now given me cancer' whereas if it's a shared thing between you and the doctor's, they can say 'well you asked for it' so therefore you can't, it basically takes away the worry that the doctor has of being sued for like giving you something that's given you something else. I don't know what else I can add to that?

I Just anything else you want to contribute?

M I'm quite happy not working; it gives me time to do most of the things that I wanted to do before. I mean we can just, at the drop of a hat, we'll be in the caravan or whatever. My wife tends to dote on the grandsons though and basically she'll say 'well I'm able because my daughter works with handicapped and she takes them out on a weekend and that's when we have the grandson, most of the weekends, so it's quite hectic in here on a weekend. The, during the week it's quite quiet, I'll just poddle about doing bits and pieces and I'm usually backwards and forwards in the car, dropping paperwork off, picking paperwork up. Or I'll pick somebody up because it's cheaper for me to go and pick them up than it is for ringing a taxi for them. I've joined a photographic club with one of the lads from the Parkinson's who, he's quite bad now, so I'll go down with him and we do like photo competitions and bits and pieces like that but I'm not one of these with a big, massive camera, I just use my normal one that I bought when I retired. I get a small pension from the company I worked for, but the government just takes that off you in your benefits anyway and then when my wife got her pension they did exactly the same; like we'll get £6 a week off the pension so they take £6 a week off your money so you're no better off. It's saving your money whereas they keep saying 'ah everybody should have a pension' I mean I just got into it because it was a union thing, with the firm I worked for although I was only there four years I transferred my private pension into their pension fund and even the lad who had started my private pension said it's the best thing I could have done 'cos the pension money I get although it doesn't make any difference to my thing, my income support because that's set at a level where you've got 'x' amount to live on, anything above that, they take it off you. I've talked about my DLA. The new thing that's coming in with the Government's got a lot of people worried now; with where they're assessing you for employment and saying if you can stand up, you can sit down, you can sit behind a desk or you can sit behind a counter so you can go to work which I don't think is going to work because they're putting everybody out of work anyway! But it's causing quite a few people to have worries about when they go to see them if they say 'oh you're capable of work' they, it's not so much they change the way around that you have to go looking for a job because you can go every day and look at the thing and say I'll apply for that job, I'll apply for that job, I'll apply for that job but the, it's, if you're getting DLA they're going to say 'well if you're capable of working, why are you getting DLA?' So I mean it's, it doesn't, I mean people, they'll ask me if it's me who's got Parkinson's or my wife, 'cos I don't have that much of a tremor; but they don't see me on the bad times because when I go to the Parkinson's I'm already g'd up anyway and I've got to take that much stuff up with us 'cos I keep, like all the laptop and all the AV equipment here that we've got, I've got all these slide projectors, and projectors and they all stay here so when I come off the committee somebody else is going to have a garageful because I've got all the fund raising equipment here. I suppose if I didn't do work for the Parkinson's Disease Society I would just be messing about on the computer anyway doing other bits and pieces but it just gives me ... and you'll go to a meeting with other chairs and other secretaries and they'll see 'oh we do four hours a week' and I think 'well I do about 40 hours a week' rather than just sitting about I'll go upstairs on the computer and I'll design next year's, I'm in the middle of designing next year's programme now. And I'll spend a good 100 hours on that, just getting everything right and contacting everybody, sending letters out to ask if they could come as speakers and what have you. Like I say my medication, every time I go to the hospital they change it slightly but I've been one of the lucky ones I haven't actually had to go into hospital where the nurses would give you the medication when they came round, with Parkinson's, you know when you need it so that can be a problem for some people. But I haven't actually been in hospital so I haven't had that first hand. I'm just trying to think .. what else?

My pills, I usually keep my pill timer and it bleeps but I usually ignore it because I've had them too late before so it's not really an advantage having them as a beeper and the only thing is I can tell if I've taken them because I've got five compartments so you know 'oh I haven't taken my dinner time ones' but usually an hour after you're supposed to take them I've found, I've started to go off so I know that it's time to go in and take my pills. Apart from them problems I don't have any other problems with the medication. I just, they say 'take it', I take it and if I get problems I'll just phone them up. Just trying to think what else.

I'm just involved in research on the difference between MSA and Parkinson's 'cos they're, one of our members who's just recently died, he had MSA where he was originally diagnosed with Parkinson's disease because they present the same symptoms and then he was told that he had MSA and they had only given him like ten years from diagnosis; so basically they took it from ten years from when he first got diagnosed with Parkinson's and I think it was seven years and he died. So he's quite a loss because I quite liked him, he was, I mean even though he was really seriously ill, he would always have a laugh and a joke. Whereas you know, you get some people 'ooooh I'm having problems with this and I'm having problems with that'. I tend not to say if I've got problems, I mean I'll go to the hospital, if I go by myself I've literally got to take my wife to remind us what to say 'cos by the time I get to the hospital I've forgot what I'm going in for! The, because with the sleep problems, she was, it was affecting her more than it was affecting my 'cos I was asleep, I didn't know that I was jumping all over of the bed! I'd wake up in the morning, absolutely wrecked, you'd think I'd done a marathon!

But a couple of times when I've just gone up by myself, I've basically just will say 'well are you having any problems with this and that?' and I'll say 'no'. Just get on with it. I mean my own doctor when I first got diagnosed, he says, like I went down to see him, he says, 'oh blah, blah, blah', and then says, 'well you seem quite upbeat about it' and I says, 'well there's nowt I can do about it'. I says, 'I've got it' I says, 'I'm stuck with it' so he got quite miffed and he says, 'well there might be something we can do medically to like make it easier'. And I thought well, you just try the pills and if they work they work and if they don't they don't, you just change them round. So I ended up with a cupboard full of pills! I need my shopping bag every time I go down to the chemist 'cos I get them every month. I mean when I first got diagnosed, when I was having to pay for my prescriptions I asked them if I could have three month prescriptions and they says, 'no the most we can do is two months' so you were basically getting four lots of pills every two months which was costing us like £35 a month so, but I don't have to pay for them now.

I mean basically if you've got diabetes, you don't pay for your medication, you get prescriptions. If you've got, I forget what the other one is, but there's something else where you, it's a long term illness; well, Parkinson's is long term, you don't get better from it. It's like if we have somebody in hospital, we never send them a 'get well soon' card because even if they're not in for their Parkinson's, they're still not going to get better from the Parkinson's. We'll send them a 'hope you're feeling better' rather than 'get well soon' because it basically, I would think 'well why are they sending us a get well soon card when they know I'm not going to get well?' But it's not the Parkinson's that kills you it's something else usually. That's about it.

I Alright, ok, thank you very much