

**Bangor University**

## **PROFESSIONAL DOCTORATES**

### **Receiving an uncertain diagnosis experiences and discourse**

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Interview Transcript – Andrew

Interviewer: Ok, urm so I'd like to talk to you today about your diagnosis of mild cognitive impairment.

Andrew: Yeah that's my understanding of it.

Interviewer: Yes about your understanding of it.

Andrew: If you could speak plain English we'd get on better!

Interviewer: (laughs) So, can you say what you think mild cognitive impairment is?

Andrew: It's a form of short term memory loss I would reckon. [Right okay] That's, I'm, a (PROFESSION) view of it, you know.

Interviewer: Yeah. Okay. And ur.

Andrew: Or is there another definition to it? Or explanation for it?

Interviewer: Well what I'm really interested in is your understanding of this diagnosis that you've been given.

Andrew: Urgh. (.) *Well*, I've, just that it's short term memory loss, but what causes it I couldn't tell you.

Interviewer: Okay. Okay. And before you were given the diagnosis had you heard of it before?

Andrew: (.) T to be honest I don't think so. [No. Okay] Not this short term mem, (laughs) being a, being a person I had to go short term, it's still bloody memory loss, you know! [Yeah] This term short-term seems to disguise it in some way you know!

Interviewer: Right okay. Yeah. And urm do you remember being given the diagnosis?

Andrew: (..) I I would imagine I must've done, what people have seen etc etc.

Interview Transcript – Andrew

Interviewer: Yeah. But you have no clear memory of being given the diagnosis?

Andrew: *They call it memory loss* (laughs).

Interviewer: Sorry, what was that?

Andrew: They call it memory loss, you know (laughs).

Interviewer: Yeah. Yeah, do you.

Andrew: It must've been the last, or then again, this is surely (indecipherable) this just **surely** guessing, must be maybe two year ago or something.

Interviewer: About two years ago?

Andrew: I would imagine. It's that vague, so vague.

Interviewer: Yeah. Yeah. And were you given any information about mild cognitive impairment at the time?

Andrew: Like paper handouts? I don't think so. *I don't think so.*

Interviewer: No paper handouts? No okay. Urm, ur, why did you.

Andrew: Am I speaking loud enough?

Interviewer: Yes. Yeah. Urm, do you remember why you went to the memory service?

Andrew: (laughs) I'm not laughing personally luvie, I've got memory loss! In my short abrupt (PLACE) way, it's **bloody obvious!** (laughs) That's how my mind operates!

Interviewer: So you don't remember why you went to the memory service, in the first place.

Interview Transcript – Andrew

Andrew: Well I think that was recently that (indecipherable) five half days I attended the local one. [Yeah]. I don't think I had any other professional assistance.

Interviewer: Yeah. Yeah. Urm, so do you remember when you first noticed problems with your memory?

Andrew: That is a real cracker, that one! [Interviewer laughs] If it was a professional magazine I'd write in about that one. No, quite honestly no, *quite honestly no* [No, no] No. I mean let's face it, we all now and again forget things. [Yeah]. So when it becomes a regular thing (laughs). You just don't react to it the same.

Interviewer: Yeah. So, did you maybe not really notice the memory problems to start off with?

Andrew: **Oh** at the beginning, I think that would be an obvious thing for anybody like myself. [Yeah] You don't really notice it at first. [Yeah]. And if you don't notice it you can't get help can you.

Interviewer: No. Exactly. So there must've been a point where you started thinking it was a problem.

Andrew: No doubt. No doubt. And I can never argue or discuss it because I've got a memory loss!

Interviewer: Yeah. Okay. Urm so what does this diagnosis mean to you? What do you think it means, mild cognitive impairment? How has it affected your life?

Andrew: Well the actual words (indecipherable) because those are American words. What was the last bit you said there?

Interviewer: How has it affected your life?

Andrew: (.) Well (sighs) I've started keeping a day to day diary, just for that reason. [Right] But urr (.) I've got a very restricted social life now. We've moved so often, well I've been

here since 1975, life, it's hard to keep up with old friends, (.) it's mostly job hunting. We don't have a big lot of active social friends at all. [Yeah]. We've good neighbours and everybody across the road, but if you don't go out, it's no odds to go out. And we got (.) we've got transport problems. People still talk about public transport, it's not bloody public, it's **privatised**! And it runs when it wants to run. To suit themselves not to suit me! And course, with my walking problems (.) I had err two, roughly speaking, the last two years I had two 10 day (.) visit's to the (PLACE), and the last time I came out, I remember the professor saying to me, Mr (NAME), house, up or down? Keep off. [Right] And I've got no car. [Yeah]. But you canny be a bit bold, I sometimes I go down, 100 yards down the road there, next street, to see a pal you know. [Yeah] *Got to be* cautious, you know. I still have an odd drink of whiskey, half water, half whiskey, not every day but you know. [Yeah]. If you, you're sensible about things (indecipherable) this strict with the clinic, clinical decision (indecipherable) life buggared in it. [Yeah]. You can't even let the medical people buggar up your life, the state have made a good job of that. I may as well mention, 21 years unemployment. [In employment?] Un, unemployment. [Unemployment? Ok] There's not many people that understand, you do not have the right to **employment**! [Yeah]. Did you realise that? Not many do.

Interviewer: Well I, yeah I can understand that.

Andrew: My favourite one is, parliament gives us the right to vote but no right to employment. [Mmm] This is just the character I am, you know. [Yeah]. It comes from me (.) (PLACE) primary education. I was taught the three Rs. Reading, writing. (.) Go on, reading, writing and.

Interviewer: Urm, I don't know.

Andrew: (indecipherable) *Reading*, reading, writing and summit else. It was reasoning. The three Rs, the third R I got told was reasoning. [Okay] If you think about it, could you get educated without reasoning? You need reasoning to tell you two add two makes four! It's a fundamental part of a. [Yeah] In that day, (clock starts chiming 11) primary school education was fantastic [Yeah] it really was. Right let's get back to your. **Shut up!** (shouted at clock chiming).

## Interview Transcript – Andrew

Interviewer: We'll just wait for that to stop.

Andrew: There's this story that, one of my teenager pals, we'd a bit of a bevvy and stopped over at his house as pals do and he had a clock, (laughs) three pair of boo, three pair of boots set it on time! [Yeah] Anyway, short term memory, *let's talk about that*.

Interviewer: Yeah, so you were saying about um, 21 years unemployment.

Andrew: Yeah. I know I, I, I had no ri, nobody had a right to employment. [Yeah]. That was the mind boggler. [Right]. And nobody else understood that.

Interviewer: Yeah. Yeah. So does that relate at all to the mild cognitive impairment or short term memory loss?

Andrew: God knows what it all affects (.) seriously. [Yeah]. It must've affected my whole personality I think. [Right] Not that I'm qualified to say that, well, person that's college qualified, I'm qualified by experience, by life. [Yeah] I certainly think (.) I think, I and my wife are lucky that I've done this and I'm not better or argumentative or violent, you know.

Interviewer: Yeah. You mean now that you've got short term memory loss, that.

Andrew: No being unemployed.

Interviewer: Being unemployed, okay. Yeah.

Andrew: 21 years a long bloody time. [Yeah]. I think its seven thousand, six hundred and 65 days. [Right!] And the reason I quote that is, due to security at the Falkland's conflict, ur correspondence (indecipherable) oh that was it, he couldn't ask how many of the planes come back (indecipherable) BBC man said we counted them out, we counted them in again. Subtle way of saying things, you know. [Yeah. *Yeah*. Okay] You carry on again cos I get distracted a wee bit. Sometimes distraction is justifiable, other times it's *not*.

Interviewer: Yeah. Do you think that's related to the mild cognitive impairment, the getting distracted?

Andrew: **Surely, surely**, it must be. (laughs) I'm a (PROFESSION) right (laughs). Or as they used to say head bangers like. Yes it's **got** to!

Interviewer: Yeah, so in the past your concentration has been really good, but now you're more easily distracted onto different topics?

Andrew: Oh very, very distracted, I mean (.) I wasn't your ordinary DHS applicant. [No] When I came off the system, I'd four big council paper bags full of correspondence. [Yeah]. At it all the time.

Interviewer: What, writing letters?

Andrew: To the DHSS.

Interviewer: Oh right, what about?

Andrew: About being unemployed on the benefit's system. [Okay, yeah] It was an educational thing (laughs).

Interviewer: What do you mean?

Andrew: (indecipherable) write two words. Err (..) The method of equating an unemployed persons unemployment money, you know. (.) It's a bloody conspiracy job. But I saw through it all. I we had no DHR DHS office locally, so I was privileged to having home visits. [Right] And usually two ladies. [Right] They were my stage. I exploited it something disgusting (laughs) not abusively, you know. [No] I had different techniques. Sometimes I'd stay up half the night, create them, harshly (.) and shaving. And the next day, I used to have a three piece suit in those days, (indecipherable) *this* three piece suit on. [Yeah] And then I'd change the *seats we used to sit it* (laughs) psychological warfare! Whether it paid off I do not know but I had to do something. [Yeah] And I, I wasn't your ordinary unemployed person, *you know* (laughs).

Interview Transcript – Andrew

Interviewer: In what way weren't you the ordinary unemployed, how would have described yourself?

Andrew: Eccentric maybe, I don't know. [Okay] I'm not very good at English, I'm (PLACE) you see! (laughs)

Interviewer: I had noticed (laughs).

Andrew: Cheeky bitch! (laughs)

Interviewer: Umm. So would you, would have said that you were maybe brighter than others?

Andrew: Oh (PLACE) educa, I just told you. For my first, I came back from being evacuated, my first day in primary school I said I was taught the three Rs. Reading, writing and reasoning and that's been with me all the time. Obviously I'm 79 and I can **still remember it!** [Yeah]. They definitely, they used to say a good old (PLACE) education, there's no doubt about it.

Interviewer: *Yeah*. So was, was it and is it quite important to you to be urm seen as quite bright and intelligent and on the ball?

Andrew: What was the key word in the question again? Was it the please or the happy? [Pardon?] What was the key word in that last question you put?

Interviewer: So was it and is it still quite important to you [Oh yeah!] to be quite intelligent.

Andrew: Status it's my, my personal status. I'm not a **bloody idiot!** [Yeah] And I tell them loud and clear. It's simple, polite language. [Yeah]. There's an old saying there's no point knocking if there's no bastard in (laughs). [Yeah! Urm] Put it this way, (laughs) I'm not a criminal, but (.) I canny mind, I've only been in the magistrates court once (laughs) and there's a guy not much older than myself, pompous bastard. And he s, and at the end of the proceedings he says to me, I do not I do not want to see you in my court again! All I said to him quite simply was don't sit there looking (indecipherable) I've got you (indecipherable)! In those days there were other people in the court now they've got down one mat one one



magistrate and one person you know. [Yeah] But them days it was like community session. You're sat there waiting you turn to speak to the bench you know, [Yeah] and he did not like that at all. A snigger ran round the room you know (laughs)! [Yeah] I take it as me, you shouldn't have said to me you idiot you know.

Interviewer: Yeah. Yeah. Urm, so do you think that, urm, how do you think about yourself now having got short term memory loss and this diagnosis of mild cognitive impairment?

Andrew: Well there's one thing there's no self-pity in me. [Okay] And I just, after, I should've done it a long ago but that's the benefit of the memory loss clinic that somebody rang. No I thought most of it, not rubbish but (.) all depends on the students taking part. The only relevant thing I can say is oh is the last week when the clock (indecipherable) get yourself a diary (NAME). [Yeah] I can understand the mechanics of that, *you can look back*. It starts it starts to trigger your memory by well by reminding you!

Interviewer: Yeah. And have you found that quite helpful then, using a diary?

Andrew: Well I'm enjoying doing it. [Yeah] As of yet I've I've not (.) had a topic to, oh arr there it is you know. The reference aspect of it, it'll come out one of these days. Look it up.

Interviewer: Yeah. Yeah. So you can refer back through it?

Andrew: This all, this all comes back to the mechanical self you know, this a mechanical reaction, you know. Oh aye. I I don't know, I don't know if I think they'll ever cure it, but if I can reduce it.

Interviewer: Yeah. And do you think a diary could reduce your memory problems?

Andrew: Oh yeah because (.) I can't rec, I've only been doing it this year, I can't recall having actually used it. Yeah I sometimes look back to see what I did or who it was I was speaking to at the supermarket that day. Yeah, yeah I think there's, early signs of it working.

Interview Transcript – Andrew

Interviewer: Yeah, yeah, okay. And what do you think the outcome might be of having this diagnosis of mild cognitive impairment? Where do you think it might lead in the future? Do you think that it might get better?

Andrew: Oh yeah! Yeah I'm hopeful. A slight improvement would be great, great.

Interviewer: Yeah. Yeah. And that that's what you think might happen?

Andrew: Yeah. You know, that's what I think might happen. It **could** happen. And bloody well **better** had! (laughs)

Interviewer: Right, yeah. *Okay*, urm.

Andrew: Especially as I've not got much company now. (.) Ur if you're out anywhere I mean company. Then I think it could be very embarrassing or very **off** putting you know. [Right] Have you have you seen (NAME) lately? Discreetly *you know* (laughs).

Interviewer: So people whispering behind your back?

Andrew: Well not, between themselves like!

Interviewer: What what do you worry that people might say about you?

Andrew: Ohh they can say what they like it's a free country, I'm a (NAME) a true (NAME). [Yeah] And I don't think my small circle of acquaintance and friends, I can't see any of them, they're better educated people. [Yeah] I mean that in the broadest sense of the word.

Interviewer: Yeah (.) urm but do you worry that people [Nooo!] might say things?

Andrew: No. [No] There's no profit in worry. That ends up leading to other illnesses, disorders. Oh no.

Interviewer: Yeah. So you try not to worry about what other people think?

Andrew: **Oft** to hell with that! When the days is they start paying my rent they can do that. [Yeah] No no, no no. [Yeah, have you] Having said that everything great thing, you know (.) I got, we got 10 grand when I got made redundant, well we didn't get made redundant I did not get made redundant, you did not get made redundant! Bloody job got made redundant! You know. And, everybody was booking holidays. What was (NAME) doing? Straight down the building society. Pay that mortgage off. That was *my* security. That was my *first* (clicks fingers) instant reaction. So redundancy did us a big favour, cos it was just enough to cover the mortgage, you know. [Right okay. Yeah] It was a wee bit ur, it was a little thing that happened to yourself, had a had a good side, and I I exploited it, that's not the right word, every other buggar was booking foreign holidays. Oh *no no no*. Once I got that thought out of my head I'm laughing now. [Yeah] Very bold (laughs).

Interviewer: Yeah. So you thought quite practically about the redundancy?

Andrew: I am because I'm a (NAME)! [Yeah] Everything goes up and down and roundabout in my world, you know (laughs). [Yeah] Mind you I did have a (.) in tho, in those days (PLACE) had other cen centres, (PROFESSION), it was an (PROFESSION) *community*, but eh (..) one of the **best** apprenticeships you could get, was, you never hear it now (coughs) the government labels change. We were the (PROFESSION). Government run (.) *and the* (..) the journeymen that we were put with were all self-selected from the past (indecipherable) employment, *you know*. [Yeah] Top class. Top class. So I had a good (PROFESSION) apprenticeship and a good education. No doubt about it. [Yeah] I mean, I'm I'm never embarrassed, you can put me, you can put me with barristers, a high court judge and I'll stand my corner. Right (.) judge, I can't remember the run up to it (.) oh that was it. Through, through radio and films and that, through life I gleamed this, I'm watching, watching the (.) films and that court cases and I sussed this thing. Barristers are crafty little bastards. They want a yes or no answer, which is lovely. Or (.) the, the other type of answer, the indefinite answer. So (.) I played this (indecipherable) in a court a big court once and there was a road traffic wi witness and I could see the way this barrister was heading. (.) Excuse me, the judge was only over there. Down I went. Shoe s, socks off. Shook my socks out, shook my shoes out. I come back and hang on I'm sorry I says but, I can't remember who I was speaking to, you all look the same with those wigs on you know. And there was a titter somewhere in the court (laughs) this bastard, no more questions, I thought I dodged that little trap pal! *You know*. Been blessed that way you know. [Yeah] But it's your turn again.

## Interview Transcript – Andrew

Interviewer: Yeah. So you've always been, I guess, been able to.

Andrew: Fend for myself. [Yes] Too true. [Yeah. Urm] You look that way, I'll make a belt for the door, you know. [Yeah] I never get embarrassed. Anyone tries to embarrass me I swing at them, and educate them.

Interviewer: Yeah. Yeah. Urm. Has having short term memory loss changed that at all?

Andrew: Hang on. Repeat what you said a minute ago.

Interviewer: So you've always been able to.

Andrew: This is an example of how short short term memory I've got (laughs).

Interviewer: (laughs) So, you've always been able to fend for yourself.

Andrew: Yeah, yeah yeah. [Yeah, urm] Not so much with that because I learnt a wee lesson, ru run legs your body's in trouble. (Interviewer laughs) [Yeah, so urm] He who lasted, laughs lasts back another day can he. [Yeah] That's the college I came up with.

Interviewer: Ok, urm so you've always been quite sharp, on the ball. [Yeah] Always been able to get yourself out of scrapes. [Yeah] Not get embarrassed easily because.

Andrew: Oh why should I get embarrassed, it's **them** who should get embarrassed not me!

Interviewer: Yeah. Have you found that's changed at all since having short term memory loss?

Andrew: Yeah do you really think, when you just asked me that question are you referring to me or the society I'm in?

Interviewer: You.

Interview Transcript – Andrew

Andrew: Me? No, no (laughs). [No] (indecipherable) kiss my arse and say goodbye.

Interviewer: Yeah. So do you feel that you've changed at all since having this short term memory loss?

Andrew: (..) You're the student of this subject, I'd have thought you (indecipherable)

Interviewer: I'm really interested in what you think about yourself, now.

Andrew: I'm not big headed, I think I'm very ordinary. Which baffles a lot of people.

Interviewer: Ordinary, did you say?

Andrew: Yeah! [Okay] It's not a problem that I'm a wee bit better sometime, education, this that and the other. Some people are unfortunate in not having to match my knowledge and my wit, you know.

Interviewer: Yeah, yeah. And, urm, has your knowledge and wit changed since, the.

Andrew: How would I notice that? You know what I mean (laughs).

Interviewer: I don't know, have you noticed it?

Andrew: It was just an explanation for the machine you know (laughs) (Interviewer laughs). It's a hard one to answer that. [Yeah] You got to be honest, that the question (indecipherable) *couldn't really* tell you.

Interviewer: No, so you're not sure if things have changed?

Andrew: There must be one or two officials could answer that question better than me (laughs).

Interviewer: (laughs) Urm, and have you and your wife spoken about your memory problems?

Andrew: (.) Not clinically, *no, no*. [No] I have a wee bit, my wife and I got two different intellects.

Interviewer: What do you mean?

Andrew: Well, she, she's, she's not a thinker like me. (..) She can get embarrassed sometimes when I start spouting off. [Yeah] Cos she's lost, *you know*. I honestly try to keep, avoid that situation for her. [Yeah] Sometimes I can manage to, put it in simpler language, you know but then again if it's a spur of the moment an you're bloods raging. The two. How, how, many people have said it, how the hell we ever let this marriage lasted. Not just because of economic circumstances, but of difference, you know.

Interviewer: Yeah, personal differences?

Andrew: Yeah yeah yeah, we just. [Yeah] (.) I I've never asked her but I've got this attitude to her, her (indecipherable) going through divorce or something, papers you get married (laughs) for less than two years! [Yeah] And then again, for relationships, if we'd had annual holidays, that would have affected relationships wouldn't it. [Yeah] I think (.) The fa, the family arrived five years after we got marriage sort of thing. We had two coach tour holidays. For a life time that aint much is it? [Mmm] Holidays, holidays are part of your healthcare. But not many people understand that, we go on holiday to enjoy the holiday. It's part of your healthcare. [Yeah] Don't conceive that all, you know.

Interviewer: Yeah. So how come you've only had two holidays if you think it's.

Andrew: Economics. [Okay] (indecipherable) (.) my wife never worked. (.) That suited me. We we had a we had a wee bit experiences when we were just married, coming at night having a hand round it for some short (laughs). I say that for that for me. And I di, my wife wanted to work. Urm. She wanted to be a ho house (whistles) house wife you know. So that's, has that, has that answered that question. I forgot the bloody question!

Interviewer: Yeah. Yeah. So you.

Interview Transcript – Andrew

Andrew: I try not to digress but, depending on the line of answer you get, some I digress, they pull you away from the subject.

Interviewer: Yeah. No that's ok, that's okay. Urm so you, you and your wife, you and your wife, you don't really talk about your memory difficulties?

Andrew: Well (.) I doubt if she could talk about it.

Interviewer: Right. What do you mean?

Andrew: Clinically or mechanically or you know. [No. Okay. And] It's just another affliction to me as a (PROFESSION) person (laughs).

Interviewer: (laughs) Do you ever talk about your problems with anybody else?

Andrew: (.) But. I mean my, my so social circle, my (PLACE) neighbour across the way, (NAME) next door (..) must be somebody else that we see now and again, but no. That's my little. Wo wouldn't understand it in any case, they might come to d daft conclusions.

Interviewer: What daft conclusions do you think they might come to?

Andrew: That you're a hand banger or something! [Right] Just cos you've got slight memory loss, doesn't say you're an idiot or not responsible for what you're saying like.

Interviewer: Yeah, yeah. So do you ever, would you think that they might think that you're not as intelligent as you actually are?

Andrew: Oh I don't think that that there not many people that understand that word intelligent. [Yeah] Clever. Clever maybe. But not intelligent, no.

Interviewer: Okay. And what would you say you are?

Andrew: (.) Well with all modesty I must be pretty intelligent. [Yeah] I mean when you can embarrass the high court judge (indecipherable) (laughs) [Yeah] I know humour can come

into that escapade in the court room you know. [Yeah] It's a great thing a sense of humour. As long as you don't use it against other people, you know insultingly (.) are you (NAME) (laughs) I can only see why though (laughs). If they ask me a lot of stupid questions, they get a stupid answer, you know. [Yeah] But it was better the old days, it was one to one in court. *I don't know*, about the first 30 years of my life maybe. It was a big community thing, you were all sat there until your case came up and the judge and magistrates address you, you know. (*indecipherable*) [Pardon?] They've got you. Urr what's the word, secure, not secure you. They've got you on your own, now. And if you haven't got the personality I've got, you're doomed. There's strength in numbers wasn't there, and they were conscious what they said to you because of the rest of the people in court. (.) [Yeah] Can you imagine me with a (PROFESSION) on? [With a?] With a (PROFESSION) (laughs) arr. Best best three years of my life. Got paid to walk up and down the street, help old ladies across the road, talk to people. That was part to me that was part of the job (*indecipherable*) you don't get that much talk and listen, *you know*. [Yeah] *I enjoyed it, I enjoyed it*. [Yeah] *Dead fun them days* [Yeah] (.) especially walking round (PLACE), *bloody hell*. [Yeah] (laughs) (.) There was (.) there was quite a posh community in (PLACE) (.) that that dine with this one and that one, you know. And ur, I'm only, I'm only uniform, walking down (PLACE) (*indecipherable*) lady was in front of me (.) *quite well (indecipherable) lady*, and she's got thin thin heels. And she went right in front of me and she went down (claps hands once) and, you know. [Yeah] Parry, are you alright hen? **Don't you call me hen**, so I just chucked her back on the pavement (laughs)! Oh (laughs) I was in front of the (PROFESSION) next morning, best uniform (*indecipherable*) (laughs). [Yeah] What else did she expect from a (PLACE) (laughs)! [Yeah] I mean I thought *I thought*, you know what I mean, I was only walking up this woman's back and she goes dud dun, you know. (*indecipherable*) I've been a naughty boy once or twice but I got away with it, you know. [Yeah!] I had to, the they got a bit (*indecipherable*) (PROFESSION) to march me in to the (NAME). And you'll never guess (laughs) I was there, I never did military training. [Yeah] The jocks marchin me in and I end up my face (.) my face is, instead of facing them, the boss man, I was facing the other way. My (NAME), my (NAME) was a good old (PLACE). He'd been (.) he'd been unemployed back in the 20's and the (PROFESSION) was a favourite idea for unemployed people. And he just shook his head and said (NAME) they're the wrong way round son. (.) Right let's get back and close again. (*indecipherable*) digress. (Interviewer laughs). **Not** that I'm digress able!

Interviewer: No, no (laughs) not at all!



Andrew: Two faced git, you!

Interviewer: (laughs) Urm, so how do the memory problems affect you in your daily life? Or do they?

Andrew: I (indecipherable) (.) I've, I had an instant reply there that's slipped my memory again. (.) You just got to get on with it haven't you. It's like unemployment, you've just got to get on with it.

Interviewer: Yeah. Ok, so you see this in the same way as being unemployed?

Andrew: Yeah, I don't get self-conscious about it. [Yeah] I've got bad memory. (.) [Yeah] So (indecipherable) put me in a home or summit, *you know*, which I've not doubt they did years ago, if you go back far enough. *No, no*.

Interviewer: Yeah, so that's not something that worries you, being put in a home? [What's] That anybody's going to put you in a home.

Andrew: What's that word worry? That's the word that gives you ulcers. [Yeah] And gets you all bitter (.) I've *fo*, (indecipherable) it'll be funny, any home they put me into, I tell you what. [Yeah] No doubt about it! Real chivalrous fun, you know (laughs). [Yeah] But there again, there, there, becoming less and less such homes, can't afford them places. Unless you're particularly dangerous. [Right. Yeah] I mean wh, wh, why, **why** would we go to all of the expenses, I'm very conscious of expense of course, and for some serious crimes, they walk out the court, it's a bloody joke! (.) I I I if I've got to worry, my worries where societies heading.

Interviewer: Mmm, where do you think it is heading?

Andrew: Oh. (indecipherable) it's all undermined by economics. We can't afford this, we can't afford longer judges, and we can't afford better trial. It's a *cut, cut, cut*. (.) It's suicidal but (sighs) it's just democracy. You know, that's the great misconception this democracy. It er (..) this is one of my problems this, any general election, the average citizen has no social

or economic or legal personality. They're **open** to other peoples (.) (whistles) influences. It's wicked, it's serious. And, and I, when I first became unemployed, I took babies, one of the babies had just started *infant school*. [Had just?] Had just started infant school. [Okay] What did (NAME) do? Went down the school! Got involved down there. Primary school. And then when they went up to (PLACE), I followed them up there. Things got so out of hand, so to speak, with them recruiting new staff. I was (indecipherable) little school bfff, I might just call into use the cant, cup of tea with the staff. This new face said hi (NAME). (.) (indecipherable) I says I'm walking (indecipherable) my school, walking along and somebody calls me (NAME) I've never met before. My my fault he said. New member of staff recruited he says. And he says through this experience you've taught me something, with you in my school, new staff have got to be told about you at the interview (laughs) (Interviewer laughs). Seriously! [Yeah] (.) And if, if any, if any of the staff was looking for the head, all they had to do was look for me. Their first stop would be. And somebody would ask the head, have you seen (NAME). Or I'd ask has anybody seen the head, you know. What's and we never stood on each other's toes, you know. And that's what t, that that's my answer to 21 years unemployment. Get involved. Get right in there you know. [Yeah] It's what, what was the (indecipherable) said one or two existing staff and new staff took a wee bit of getting used to. Have to ask (NAME) to speak to the head for them (laughs). [Right] But it was all very harmonious, very *harmonious*. Christmas time (laughs) this is when you drink and drive before the drink drivers had. (NAME), she was the head of English, and she had two two big carrier bags of goodies for my two kids. What a school, *I tell you what*. I don't think I'd be the man I am after 21 years unemployment, had it not been for this schools particularly.

Interviewer: Yeah. So what did you do in the schools?

Andrew: **Any** bloody thing. **Everything**. [Yeah] Eh resources. Eh once instance I was putting up the, drama took a big part, I I was, kids were getting into a play or summit, and this particular one was a pub. So somebody says we need pub furniture, see (NAME)! (laughs). [Right] (Interviewer laughs). Took me about four tr, I only had a favour, *you know*. It took me about four trips to get this *fucking* furniture to the school. And I had to return it at the end. That's just one of the, besides (.) new members of staff had to be inducted, there's a mad (PLACE) man who runs round, he's friendly enough and if you want anything, bff. It was short, (indecipherable) cotton tails. [Yeah] Aerospace here I come. But then there's three

changes the regime in there, my access was limited to twice and that was it, you know. I didn't know this but when I got in there, there's hand on training instructor was a bit of an invalid, he got injured at work, he did (indecipherable) in his job. He went, he was a (PLACE) high school man (laughs) err (.) he'd look at his cover, bff, dot. I'd just write a requisition out (indecipherable) (.) we had a lovely little network. Not criminal but oh (laughs) very very handy. [Mmm] I'm not bragging but that was (indecipherable) I probably be a different person 21 years unemployed if I didn't have the environment I was living in. [Yeah] Ohhh tooty fruity, no problem.

Interviewer: Yeah, yeah. So it sounds like, even when things were difficult in the past, so when you were made unemployed, that you, that you've been quite resourceful?

Andrew: Well and again I was conscious of unemployment, I'm a (PLACE).

Interviewer: You're a?

Andrew: (PLACE). From the (PLACE), the (PLACE).

Interviewer: Right, okay. What does that mean? (clock chimes)

Andrew: Well uh (PLACE) is a section of wee (PLACE), which has one big **political** personality. [Right] (.) Have, and ship yards, there's always redundancies. If we finish that ship and there's not another one ordered, well we make you redundant. So we used to *being unemployed*. Part of our *growing up*. [Yeah] That thing there that's called unemployment. And you learn, (indecipherable) some of the dodgers that boys were doing, you know. It got, I I think it was up here actually (.) we had a couple, husband and wife, claiming and one was and I can't remember the actual circumstances. But they were sit sitting outside these peoples accommodation, to see whether they came and went for sex in the night, and this was how crude the whole bloody system was. You, you're a student, you can accept what I'm saying, just to turn on the person and. (NAME) is prefabricating again. You've not lived! [Pardon?] You **haven't** lived! [Yeah] I mean, I always, not often had these DHS visitors because I think they used to draw bloody straws to go to (PLACE) (laughs). I'd always ask for ID. [Yeah] I'd let them come in and look round and make up my mind where I wanted to sit. This is power. I'm influencing power.

Interviewer: Mmm yeah. (Andrew laughs). So is, is that something that you often tried to do, is?

Andrew: Oh it is if DHS staff came. I let them know, I let them in by the grace of God [Yeah] cos there was nothing in the DHS act to say. Cos the act was laid out with all the DHS offices that the big cities had. But there was nothing in legislation to say that had to entertain them at my house. [Right] Why else couldn't they just arrange the same at the job centre!

Interviewer: Yeah so it really sounds like you did your research.

Andrew: *Well*, I was born into research (laughs). My fr, friends reckon that when the midwife gave me that slap, I sat and looked up at her and said what the hell was that for! You know, I've just arrived (laughs)! [Right] Even though I was only a born baby I was that reactive. [Yeah] And then of course in those days there's all those confinements. And the second marriage, carried five kids. And I was always the most convenient one to keep off school, a lot for delivery, you know. [Right] And I knew, I knew to keep to keep my coal cos you couldn't go back that way now with central heating. You needed a coal fire, cos, and plenty of boiling water. And a midwife would come with *a parcel to go*, and the fire had enough room, the fire was well going, and there was enough room to put this parcel on. And then some dross. Do you know what dross is?

Interviewer: No

Andrew: Fine coal. [Right, okay] You see (*indecipherable*) *dross*, poor man's coal. [Right, okay. *Yeah*] You should get a diploma when you leave here in social sciences! (Interviewer laughs) Now, get back on track, you better keep me on track. Ur aye. I mean, how many children in this generation have been close to a child's birth? I mean (*indecipherable*) *but* all this going on about the house under my eye (*indecipherable*) refuge you know. [Yeah] There must be some nurse, people in the in the nursing profession that never been through it.

Interviewer: No probably not. *No*.

Andrew: It's all good for education.

Interviewer: Yeah. So you've had a lot of life experiences and life education then.

Andrew: **Ohhh** aye (.) oh (laughs) this happened later on in (PLACE). This arrogant zone manager, (.) do you know who I am? I nudge my mate, phone the surgery, we've got a loss of memory job here. He never did that again, he was the laughing stock of the fucking plant. I mean, struggled, I had him (*indecipherable*). (.) He grabbed both arms so what would you do, you struggle don't you (laughs). Away he went in the works ambulance (laughs)! It was round the works in about a quarter of an hour! Did you hear that joke down there, arrogant bastard, he's sent away in the ambulance loss of memory! (laughs) How did you do that? Quite easy. Couple of me mates. (.) *I think*, I think this guy's got loss of memory, he doesn't know who he is, he asked me who he is. Go phone the a (laughs)! [Right, okay!] (.) If you want to **pick** on someone, don't pick on me! [Yeah] I've got a life time's experiences right to my hand, you know. I'm not bragging, I'm just going through it. (*indecipherable*) was that really you (NAME)? *You know*. [Yeah, Yeah] Oh. Anyway.

Interviewer: Okay so it sounds like.

Andrew: I'm an idiot, a better class of idiot!

Interviewer: (laughs) No, that the memory problems.

Andrew: Excuse me lady, you see this talking (*indecipherable*) (starts taking off his jumper). You notice I don't whack my head when I stand up (..) (NAME) is only taking his cardigan off alright.

Interviewer: (laughs). Okay, so it sounds like the memory problems haven't affected you that much in your day to day life? Or that you're not letting them affect you in your day to day.

Andrew: Yeah it's very handy cos I can always say, my memory, loss of memory is working when the magistrate was talking to me. Its, it's got its useful uses as well.

Interviewer: Yeah. So what are the advantages of having this mild cognitive impairment, or memory loss?

Interview Transcript – Andrew

Andrew: It it it's simple things, I can say I did this, I did that. If I had a memory I I could tell I could agree with you or disagree with you, you know.

Interviewer: Yeah. So you could put your hands up and claim innocence?

Andrew: **Yeah!** (laughs).

Interviewer: Yeah? Okay. Do you do that, do you do that with your wife?

Andrew: No way, she's a woman, like yourself. You should ask that question. (laughs).

Interviewer: (laughs) Urm, are there any down sides or disadvantages to having mild cognitive impairment?

Andrew: (..) Like you say, walking up the street, woman stop put their arm around me to sooth me but they *don't* (laughs). I *don't think so*. [No, no] If there was you could quite well understand this character, **think** something up. No, to be honest with you, no.

Interviewer: No. Okay, so is there anything that we haven't discussed.

Andrew: Oh is there anything!

Interviewer: Well there's.

Andrew: What a question for you to ask!

Interviewer: I haven't finished yet (laughs) (Andrew laughs). Urm is there anything that you feel that we have not discussed that you think is relevant?

Andrew: Well put it this way again (.) I'm hitting the tennis ball back to you, if I if I didn't have a memory problem I could probably answer that question (laughs)! [Okay] I sound funny but I'm not meaning to be hilarious, you know. As as a matter of fact, I think in my inner self I treat it as hil hilarity. [Okay] You know, to so, as a form of medicine to sooth myself you know.

Interviewer: Yeah, yeah. I guess, does it stop you then worrying about it, if you can keep it?

Andrew: Well now, listen, listen, hang on. Worry, that's a word I've never understood.

Interviewer: Yeah, is that because you use humour instead?

Andrew: Sure. My background, my social economic background. (..) *Worry*. People get all sorts doing that. Marriages break up. Silly buggers (..) [Yeah] Then again, I think I'm relating back to a form of (..) I can't find the adjective, was going to say marriage. (..) People's marriage personality, you know. [Yeah] When I got married right away I thought you know (whistles), I've got to look after her. In more ways than one. And I've been sharpening up my skills in that department, you know. I worry sometimes that people might think I'm proud and bragging but I just talking the best I can, you know, without making it a fun thing you know.

Interviewer: Yeah. (..) Urm, do you worry that the memory, I know that you say you don't worry, but do you ever think about the memory problems changing who you are? Do you think they ever will?

Andrew: That's a bit technical for me, that one. That is a bit, I'm interested in that by the way, but a bit technical. I mean you've been (indecipherable) about it, and you know what sort of character I am but I'm just. Give me the question again, do you think it would change me.

Interviewer: Yeah, do you think that the memory problems will ever change who you are?

Andrew: *I doubt it*. [No] That's as honest as I can be, I doubt it. [Yeah] How do you change the personality *in me* (laughs). Many might want to! [Yeah] (Interviewer laughs) But I still take the tablets!

Interviewer: (..) *Okay*. So I think we're coming to the end of the int.

Andrew: Oh to hell, she'll have to make the dinner!

## Interview Transcript – Andrew

Interviewer: (laughs) Urm, is there anything else that you think is relevant that we haven't discussed, or have you got any questions for me?

Andrew: (..) I wasn't prepared for questions (laughs).

Interviewer: (laughs) That's okay, you don't have to ask any, I was just wondering if you did.

Andrew: (.) No. I hope (.) the contents of this interview has been useful, I've tried to make it as useful as I could. [Yeah] But I'm the amateur and you're the professional (laughs).

Interviewer: But you're the one with the knowledge and the experience

Andrew: (.) Give us a kiss and I'll agree with you (laughs).

Interviewer: (laughs) Okay so no questions.

Andrew: No questions [No, okay] no come back, you say no questions no comebacks.

Interviewer: (laughs) Right I'll turn this off then.



## Interview Transcript – Clive

Interviewer: Okay, so urm, I'd like to talk to you today about when you were diagnosed with mild cognitive impairment. Can you say what you think mild cognitive impairment is?

Clive: I don't really know, but I know it's to do with my, memory loss, short memory, short term memory loss. [Okay] Urm (.) I can remember things from the 1950s [Yeah] as if it happened yesterday, but I can't remember what I did an hour ago.

Interviewer: Yeah. Okay, and that's how it's affecting you now is, with your short term.

Clive: You see I can give you an example, I was doing a little bit of work in my garden on one of the nice days, recently, and I came in for a cup of coffee, and I was working with gloves, gardening gloves on. [Yeah] And I walked in the house with them on, and I just, I keep all my ur battery chargers and everything and different things that I use, like my tablet and phone and things like that, in a round container, and that was on the floor by the table. And I threw my gloves in there (.) [Right] Perfectly on view and everything (.) I walked out to start work again (.) and I couldn't find my gloves. [Right] I looked everywhere. (.) And I didn't find them until the next day and I was sitting in the chair, watching the tele and I looked at this thing and there were my gloves. [Yeah] Why couldn't I remember where I'd put them? [Yeah] You know it's those sort of problems, they aggravate you to death. There's no **harm** in them. [Yeah] But, you feel such a fool when you talk to somebody and say I can't find my gloves. [Yeah] I do, and my wife you know, and she'll walk round and find them, what in a couple of minutes where I dropped them. But *I can't* remember for the life of me (sigh).

Interviewer: Yeah. And how do you feel about kind of things like that happening during the day?

Clive: It aggravates me. [Yeah] You know, to think that (.) I've been so active and able to remember things and, that seems to have all gone (.) And I can't weigh up why. You know. [Yeah] Urm, my son lives in (PLACE) [Mmm] and we go there visiting, I drive there and all this business doesn't seem to affect my driving at all. [Yeah] I can remember which way to go and, where I should turn and I can look at the map and, think oh I should go down there and I can do it (.) but (.) I've got a sat nav which I use a lot (.) and without that I couldn't do it I couldn't go to his house, *I couldn't find it*. [Yeah] It's that sort of concern I've got really

(laughs). [Right okay, yeah] And ur (.) we've got a little dog ur (.) ur a King Charles spaniel. And we share taking him out, I take him out at night in the dark and my wife takes him out in the morning. But sometimes I'll be sitting looking at the tele and I usually take him out about half past six, and I'll be there at nine o'clock and think oh god I haven't taken the dog yet! Then I have to get up and go out then, like, which I don't like doing. [Yeah] Alright we all live in a rural area you know (laughs) you never see a soul. Everybody with any sense is in the house (laughs), [Yeah] but those sort of things that ur (.) **aggravate** me I suppose you would say. [Yeah] You know (.) I feel I should still be able to do it and I can't understand why I can't do it. [Yeah] Urm (.) **but** one of the reasons they seem to think, (NAME) seems to think, we've had a big upset in the family (.) urm. (..) This is my second marriage, and (NAME) had got three children of her own like when we married, two girls and boy (.) urm and, I seem to get on very well with them for years (.) and then (NAME), that's the youngest daughter, she's (.) about 37, 38, 37, and ur, she's got a partner and they live on a farm (.) and, this partner (..) everybody in the family feels that he's a thug. (.) He's a **nasty** piece of work if you get on the wrong side of him. [Yeah] And (.) when (NAME) and he were on their own living together, it was great, they've got two children, a boy and a girl. But then our other daughter, (NAME), divorced her husband, and (.) she came to her mother and said ur the next man I have will have plenty of money, and I don't care whether he's married or living with somebody or whatever, I'll have him. So she was chasing money. [Yeah] And we had **terrible** rows with her over different things. She has got two children as well, a boy and a girl, the girls the oldest with (NAME). And urm, we are very friendly, with her ex-husband, he's a lovely lad, he'll do anything for us. And (.) she doesn't like that. (.) Now, we brought those children up from babies to school age because they were both working, and they asked us would we do it, so we said yeah we'd love to. And we used to have two of them when they were babies at half past six in the morning, until about three o'clock in the afternoon when (NAME) came home from her work. [Yeah] And that went on alright, no trouble. And as the children grew up, and well they obviously loved us cos they were with us all the time. And urm (.) when all this separation business started (.) ur (NAME) (.) during a serious shouting row, told us that we would never see the children again. [Yeah] They would be kept away from us. [Right] And (NAME) didn't agree with that, he said no they won't be kept away from you, you'll have the children like you've always had them. [Mmm] And that led to conflict. And it affected the children, that's what we were upset about. [Yeah] Because she wasn't treating the children properly like they, (NAME) agreed that the children would always go to see their mother. He didn't want to stop them seeing their mother. And he

arranged it all so that they could go to her. She has them on ur Wednesday evening, and then she takes them to school on the Thursday, then he collects them from school on Thursday and then, every other weekend she has them again. And (sighs) (.) we've been quite upset about it cos, you know, I think it's better now. But, when it first started, (NAME) he's my youngest daughters partner, wouldn't have them in the house, (NAME)'s children. [Oh] So (.) (NAME) lived in (PLACE), and the farm is in (PLACE) alright it's about a mile and half apart. [Yeah] And urm (.) (NAME), that's the youngest daughter, used to go pick them up to bring them for the day like, at weekends. Anyway he stopped that, he wouldn't let her do that. (.) And (NAME) and the children had to walk through that bad winter two thirteen. And they were walking, like it's a good hour's walk. (.) And they were having to trudge through that snow at *half past six in the morning*. [Right, yeah] Now when they got there, they weren't allowed to go in the house, they had to go in a farm building. And **stay** in there until their breakfast was ready. [Yeah] And then they could come in the house, have their breakfast and then out again, no matter what the weather was. [Yeah] Urgh dear me, and that really (.) I think that's one of the factors that started my memory trouble. [Right, okay] The strain, and the stress of all that you know. [Yeah] And I have explained it to (NAME), and she wrote it all down like, but (.) it was awful, it's not so bad now because they've been to court and they've had their divorce done, and (NAME) has (.) ur chief carer of the children. [Right] What he says goes, you know, as he's said in the past, he doesn't want to stop them seeing their mother. [Yeah] But when they come back to (NAME) on a, we were there last, yeah last night when they came home from school. And they're really unruly and shouting and screaming, and their clothes are dirty. She doesn't do any washing for them. [Yeah] And (.) ur, their feeding is better now, but she didn't used to feed them. [Yeah] You know, I think it was just **spite** against (NAME) and she used the children to, for that reason. Because she told us, I don't want kids, when they were babies. [Yeah] But (NAME) wanted children and so we had children. [Yeah] But she said if I had my way we wouldn't have had any. And that's the way she's lived and treated them. [Yeah] And ur.

Interviewer: So it sounds like you've had a lot of, kind of family stress in the past couple of years.

Clive: That's right, we've both had ur my wife's, she's going to urm, a counsellor. [Yeah] Cos she got to the, so depressed and (.) upset about it all she stopped eating. [Right. Yeah] She's younger than me, she's 70. And she's gone to nothing, she's a frail little thing. And

before all this started she was quite a strong and healthy woman. [Yeah] But it's really knocked her to the ground. [Yeah] And I think that is another thing that is worrying me. [Yeah] Because the way she's going I don't know whether she's going to last 12 months. [Yeah] I've tried **everything** to get her to eat but, whether this counsellor will be able to talk to her and get her eating again I don't know. Hopefully it will. But **that's** all the stress and strain that we're under at the moment.

Interviewer: Yeah. And so do you think that that's having an impact on your memory at the moment?

Clive: Yes I do. Yes I do. [Yeah. Yeah] Urm I can never stop thinking about it you know. [Yeah] I worry about the children all the while. Urr like we've got 12 grandchildren. [Yeah] And all the others are fine. Got two living in (PLACE). [Yeah] And urm, they're lovely, no trouble the pair or anything. But these two poor little so and so's (sighs). It's horrendous what's happening to them.

Interviewer: So do you remember going to the memory clinic and urm going through the process of assessment which ended up your diagnosis of mild cognitive impairment?

Clive: Yes. [Yeah] I explained all this you know, they virtually said this is all **your trouble**, this is what's causing your trouble. [Yeah] All this stress. [Right] But there's no way out of it I can't get away from it. [Yeah] You know, (NAME) has said that, the granddaughter she's 12, she said when I'm, I'm 12 now, I could leave, I could come away from mother, and live with dad all the time, but I can't do that and leave (NAME) there on his own, he's only nine you see. [Yeah] So she's got to put up with all this until he's 12. [Right] And then we think, we haven't said anything to them like, it's only what they say, we think they'll be from her, they won't go near her. [Yeah. Right] But until that happens I don't know.

Interviewer: Yeah. It sounds like it's a very difficult time at the moment and it has been for the past couple of years for you, with a lot of worries.

Clive: Yes, it's been going on for four years.

Interview Transcript – Clive

Interviewer: Yeah. It's a long time. So do you remember being told about the diagnosis of mild cognitive impairment?

Clive: No. [No] No.

Interviewer: So what did you take away from the memory assessment that you that you had at the memory service?

Clive: All I had (.) was a note from someone, I don't know if it was from the hospital or where it came from, to my doctor, to say that I'd got this, cognitive ur impairment, **mild** cognitive impairment, that's what was on it. [Yeah] And I thought, *what the hell does that mean?* [Yeah] I'd no idea what it was. And I didn't go and ask the doctor cos he'd, he'd retired and you know, and I didn't do it anyway, and I've left it until I've come to this memory clinic. [Yeah] And then I found out really what, what I've got and what that means, I think.

Interviewer: And what do you think that that means?

Clive: It means I'm struggling with memory. [Yeah] I think that's what it does mean, doesn't it? [Yeah] Or is it something more complicated?

Interviewer: What I'm interested in is your, is your understanding of what the diagnosis means. [Yeah] Yeah, so that it impacts on your memory?

Clive: Yeah. I'm sure it does. Yeah that's what it means. [Yeah] Urm **and** *there's no answer to it obviously, you know. When you lose your memory that's it, that's the end of it isn't it.* All you've got to do is try and adjust and live with it. As best you can.

Interviewer: Yeah. And is that what you think that you're doing at the moment?

Clive: I think I am coping with it now, yes. **But**, as I said (.) from when I finished with (NAME) (.) I think it's gone worse. [Right] Because I'm (.) I'm I'm forgetting things that I did two minutes ago, you know. [Yeah] I'll go find a hanky and if I haven't put it in my pocket I will have no idea where it is or what I did with it. [Yeah] And I can walk around the

house and I can't **find** it. [Yeah] But (NAME) can go put her hand on it straight away wherever it is. And **that** worries me a bit, why I'm that bad. [Yeah] You know. Urm (.) I know everybody does this, but when I'm in the garden and I want, say a, fork or a spade or something, I think oh I think I know where they are, and I've got workshops and garages all over the place at home. And I think it's in that one (.) so walk half way, which is (.) 25 yards say, and I've forgotten what I'm looking for. [Right] (.) And I have to walk back and look what I was doing and try to weigh up what I wanted. [Yeah] And the **second** time I'll go and get it, but that first time, half way (laughs) and it's gone. [Yeah] I can't remember where it is or what I wanted even. [Yeah. *Yeah*] So (.) that's short term memory isn't it? [*Yeah, yeah*] Yeah that's my troubles. And yet I can bring things back from the 50s, 60s, 70s, with no trouble (.) but I can't remember what happened 10 minutes ago.

Interviewer: Yeah. So how, how do you think about yourself, urm compared to before you had the diagnosis of mild cognitive impairment to now?

Clive: Oh it's **definitely** worse now. [Yeah] Yeah, **definitely** worse.

Interviewer: Has it changed your perception of yourself, or the way that you think about yourself having this diagnosis?

Clive: Yes, it's a bit depressing *to be honest*. I have down (.) days you know where I feel ohh (.) I haven't got the energy to do anything. And then I think about (NAME) and I think I've got to get going because of her. [Yeah] I can't let **her** see that I'm depressed or, no interest in doing anything, I've just got to get up and do it. Even though, I'm feeling that way. [Yeah] To save her worrying too much about it. She's got enough to worry about with these two daughters.

Interviewer: Yeah. So does your wife worry about, the diagnosis, about your diagnosis? Or about your memory problems?

Clive: I never ask her. [Okay] I never ask. I think she obviously does. [Yeah] But I don't like to talk about it with her.

Interviewer: Why, why is that?

Clive: I don't want to upset her and put more worry on her. [Yeah] She's got enough worry now without worrying about me. [Yeah] And like we're living alright, we go out too, occasionally to see friends. We go to see my son in (PLACE) urm (.). We **don't** go to see (NAME)'s family because she's got a son, who only lives a mile away and the only time we see them is at Christmas, bring us up a Christmas gift. And they only live a mile away and never come near us! [Yeah] (.) And he's alright (NAME). Like we've got a burglar alarm on the house. And when we go away we ask (NAME) to keep an eye on the place you know, and if he sees anything wrong to get the police or anything. (.) But (sighs) we hardly ever see them. And when they come you know they're lovely, they'll talk for an hour, about all their things. And they've got two daughters grown up, and ur, one is a (PROFESSION) in (PLACE), and the other works for (NAME) she's got a good job in the office doing something, I forget what it is. And ur, they were two clever girls, they went to the (PLACE). [Yeah] You know, they were not behind the door with brains (laughs). But ur, yeah they never come near us.

Interviewer: So, so you say you don't speak to your wife about, about your memory problems?

Clive: **We do** have little chats about it occasionally, but I don't press it, you know. [Yeah] I don't want to upset her or worry her to death about me, because we're still living together we still love each other. [Yeah] I look after her. Urm (..) I wouldn't do anything to hurt her for the world. And I think this might if I started going into what (..) what I worry about with it. [Yeah] Urm, maybe I'm wrong I don't know.

Interviewer: What do you worry about with this diagnosis?

Clive: It worries me that I can't find things. [Yeah] When I can't, I've put them down 5, 10 minutes ago and I've got no idea where I've put them. (.) And I don't, the sad part of it is I never find them, my wife has to find them. [Yeah] Like tools in the garage. I put them down and go and do something else, and then when I come back to doing what I was doing, the tools have gone, I've taken them with me and put them down somewhere. [Yeah] *Oh dear me, it's mad* isn't it.

Interviewer: So do you speak to anybody else, within your family or your friends, about the diagnosis, or have they said anything to you about the memory problems?

Clive: I've spoken to ur (NAME) and his partner about it, *and to say that I'm losing my short term memory and I can't remember where I've put things* (.) and ur they don't make any comment but they take it in you know. They know they can't do anything about it, so. [Yeah] *They don't say much.*

Interviewer: Is that what it feels like that [Yeah] you can't do anything about it, that nobody [Yeah] can do anything about it?

Clive: *Yeah. Yeah* (..) I've tried doing crosswords and things like that you know, but I was never very good at doing crosswords anyway. I have to have a (.) I call it a Brontisaurus, I don't know what the proper name is for it! A book where you get proper explanations of the word. [Oh right yeah] And substituted words you know. [Yeah] I can't do a crossword without that (laughs). [Yeah] I know I can remember how to look for things and things like that I don't have any problems with that at all. [Yeah] I read a lot. [Okay] Urm (.) everybody laughs at me. I've always been interested in motorsport and when I was younger I used to do rallying (.) and, there is a, not a magazine, it's a newspaper, out every week, it's called Motorsport News now, it used to be called Motoring News, and ur, this is the 60<sup>th</sup> year of their publications. And I was saying to (NAME) the other day (laughs), I've had this paper **every week**, since 1956. [Oh gosh!] I haven't missed a week. [Yeah] Because I'm so interested in motorsports. And it's all in there, and I love it I put everything down when that comes on a Wednesday. [Yeah] And I read it from cover to cover. [Yeah] Every Wednesday. So.

Interviewer: (.) So are there things that you do in order to try and keep your memory, or (Clive coughs) keep your memory working?

Clive: Well I think this reading helps, [Yeah] it must do (.). But I can read an article, and now I've noticed in these last few weeks, that I can read an article (.) and I'll read others around on the same page, and I'll look at that one and say I don't think I've read that *one* and I'll read it again and I can't recollect that I've already read it, until I'll probably get to the last few lines and I think oh god I've done this, **ten** minutes ago! You know, that's starting to



happen now. [Yeah] And ur I can read the paper. Urr I take (NAME) to the supermarket and I sit in the car. And I get a paper and I read the paper in the car. And she'll come and when she comes back, is there anything in the paper? (.) Yeah there's quite a bit but don't ask me I can't remember all of it. You know, I've read it and taken it in, but I can't reproduce it to tell (NAME). [Right] You know this trouble in (PLACE) ur on the weekend, where that fellow was stabbed or something? [Yeah] That was in the paper yesterday. (.) And I read all that *but ur* (.) I was only able to give (NAME) the outline of what had happened. [Yeah] But I couldn't go into detail because I couldn't remember it. [Yeah] Things like that you know that (.) I think tell me that I'm getting worse.

Interviewer: Yeah. So you're noticing subtle changes?

Clive: Yeah. Yeah. [Yeah] And a lot of it like I can't put my finger on. Urr (..) it's **sad** really because as I read, I've always been interested in the RAF, and particularly the RAF during the war. And I've read **no end** of books on it, and I know a lot about it. I can recall a lot of that because I did it 10 years ago. [Yeah] You know. I just finished one now. I know the gist of it but I couldn't give you any details out of the book. [Yeah] (.) But ur yeah, things like that. [Yeah] And I suppose, I've realised that's what this (.) ur mild cognitive impairment means. That that's what's (.) wrong with me. [Yeah] (.) Does it happen to all old people?

Interviewer: Not everybody, no.

Clive: No. [No] No cos you hear people on the tele age 90 odd, and they can speak as if they were 25. (..) I know I belong to an (NAME) group. And ur I go to meetings, particular ones because I want to hear the man that's coming to speak. And about six months ago I went to one and ur, there was a man of 93 (.) and he was a bomber pilot in the war. [Right] And he could recall nearly every **day**, never mind. (.) Yeah, amazing man. [Yeah] How he could remember it.

Interviewer: Do you find yourself then comparing, your abilities now to other people of a similar age or older?

Clive: Yeah. (.) Yeah. [Yeah] You see, like he was recalling what happened in the 1940s, although he'll probably have only been 20 I expect then. [Yeah] And I can recall things that

happened in the 50s, or when I first started grammar school, I can remember all that. [Yeah] And you know and, I can bring it back in a flash. But *as remembering what happened last weekend*.

Interviewer: Yeah. Is it, so you're describing short term memory problems so remembering things, having difficulties remembering things that happened recently. Is there any other way that it affects your life or you think that it affects your life?

Clive: Well, I wouldn't think it affects my life because I adjust my life to cope with it I think

Interviewer: Okay, and what ways have you adjusted your life to cope with it?

Clive: Well (..) when I lose something like I've just been describing, I have to forget about it and carry on do something else [Yeah] and forget about, then maybe I'll come across them when I'm walking about. [Yeah] Yeah and very often I do. [Okay] Urm, but to find them there when I put them down, and to find them in 10 minutes time, I've no idea where to look. I could walk around everywhere three or four times and not find them, my wife could have a look and go straight to them (laughs). I don't know whether I'm seeing them and walk past them. [Right] Or what's happening (..) *it's strange*. Anyway that's a minor detail I think. I enjoy life. Urr we do virtually what we want to. [Yeah] Anytime, I can still drive, if it stopped me driving that would be it. I'd be gone in a month. [Yeah] That would be *terrible to have to stop driving*.

Interviewer: (...) Do you think it might progress to the stage where you would have to stop driving?

Clive: I can see it happening, I wouldn't be a bit surprised. [Yeah] Urm (..) I I used to (..) I had me own business for 25 years, (PROFESSION), I never did sales, and people used to come all over the country for us *to do it*, you know. I used to specialise on (PROFESSION). [Right] Tuning them and setting them all up. We used to have doctors coming from (PLACE). [Yeah] We had a little workshop in (PLACE) near (PLACE)! [Yeah] They were amazed at all that. But I can recall all that you know. I was talking to somebody the other day about (..) what I'd been doing with the doctor's cars. Can't remember who that was (..) oh yes I can it was (NAME). We went up to, (NAME) is a friend for many years, and we go up to

see them occasionally, they live in (PLACE). And we went up on Wednesday night. And I was telling them about doing these (PROFESSION) (laughs). Because he is (PROFESSION) minded, you know, he worked at (NAME), he was a (PROFESSION) at (NAME). And I used to do his, he's a motorbike man, and he used to ur look after his motorbikes and his car and everything. [Yeah] I think he still does, to a certain extent. So I was talking to him about it. [Right] But I was able to recall everything.

Interviewer: Yeah. So everything that happened in the past [Yeah] is still quite fresh in your mind.

Clive: Yeah. [Yeah] Is that normal with someone having short term memory? Does it happen that way?

Interviewer: Urm quite often yes. [Yeah] If it's short term memory that's affected then [Yeah] it's what happened recently [Yeah] that's difficult to remember. Whereas past things, they stay in people's memories. [Mmm] Yeah.

Clive: I'd love to know what happens (.) when you lose your short term memory is it cells in the brain dying or what? Or is it the acid that's not (.) working properly, or.

Interviewer: Well it's different for different people.

Clive: People yeah.

Interviewer: Yeah, so what do you think (Clive coughs) the explanation is for you, have you got an idea in your head about what you think? Or what you think contributes to short term memory loss in other people as well?

Clive: (.) Urm, not really, no. No. I've no idea really. But I do think about it, what causes it. [Yeah] But I've no, I'm not a doctor. And I don't know much about the brain. I've never read anything about it. [Yeah] So you know I'm totally in the dark regarding what causes it and what happens.

## Interview Transcript – Clive

Interviewer: Yeah. Yeah. So for you, do you think that it's something that's happened in your brain?

Clive: Brain, yeah. [Yeah] Like they say, the older you get the more cells in the brain that die. [Yeah] Well (.) is it cells dying that do the memory thing? Are they dying? [Yeah] I don't know, I'm just guessing. [Yeah] Yeah.

Interviewer: Yeah. So, it sounds like, that you haven't had a concrete explanation about why.

Clive: No.

Interviewer: It's happening for you?

Clive: No. [No] I've never smoked and I've never drunk (.) all my life. [Yeah] So it's not smoking that's caused it (laughs).

Interviewer: So have you spent time trying to work out why?

Clive: No not really. [No] I just think about it *occasionally and that I don't know what it is*. I've just got to live with it.

Interviewer: So, and that's how it feels, that you've just got to live with it?

Clive: Yeah. *Yeah* [Yeah] (.) But it's very embarrassing, you know when you're talking *to somebody that you've known for (.) 20 odd years or even longer* and you're talking to them and you can't even remember their *name*. (.) Even from (..) I don't know no it's not from years ago cos I can remember names from years ago. But I can't remember names for, you know if I talk to, spoke to somebody six months ago I couldn't remember who it was. I could see them, but I couldn't give you a name. [Yeah] No, it's it's strange.

Interviewer: And what do you think the eventual outcome might be of having mild cognitive impairment? Do you have an idea about what you think might happen in the future or.

## Interview Transcript – Clive

Clive: Well I have a dread about having to go into an old people's home, suffering from dementia. [Right] Or that sort of thing *you know. That would kill me* (..) and I suppose that's what it will come to *eventually*, if I live that long.

Interviewer: So do you think that mild cognitive impairment leads to dementia in the future?

Clive: Yeah. Yeah. Does it?

Interviewer: Not always. No.

Clive: My mother died of dementia. Well (.) she had dementia when she died, she didn't know any of us (..) And I had to give up my (PROFESSION) business when ur (.) mother got that bad that (.) she needed like 24 hour (.) attention like. And then eventually the (.) ur Social Services people said look, you're getting to the stage where you're not going to be able to cope with this much longer, because she was doubly incontinent and things like that. [Yeah] And they said I used to have a nurse coming in to look after her (.) and ur they said she's got to go in a home. So that was it. [Yeah] But I hope I don't end up like that.

Interviewer: What, what do you think are the differences or the similarities between mild cognitive impairment and dementia?

Clive: (.) I don't know. I don't know enough about either to be able to say (.) [Yeah] I know a lot of people suffer with dementia, and it's an awful affliction. (..) Alright they're starting to get (.) to be able to work out what's causing it and what the (.) best way to treat it is. They've got drugs now I think haven't they? Or they're experimenting with drugs to try and ur reduce it. They said they will never cure it. But they'll slow it down so it's (.) you're not living like a cabbage like for like 10 years, or them last years of your life. I believe young people get it as well don't they?

Interviewer: Younger people can.

Clive: Yeah. [Yeah] Yeah. Must be awful for them.

## Interview Transcript – Clive

Interviewer: (.) So (.) are there any advantages to knowing that you have mild cognitive impairment?

Clive: No I *don't think so*.

Interviewer: Are there any disadvantages?

Clive: *No* (.) it's there and I know what it is. Just got to get on with it.

Interviewer: Yeah. So it sounds like you feel that you just have to keep living your life and that the diagnosis doesn't make that much difference?

Clive: That's right. [Yeah] *Yeah*. [Yeah] Yeah. But I feel, mind you but (NAME) would never have it. I used to do the tests every time I came and (.) she said I've looked back on your tests, and after I'd had about **10**, she said there's no difference (.) between the 10<sup>th</sup> and the 1<sup>st</sup> one!

Interviewer: Right. Was this over a long space of time [Yeah] the tests?

Clive: Over 12, 18 months I suppose. [Okay] And I used to think well why am I thinking it's going worse if [Yeah] the tests are still the same, you know. [Yeah] It'll be interesting to see what difference there is after this 12 month period. [Yeah] Because I'm sure there will be a deterioration, I don't know, I might (.) hopefully I'm wrong. [Yeah] But.

Interviewer: Do you feel that you're just waiting for the next assessment then? You know that you're on the waiting list, that it's going [Yeah] there's going to be a letter coming through your door. [Yeah] In 12 months, you know in however long, however long time?

Clive: Yeah.

Interviewer: How do you feel about that, that just waiting for the next assessment?

Clive: Well it doesn't play on my mind. I know its 12 months and (.) when it comes I'll deal with it.

Interviewer: Yeah. (.) And how do you feel about the assessments not showing any differences, even though you're feeling that there is a difference?

Clive: I can't understand why I think I'm feeling different [Yeah] and the tests are showing that I'm not. [Yeah] It's (.) I don't worry about it like and (.) I don't think about it much. But it is there though, oh I feel that I'm getting worse and the tests say I'm not. I don't know, *I don't know*. One thing I've found, I'm deaf in one ear. [Right] Now I think that has had a bearing on it, because I don't hear everything that people say to me and I'm now just got new hearing aids I've had to pay for them because I couldn't get two off the National Health. They'll only give you one. [Okay]. I know, it's awful. Urm (.) if there was nobody about I could hear what people were saying to me. But if there were people behind me, *I couldn't hear anything*. [Yeah] And now I've got a hearing aid in both ears, its virtually stopped hearing what's behind, because this ear, the good ear, has a got a hearing aid in. Whereas when it was only this one I had, this ear could hear everything behind me normally. [Yeah] And it was confusing, one against the other I think. [Right] But ur I've found out since the National Health won't give you two. [Yeah] You've got to be desperate to get two.

Interviewer: Yeah. So how do you think that that's affected your memory?

Clive: (.) I think (..) It's difficult to explain, but I think (.) people have said things to me and I haven't heard properly (.) and then I end up asking them in three or four weeks what did you say about this? And I think it's because I wasn't hearing it properly, I didn't hear it the first time. Now whether that has any effect on your memory I don't know. [Yeah] Urm but, I wouldn't be surprised if that isn't a factor. And (..) I would be surprised if it wasn't a factor. But ur I don't know, I don't know. (.) Ur (..)

Interviewer: Yeah, do you think that there's anything else urm (.) that's happened to you, or anything else physically that's affecting your, your memory?

Clive: Yes I think all this trouble with the family is affecting me a lot. [Yeah] Yeah. You can't put your finger on how or why or what is, you know to say, well **that's** causing me trouble, I can't do that. But it's the general **stress**, of thinking about it all the time, and you can't get it out of your head. [Yeah] Like I'll wake up in the middle of the night and be

thinking about what they've said or what they're doing. [Yeah] And it's awful its. I don't say anything about it now to (NAME), because she's on this depression and she's in a terrible state. Hopefully. (.) This is an example of the National Health Service. Urm. We went to the doctor first and said she was struggling, and she wasn't eating properly. So she said ur (.) it could possibly be that she's depressed, and I'd like to send her to ur (.) the mental health department. And we went to (PLACE), you know in (PLACE), and urr the lady that was in charge of it all (.) and gave (NAME) an interview that lasted about an hour and a quarter. She wrote everything down, and then (NAME) had to go back in a fortnight and she checked over everything again and so yes ok that's right, ur I'm going to advise you to go to a counsellor. So we thought oh great, we're getting somewhere. And then we get a letter to say that ur (.) you won't be able to get an appointment with a counsellor for 13 months. **13 months!** [Gosh] I thought (NAME) will be bloody **dead** before we get an appointment. Anyway urm, (NAME)'s partner said let me have a look on the internet, I'll see if I can find people who'll do it privately locally. (..) Anyway she did and we rang this lady and made an appointment for (NAME) to go and see her (..) and I don't know why, but when (NAME) came back from that appointment, she'd gone back, three or four months, you know in her (.) in her state like. She wouldn't do, she wasn't doing anything in the house. She wouldn't eat. Anyway I've started to get her back on her feet and she goes again on Monday to see her and hopefully it's going to be a lot better. Because (NAME) worried herself to death about going in the first place. [Yeah] And I think it got her down and she couldn't recover after seeing the lady and possible realising that she wasn't an ogre. [Yeah] You know. So we'll see what happens after. [Yeah] But it all plays on your mind, you know [Yeah] it's a worry for me about (NAME), and I (.) because I can see her disappearing. She's a little old woman.

Interviewer: Yeah, that does sound, like what's happened has been very difficult for both of you [Yeah] and it's played on both of your minds [Yeah] a lot and you're probably worrying about it each other.

Clive: Yes, as well.

Interviewer: Yeah, on top of that. Okay.

Clive: So it's difficult (laughs).



## Interview Transcript – Clive

Interviewer: *Yeah*. So, just want to wrap up the interview now, and I was just wondering whether there was anything else you think is relevant that we haven't talked about?

Clive: Urm (..) no I don't think so I think I've painted the picture pretty good, to what's happening to us. [Yeah] And (..) hopefully when I go to see (NAME) again, I might be able to make some changes or something.

Interviewer: What changes do you think might happen? Or would you hope for?

Clive: I wonder if there are any drugs that can deal with. [Right] I don't know whether there are, I've no idea but. Perhaps I will ask (NAME) when I see her again if there's anything that can be done to slow it down or, I don't, there will never be anything to make it return but to stop it going worse. [Yeah] I don't know, I've no idea. (..) But urr that will be one of the things I will ask her about. [Yeah] But ur it's just a matter of living with it and coping the best way you can. We still **laugh** a lot together you know, we're not miserable all the time! (laughs) [Yeah] We laugh about different things.

Interviewer: (..) Yeah. Okay well thank you very much and I'll turn off the recorder.

## Interview Transcript – Gwen

Interviewer: So, as you know we're here today to talk about, what, mild cognitive impairment is and your experience of your diagnosis of it. Urm, so I was just wondering if you could tell me, what you think mild cognitive impairment is?

Gwen: Well it's a bit (.) ah, to me it sounds as though, how much I understand now, you know has it affected my brain (laughs), well you know affected me [Yeah] me ur stroke. [Yeah] That's the only thing I can think of.

Interviewer: Yeah. So, urm, had you, had you heard about mild cognitive impairment before you were diagnosed?

Gwen: No. No.

Interviewer: No. No. So what did you think when you were told that you had this diagnosis, can you remember being told?

Gwen: (..) No not really I just, I mean, it hasn't affected me (..) uh bodily you know, so of course it hasn't brought it to the fore sort of thing you know to make me say oh that's caused by (.) my stroke or anything so no I'm quite happy to go along as I am! [Yeah yeah] I mean they won't let me drive now which is an annoying cause well the doctor did say I could go, I could drive again now. [Right] But my son says no you can't it's my car (.) so. [Oh. Right!] Which it's his car but of course he had his car altered so it would take my husband's wheelchair. [Yeah] So it's (.) I mean (.) it wouldn't be sold very easily sort of thing you know cos it's got a ramp to take his wheelchair in cos I used to drive him around. But since I've had this it's, it's stopped me doing anything for him really you know.

Interviewer: Yeah. Yeah. So how, how has this mild cognitive impairment affected you. Do you, has it really affected you or, have you not really noticed much difference?

Gwen: I don't notice much difference you know, I mean if it had affected me bodily I would notice it more I suppose. [Yeah] But ur, I think my daughter (NAME) says I do forget (.) which **I do forget** you know, I tend to have to write things down I forget a lot. [Yeah] Even **easily** you know I'll (.) and then I'll think, and I don't at all (laughs). [Yeah] And then (NAME) will ask me something and oh I dunno (laughs).

Interview Transcript – Gwen

Interviewer: Yeah. So it's affected your memory, mo-mostly?

Gwen: Yes.

Interviewer: Yeah, with kind of short term memory? So with remembering things people have told you?

Gwen: Yeah, *I suppose*. (..) But ur (..) I'm not too bad, I don't, it doesn't really bother me that much but I have to write things down or (..) my daughter reminds me you know (laughs).

Interviewer: Right ok. Yeah. Urm (..) and you said about having had a stroke. Do you think, is that what caused the mild cognitive impairment, is that what you think caused it?

Gwen: Yes. Yeah.

Interviewer: Right ok, yeah. Urm (..) so (..) what does it (..) has it changed your life in anyway having this diagnosis?

Gwen: Oh yeah, you know. Can't drive that's the main thing! I miss that a lot, but urm (..) now things have to be arranged you know, I used to just be able to say I'll go somewhere and now I can't unless it's been arranged sort of thing, you know so, that's annoying. [Yeah] But urr (..) there's people in worse states than me I suppose (laughs).

Interviewer: Yeah. And is that what you think of when you get frustrated?

Gwen: Well yeah I mean (..) it's nobody's fault it's just happened you know, it's whether I can manage it and whether I can (..) sort of let it get me down. [Yeah] But ur (..) I mean they've taken (NAME), I went into hospital and then of course I come back they took him into a home, said I couldn't look after him, you know so. I mean, we've never been apart for 54 years then all of a sudden he was **gone** you know so I'm here on my own. [Yeah] So ur, but I manage it.

## Interview Transcript – Gwen

Interviewer: Yeah. So it's ur affected you, affected you practically in that you can't drive now and it, it was also the start of your husband having to go into a home?

Gwen: Yeah. [Yeah] I mean it was just the two of us and I was looking after. It wasn't physical or anything but I think they thought it got too much for me [Yeah] in the end. So ur (.) *it's one of those things* I've managed (..). So, the son that's abroad arranged for a taxi to pick me up and pays for me to take me to see him Monday, Wednesday, Friday you know and then my daughter comes over, weekends *you know*, one day of the weekend and she took me there for Christmas so I wasn't here on my own you know. [Okay] So ur then we came over to see him (.) but ur just one little stroke affects every, not just me, [Yeah] but **the rest of the family** sort of thing you know.

Interviewer: Yeah yeah. So it's had a wider impact on [Oh yeah] lots of different parts of your life? Yeah.

Gwen: I've got good neighbours and good friends you know, and they all come down you know are you alright, do you want anything. They've always been very good. And we've been here (.) 54 years *so*. [Yeah] I mean there's the same people next door to us and that you know, we've been neighbours all that time. [Yeah] But (NAME) came later but he own (.) his father owned the field so built a bungalow, so we used to have a lovely view right out (laughs) but now we just have (NAME)'s roof!

Interviewer: Yeah it's not quite the same is it (laughs).

Gwen: No (NAME) said oh mam you, well nobodies entitled to a view! You know we've got a marvellous view out of the back from the kitchen, [Right] from the sink right over (PLACE) and [Yeah] (PLACE) you know. But I mean no one's entitled to a view so. [Yeah] You just get on with it (laughs).

Interviewer: Yeah, yeah. So, how did you find out that you had a diagnosis of mild cognitive impairment? Do you remember who told you?

Gwen: No.

Interview Transcript – Gwen

Interviewer: No. (.) Was it while you were in hospital? Was it after, *that*?

Gwen: I really don't know.

Interviewer: (.) No *okay*. Yeah. So you haven't got a specific memory of being told about mild cognitive impairment?

Gwen: No just that I remember my son saying you **can't drive** (laughs).

Interviewer: Okay. Yeah, so really the label didn't mean [No] that much. It was actually what it meant practically to you in your day to day life.

Gwen: Yeah. Yeah. Yeah.

Interviewer: Yeah. That's been the thing that's stayed with you.

Gwen: Yeah.

Interviewer: That's the bit that you remember is [Yes] being told not to, you're not allowed to drive.

Gwen: Yeah. Well the doctor said I can drive but my son said (.) no. [Yeah] So (NAME) said he's only worried about you mam going driving so I said okay it's his car I can't do anything about it you know. [Yeah] So ur (.) Which is right, he was only worried about me being you know she said he's frightened you'll go out and crash or, something so. (.) [Yeah] I managed before. I mean when we first moved here, just before (NAME) was born, and he's 55 I think now? [Yeah] And urr I used to push pram from here to town and then when (NAME) was born he used to be sitting on the top and we'd go here to town I'd be like the old covered wagon going up and down! (Interviewer laughs) I mean there was no, people didn't drive cars then you know and my mother in law was most put out when I learnt to drive! (laughs) [Oh really?] Yeah oh well it was (NAME)'s car, you know. [Yeah] But ur when she went into hospital and that and we visited and it was different. [Yeah] You know, will you bring Mrs so and so to visit me an all that sorta thing, you know. But ur, no she didn't like me driving (laughs).

Interviewer: Yeah (.) So what does the loss of being able to drive mean to you?

Gwen: Oh, it does (.) it interferes a lot I mean I used to go out with a friend, I mean the she still picks me up and we go out for a meal and that sort of thing, and that. But urm (.) I used to be able to just go out and get in the car and go where I wanted or even if it was just up to the shops or into town you know, I didn't have to bother about the bus and that, although it does stop outside the gate so I have to go on that now you know. [Yeah] So ur (.) it's just getting used to things changing. [Yeah. Yeah] Now I mean nobody, nobody knew it was going to happen and nobody did anything on purpose it's just happened. [Yeah] I mean my sister's never been able to drive, I used to go down and see her in (PLACE). So now, I get a taxi. [Yeah] And go down and see her and *then get a taxi back up*. [Yeah] Well I suppose I don't spend it on anything else, you know, I don't have any ur, I don't go drinking I don't go dancing I don't go boozing, so I spend it on taxis!

Interviewer: Yeah, yeah, so getting out the house, that's what you spend it on?

Gwen: Oh yeah, yeah. [Yeah] And I've got good neighbours, I mean when we had the bad snow last year, the woman that brings the newspaper, sends the newspaper, her husband delivers them, and he came down and he cleared all my snow path right to the road. [Right] *So*, they're good people, next door. [Yeah] They've been together for 54 years my neighbours. They've seen the kids grow up and had children of their own all that and we're still here (laughs)!

Interviewer: Yeah. Yeah. So have you found that your neighbours have been more helpful since you've had the stroke?

Gwen: Oh yeah.

Interviewer: Yeah?

Gwen: I mean I, (NAME) said at Christmas if you're going to (NAME)'s lock, make sure every where's locked up. And I went and locked the porch door which I've never locked before, and I couldn't open it. [Oh no] Oh god it caused more trouble, but fair play (NAME)

was over and, they did get it unlocked, for god's sake throw the key away! [Yeah] It was only to stop the wind more than anything, that porch. [Right] So coach doors cos he made them himself. [Right] So urm (..) they were as I say when (NAME) was in hospital they used to come down you know, do you want anything, can I take you anywhere you know, do you want any shopping. They've always been good, I mean, next door but two (..) they know (NAME) and (NAME)'s family since (NAME) was born and they were born and (NAME) has been next door since they first built next door. [Yeah] And that so, and the people next door but one, they came in late but they're good friends and they always come round, do you want anything, you know. Cos they make sure I've got their number there (..) if ever anything happens and I want them, you know, they'll come round. They're very good neighbours.

Interviewer: Yeah. Yeah. So have you told them that you've had problems with your memory or have they said anything to you about (..) your difficulties?

Gwen: No, they know I've had a stroke. [Yeah] But ur (..) I've never actually discussed it with them! You know, it's just (coughs) they just come round and say are you alright do you want anything, and all that sort of thing, you know.

Interviewer: Yeah. Yeah. And what about your family, what have they say, said about urm about your stroke and your memory problems and.

Gwen: Well my daughter lives in (PLACE), she works in (PLACE), she's a (PROFESSION) now. [Yeah] And ur (..) she comes over every weekend, either a Saturday or Sunday. I went there for Christmas and she always says, you know, anything happens to dad, you want to move to (PLACE) by me. And **I don't want to go to (PLACE)!** I've always lived here you know. I was born in (PLACE) and lived there til I was married, then I moved up here, so I haven't been far away you know so. Oh no you come by me save me driving from (PLACE), **well don't come then!** (laughs) [Right!] Oh dear! So I have to come along, cos the lads are away so she feels as if it's all on her to come and see I'm alright, you know, but ur (..) she said oh they've got old peoples bungalows up there she said, I mean you could sell there, I mean you paid for this as you built it so we didn't have a mortgage, so she said you could sell this and come and *live up*.

Interviewer: Yeah, you don't really want to do that (laughs)?

Gwen: No. But ur, I know my friends they're all old as well, they're getting older, so. [Yeah, yeah] (.) You can't, you can't make everybody stay in the same place all the time so. [Yeah] I get on alright with people anywhere (.). *I don't bother!* Just see, see how things go. [Yeah] You know I mean, if I'm left here and that well I can sell it (.) it's worth quite a lot now so.

Interviewer: (.) Yeah. So do you get the sense that your daughter is worrying about you?

Gwen: Well, yes I suppose, and both the lads do, I mean, (NAME) rings up every day, he's in (PLACE). He pays for a taxi, three times a week to take me up to see (NAME) you know, [Yeah] he does everything he can you know. (NAME) comes up from (PLACE) when he can (..) but (NAME)'s the one that always arranges everything, and pays for everything, you know. He's got a good job, he's an (PROFESSION) in (PLACE). [Yeah] And ur, he married a (PLACE) girl so of course he stayed there. [Yeah] So ur (.) you see he always arranges things (.) people to come, somebody comes in, and does some cleaning and washing (.) I think it was (NAME) who paid, **it was one of the lads**, I don't know who it was, they just turn up, and say you know, I've come to do the cleaning, I've come to do the something else, oh you better get on with it (laughs). [Yeah. Yeah] They're very good.

Interviewer: Yeah. How do you feel about them, that, them arranging for the cleaners to come in, and [I don't mind] for people to come and do bits and pieces?

Gwen: *I don't mind*. [Yeah] They're nice girls, we have a bit of a jangle. And we. Oh that's a funny word, do you know about that word, jangle?

Interviewer: No I don't think I do!

Gwen: I was talking with my sister in town and somebody came along and I said oh sorry we're just having a jangle, what the hells a jangle? I was **chatting**, just **gossiping**!

Interviewer: Oh okay right!

Gwen: That's just our word for jangle, whether that's the family or local or what, but we always call having a gossip having a jangle that's all, a chat.



Interviewer: Oh okay. So you have a jangle (laughs) with the girls who come, the cleaners?

Gwen: Yeah. Yeah, yeah.

Interviewer: Yeah. And, have your family changed since you've had the stroke, so have they changed in the way they are towards you, or are things still the same as they were?

Gwen: (NAME)'s been more protective I think. [Yeah] Cos she's a (PROFESSION) she knows what can happen I suppose (.) well ur cos a (.) both the kids contacted next door, (NAME), cos we've known her since they born and (NAME), so if if they notice anything, you know, to get in touch with them and that, [Yeah] if they think I need help or anything you know, so, I should move in with your dad it's nice up there! (laughs) No work! (..) But I don't know how much it is, it's paid for (.) don't know if it's the council or if it's the.

Interviewer: Yeah it could be the council.

Gwen: (.) Something like that. I know (NAME) went up and they had a discussion, saying how much it costs (.) I think it works out it's, it's even for them (.) their money instead of paying for, they pay for (NAME) there rather than for somebody to come look after him, I think it evens out, you know. [Yeah] So (..).

Interviewer: Yeah. Yeah. And do you mind me asking why he's in a home, so why he's moved?

Gwen: Well they said, urm he's got inclusion body myositis. [Right] And he can't eat, and he can't drink, and he can't walk. [Okay] So he's, he's got a muscle wasting disease and it's wasted the muscles in his throat so he can't swallow. [Oh okay] So he's fed through a tube in his stomach, you know from a sort of litre, litre bottle a day. And it's on a stand and it sort of drips in. [Right okay] So he goes on about ten o'clock in the morning, although he's rung up this morning and he's gone on earlier urm, and he comes off it about six o'clock at night. [Yeah] And then he can have it done while he's sleeping sort of thing, but he's frightened of it being pulled out when he turns you know, although he can't move a lot. But urm (.) that's the thing, he can't eat, he can't drink, and he can't walk, so, they said I couldn't look after

## Interview Transcript – Gwen

him. And then when I had a stroke when I came home they'd taken him [Yeah] into the home so (.) that's where he is. [Yeah] They said I won't be able to have him back, because I can't manage *it or something they said*.

Interviewer: Right, whose they? Who took him into the home?

Gwen: Well it's doctor and the, and I think they had the doctor because there was no one here to look after him when I [Yeah] had a stroke so, they sort of had a meeting (.) NHS and whatsit, and they decided the best place for him was in there, so of course when I came home he wasn't here. [Yeah] And they said well (.) I wouldn't be able to look after him because he needs so much doing for him now. [Mmm] *So ur* (.) it's a good job you don't know what's coming (laughs).

Interviewer: Yeah, that must've been really difficult coming back from hospital and him not being here?

Gwen: Yes.

Interviewer: And my guess is that you were caring for him before.

Gwen: Oh yes it was only just me and him. [Yeah] Sort of thing, you know. We got on alright, I mean there was no, he could get out of bed, he had the bed that used to lift him up. And then he could get onto the side then he could eventually get up. But (.) I didn't have to do much for him but I had to be there [Yeah] just in case he fell. I mean a couple of times he went on the toilet and he just couldn't get off. [Yeah] You know so of course we had to have the toilet made higher, and the bed had to be higher, everything had to be higher, we should had nosebleeds! (laughs) But urm, I mean once I said he couldn't get off the toilet we had the ambulance men came and got him off and then one time he fell. [Yeah] So, so in the end they, when I went in and had a stroke, they said well you know can't manage him so (.) it was sorted out between the kids and the doctors and (laughs) that so.

Interviewer: Did you feel involved in that discussion or that decision at all or did you feel that it was made for you?

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Gwen: Well ur (.) I look as it more that it's inevitable, you know, I knew it had to come that, to come to that, but it's just the fact that you don't know when it's going to happen and, I mean he was, they knew he'd fall again sometime, [Yeah] and he's fallen since he was in the home, they were walking him out somewhere, and his legs just gave away. And anyway he had to go and have x-rays the other day cos he's, they think he might've damaged a bone in his knee or something. [Right okay] But ur, they're looking after him very well, you know it's just the fact that he's not here anymore (laughs), it's just (.). [Yeah hmm yeah] I go down, I go down to church in (PLACE) every Tuesday morning with my sister to communion, and ur (.) she arranges for a taxi to pick me up and take me down, and then she has a taxi up to town to do her shopping. And I come back up, he drops me off here you see (.) But urm (.) like my sister said, we don't spend our money on anything else, we might as well have taxis, as waste it on something else you know! [Yeah] So.

Interviewer: Yeah, so you're quite happy to get taxis to go places?

Gwen: Oh yeah.

Interviewer: Does it, do you ever feel like you shouldn't go out because you're going to have to pay for a taxi?

Gwen: No (laughs). (NAME) pays for everything, he's like that, you know. I've arranged for this and I've arranged for that, and we've got somebody comes in, she comes on a Thursday now, and she does some cleaning and that. It was either (NAME) or (NAME), I dunno one of them arranged it. [Yeah] Cos, well they feel that they can't do anything, they're not here so they, pay for somebody to come and help me that they can't come, you know. [Yeah] And then (NAME) comes (.) regularly, but she's got two young kids you know, whereas (NAME)'s children are grown up and (NAME)'s a grandfather himself. [Gosh! Yeah] So ur (..) but they, they arrange things between them you know, I just accept it! (laughs) You can't do much else! [Yeah] But they're good kids fair play, they do help.

Interviewer: Yeah. *Okay* (.) so I'm getting the sense that you have, you kind of just (.) have to, let things go and just.

Gwen: Well if I can't.

Interviewer: You feel like you just have to let your children [Yeah] help you out.

Gwen: Yes, this will be theirs, and I mean we had no mortgage, course they can sell it and (.) everything will go between the three of them. We've made our wills (.) that was what I was worried about in bed the other day, last night, I can't remember who's got the deeds. [Right] Urm we had a solicitor came and did a power of attorney (.) thing, and I think she's got the deeds but there are deeds to some land (NAME) owns in (PLACE) where he was born. [Yeah] And ur (.) I'll have to ask (NAME) cos I I can't remember. I can remember somebody saying I've got the deeds but I can't remember who it was. [Yeah] You know so I, I don't want to leave any hassle, if I go, so I'll ask (NAME) tonight who's got the deeds and, [Right] write it down somewhere. But urm (.) if anything happens to me like, there, there, two lots of deeds, the deeds to this house and the deeds to the land in (PLACE), she'll, I'll have together somewhere with some solicitor but I can't remember who (laughs). [Yeah] So oh god (laughs).

Interviewer: Yeah, so you're going to find that out and write it down.

Gwen: Yeah. [Yeah, right] But (NAME)'s been good at keeping a record of things, but I know (.) we had a power of attorney and that and then (..).The deeds were in (PLACE) bank, our deeds, and the deeds for (PLACE) I think. (.) And anyway they've got them moved to (PLACE), and then they've been taken, and I think the solicitors got them. But I can't remember, I know somebody's got them (laughs)!

Interviewer: So the not being able to remember, is that just something you accept or do you think oh that's because I've had this stroke?

Gwen: Yes it is, I was never that bad before (laughs).

Interviewer: Right okay so you put it down to having the stroke?

Gwen: Yes, it's something to do with it. [Yeah. Yeah] But ur.

Interviewer: Is there any other way that having the stroke has affected your life and having these memory problems?

Gwen: No I don't think so, well it hasn't affected me **bodily** [Yeah] or anything, it's just that um (.) I can't remember some things and then I find I'm awake in the night wondering (.) like I was the other night, you know. Where the heck, what happened to the deeds. [Yeah] And I thought ohhh forget it, **let them find them themselves you know!** (laughs) They're going to get the benefit of them! So ur, cos we built this ourselves and we paid for it as we built it cos we couldn't get a mortgage. [Yeah] And ur, where (NAME) was born in (PLACE), down by where the (PLACE) used to be, he's still got the land there. [Yeah] So we've got the deeds for that land. And then they were obviously, where do they have register, do they have to register land?

Interviewer: I've got no idea.

Gwen: No, I think she said. Anyway they know about it and they've got them together somewhere.

Interviewer: Yeah, it's just a matter of remembering where (laughs).

Gwen: Who and where! But ur (.).

Interviewer: Yeah. Do you often find that, that you wake up at night worrying about something that you think that you've forgotten. Has that, has that increased?

Gwen: Yeah a bit. Now I think oh have I remembered something or should I have done something. But I've seen myself get up at two o'clock in the morning and write a note (laughs) (.) ring up and question this, you get up you know!

Interviewer: Okay then, yeah. So is that one of the strategies you use, as soon as something pops into your head, you write it down?

Gwen: Yeah. [Yeah] (.) And with all sorts of bits of paper and books and that. But urm (..) I don't want to leave any hassle for (NAME) and whatsit. But, get to the point where oh god I

can't be bothered, you know, let them sort it out (laughs). [Yeah] But she's good at sorting things out (NAME), she's very (.) like his mother was a very stern **bossy** woman. And I used to say just close your eyes and you can hear your mother! You can hear our (NAME) you know! [Yeah] Cos she (PROFESSION) all her life. She wanted to be a (PROFESSION) when she left school, she went training in (PLACE). [Yeah] In the (PLACE) and then she came up when (NAME) was ill. But urm (.) she's always wanted to be a (PROFESSION) you know. [Yeah] But ur it isn't something I would (.) like. [No] It's whether you can do it or not. [Yeah] She's uh, I know one of the doctors introducing (NAME) to (.) urm (.) the new doctor who comes, this is so and so and so. And this is (NAME) he says, and if you want to know how hopeless, helpless and of no use to the (PLACE) you are, ask (NAME) and she'll tell you! (Interviewer laughs) Cos she's the only one who'll tell you! (laughs) and she is, she's very straight, [Yeah] you know, like (NAME)'s mother, oh god!

Interviewer: Yeah. And is she like that with you sometimes?

Gwen: Oh aye, she is. I know where I stand with (NAME) [Yeah] (.) I mean (NAME)'s the one who'll organise me but (NAME)'s the one who'll pay for it. [Right okay] And (NAME)'s the one in (PLACE) who can afford to but doesn't bother (laughs) [Right] according to (NAME), [Yeah] oh god, (NAME), she's got no time for (NAME), that's all! [Right okay] So ur, course he's, he's a (PROFESSION) and then he was a (PROFESSION), you know. And you just listen to him, he thinks he knows what work is! He doesn't know what real work is! (laughs) *Oh god!* She doesn't think (PROFESSION) at all, that's not work. [Right] Not her work! [Yeah] (.) But they're alright, they get on and. They do what they can to help *you know*.

Interviewer: Yeah. Yeah (.) urm (.) Do you, do you, think about yourself any differently now, now that you've had the stroke, and got, had, got memory difficulties? Would you describe yourself, would you describe yourself any differently?

Gwen: Well, the forgetting, or (.) you **feel** older. [Right] Urr. Like going up to the shop the other day and I had to stop a few times because I was out of breath. [Yeah] You know and then, I think oh god (.) and then I think well I'm **79**, you know! I'm **nearly 80** and I'm not surprised that I stop and out of breath! You know. But ur (.) when I come to think of that age, I don't really connect it with me. You know I don't feel as that I'm nearly 80. [Yeah] But I

am I suppose! I just don't, think of myself as that old. You see my sister's, she's 83. [Yeah] 84, so ur (.) you know. She had a big party when she 80 and all that you know (.) it just **crept up on me!** (laughs) You know, I don't think of myself as 80! [Yeah] Well nearly 80. Course (NAME)'s 83, he's six years older than me.

Interviewer: Oh right okay, yeah. Yeah, so (..) do you think there are any differences in the way that you would, in the way you would think about yourself now compared before the stroke, before you got this diagnosis of mild cognitive impairment, or is it just the same?

Gwen: I used to be able to do a lot more physically sort of thing, you know (.) go through the house from one end to the other and clean it when I felt like it and that, but then, now I do one room at a time and hope for the best, you know shut the door and forget it! [Yeah] It's been done so, sod it!

Interviewer: Yeah (.) *Yeah*. So (.) is it that you just, is it that you feel a bit older now than, or it's made the difference a little bit more noticeable?

Gwen: (..) Well I don't know whether I (.) I look older, I don't know, I don't feel a lot older, except when I'm walking up to the shop or I'm doing something and I have to stop, and so ohh [Yeah] it'll be my age, you know. It's just, things tire me easily. [Yeah] More than they did used to. [Yeah] Sort of thing so. (.) Put it down to my age. [Yeah] Well I think of (NAME) getting old but I don't think of myself as getting older. [Yeah] You know you think oh I'm just me.

Interviewer: Yeah. [But ur] It creeps up on you so gradually that you don't even notice, yeah.

Gwen: Well I'm 79, you know, I'll be 80 soon, and then (..) course my sisters 83, 84 and she's still getting around you know. [Yeah] But ur (.) uh. *It's one of those* things you can't help, you're getting older, you're getting old. [Yeah] (.) That's why I always have me books and me magazines, and the crosswords and god knows what. [Yeah] Just keep myself. (..) You'll never see me without a book or a magazine of some sort or another you know (laughs). [Yeah. Yeah] It's better than just sitting doing nothing (.) Keep me mind going anyway.

Interviewer: Yeah. Have you always read a lot of magazines and done the crossword? Yeah.

Gwen: Always done the crosswords and that but, since. I said I don't go anywhere and don't do anything and I never go to Bingo, never been to Bingo **in my life!** [Yeah] You know so, I spend me money on the mags and [Yeah] (.) and sometimes I give a stack to (NAME) and he gives them to the women in the, in the home, you know, they just sit there doing nothing so he dols out my mags when I'm finished with them you know (laughs). So ur. [Yeah] (.) Somebody gets use of them after.

Interviewer: Yeah. So has your husband noticed any changes in your memory? Has he ever commented on it?

Gwen: (..) Well he's always reminding me thi, I know I've only got to when he rings up, or I ring him I say, am I coming up tomorrow? No, (NAME)'s coming to your place, he know, he remembers! You know he knows when I'm coming up and what, he knows everything that's going on. [Yeah] Sort of thing you know, and then he'll say to me you're going to (NAME)'s for your dinner tomorrow (laughs).

Interviewer: Okay, so he reminds you about things?

Gwen: Yeah. [Yeah] His memory's fine, it's just the rest of his bodies that gone to **pot**. [Yeah] All the muscle, muscle wasting thing, you know. Called inclusion body mastitis, but (.) it's affected the muscles in his throat so he can't swallow. So he can't eat or drink, he's on a tube that goes into his stomach, you know. [Yeah] He fixes it up, he rang up this morning, he goes on it about 10 o'clock but he said this morning he put it up earlier and then he'll come off about six o'clock, so it's dripping right through for the whole of the day. [Yeah] That's his (.) breakfast, dinner, tea, that all dripping in. [Yeah] So (.) he manages very well. [Yeah. *Yeah*] And then the, tube, the nurses there they want it to see how it's taken out and put a new one in, you know. But sometimes, it has fallen out once. But urm (.) they want to see it in case they get somebody else in there with one you know, so. [Yeah] He's quite happy to let them see it! (laughs)

Interviewer: Urm (.) are there any advantages to knowing that you've got mild cognitive impairment?



Gwen: (.) I can **blame it on**, a lot of things on it! [Oh right] (Interviewer laughs) But um (.) as I was saying, I've got to pay the milk, I think I owe them three weeks but they haven't called for it you know, and then I find out, I haven't paid my milk bill, you know. [Yeah] So I'm going to ring them up and ask them will they come for it this week, make sure they do you know. [Yeah] Cos I don't want them to turn up and me not have the money. [Yeah] Although (NAME) (.) (NAME)'s been something in charge of all the money. This, this pension and all that sort of thing you know. [Yeah] But my pension goes into my building society, so I don't have to go collect it you know. I have to go to the building society if I want to get it. [Yeah] But urm (.) she's got money and she always comes. (.) Dad, she gets dad's money, and then, she come and give me some, you know for housekeeping, you know if I need to pay the paper bill or need to pay for food bill and that sort of thing. [Yeah] So she'll, she'll come then and pay it.

Interviewer: Yeah. Are there any disadvantages to knowing that you've got mild cognitive impairment?

Gwen: No I don't think so (laughs).

Interviewer: No?

Gwen: I don't think people know about it really. They don't know **what it is**! [Yeah] Just that you're getting old (laughs).

Interviewer: Yeah. So is that what it feels like, that the diagnosis means that you're just getting old?

Gwen: Yeah. [Yeah] Yeah.

Interviewer: Does it give you any concerns that you have this diagnosis?

Gwen: Can't do **anything** about it. So, I forget it. [Yeah] Carry on (.) they'll end up putting me in a home as well with him (laughs) hopefully! I said he sits there, he's fine, he's warm, he doesn't have to do anything, and so I say I want to go and join your father! (laughs)

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Interviewer: (..) Is that something that worries you?

Gwen: What?

Interviewer: You know, going into a home, maybe in the future or?

Gwen: **No!** [No] Thing is they'll have to sort this place out. [Yeah] I mean this, (NAME)'s baby, he built it. [Yeah] You know (indecipherable) sort of thing. But ur (..) knowing them we wouldn't want to sell it, you know, and I say go back home and look after it then! (laughs)  
But ur.

Interviewer: I guess it goes back to that uncertainty that we were talking about earlier, that you just don't know what's going to happen do you in the future?

Gwen: No. [Yeah] *No.* (..) So I, it doesn't worry me that, I mean it wasn't a very nice feeling when I got back, I mean, going into a home and there's no point (..) he won't be coming back sort of thing. [Yeah] So, but urm (..) I haven't got any worries I mean (NAME)'s got the money for keeping it running and that sort of thing, but it's not the same living here on my own, you know I'd rather be (..) somewhere else I suppose. [Yeah] (NAME)'ll say come and live in (PLACE).

Interviewer: Somewhere else but not (PLACE)? (laughs)

Gwen: No. I mean she's there, both the lads are away so it would have to be near her sort of thing, but like she said, I have to come a long the (PLACE) you know. Don't come then! (laughs) But ur (..) it'll get sorted out, I'll get put somewhere, shoved in a cupboard! (laughs)

Interviewer: Yeah. Do you think you'll be able to have some control over that decision?

Gwen: **Probably not!** (..) Well as long as I haven't got to worry about paying rent and paying, you know, and not getting, that's the one thing (NAME)'s terrified of, was debt. [Right] **He was terrified!** When we were on our honeymoon (..) he said this is your first (..) money, you know, wages, housekeeping, and he never let go of it! He held onto it, and he said, you won't get me in debt will you? He was **terrified** of debt. [Yeah?] His mother **rammed** it into him,

she was the same, she was terrified. I mean she wouldn't even have anything from a catalogue, you know, where you pay weekly. If you couldn't pay for it, you didn't have it, whereas my mother ran the catalogue for **years**, and she used to get money and we used to get our things. [Yeah] She was never in debt, she never owed anybody a penny. [Yeah] But (NAME)'s mother, if you can't afford to pay for it straight away, you *don't have it*. [Right] And he was the same you know, don't get me debt. I gave it him back, **handle the money yourself** then! (laughs) But ur (.) no it's the one thing, mind you a lot of the old, my mother was the same, didn't want to owe anybody anything, you know, they were terrified of debt weren't they. The older people. But ur (.) no.

Interviewer: Is that something that ever worries you now, like forgetting to pay for things?

Gwen: Yeah sometimes I think have I paid, but urm, I know, the milk I haven't paid since Christmas and I wish they would just come for it, you know, it's there. But I (.) *Well I don't know*. [Yeah] (..) I'd rather they come for it then I know I'm out of debt. *But ur* I'll have to ring (NAME)'s up I guess. [Yeah] I mean they're always very good, always there early, you know. But they always used to come every Thursday night. But since Christmas it's sort of upset me that they haven't been, and I don't want it to carry on like that you know (coughs) so I'll ring (NAME)'s up and ask them to (.) call this Thursday, get it settled you know, so that I can you know, it's been paid.

Interviewer: Yeah. So you can put your mind at rest.

Gwen: Yeah.

Interviewer: Yeah. Okay, so I think we're coming to the end of the interview.

Gwen: Okay.

Interviewer: Is there anything that you feel is relevant that we haven't talked about?

Gwen: (...) No, I just wondered about, me being here on my own. (..) Would I be put, would I go into a home? How would that work?

Interviewer: Is that something that's worrying you at the moment?

Gwen: Well I (..) I dunno (..) I mean it was so sudden with (NAME) going in, I mean I went into hospital. And when I came out, he'd gone. You know so what's going to happen when it's **my turn**, you know. I am going to be just (..) they didn't discuss it with the families do they? I think our (NAME), and (NAME) were *doing something* about it.

Interviewer: Yeah, I mean, from what I understand, is that it should never just happen to you, you should always be consulted and I think there's quite a big push at the moment for people to be cared for in their own home, so if there is a way of, being able to work it so that you can stay in your own home, if that's what you wanted then, you know, but who's to say it will ever even come to that point? Why do you think it might come to you needing to go into a home?

Gwen: Well, if anything happens to (NAME) (..) I know (NAME) would want me to go nearer there, she's said it time and time again, to, nearer her to (PLACE). She said they've got nice (..) old peoples bungalows there, sort of thing. I don't know who'd sort all that out and this out. And then last night I was wondering about what's happened to the deeds, I can't remember. [Yeah] I'll have to ask (NAME).

Interviewer: Yeah. Is it something that's playing on your mind quite a bit at the moment?

Gwen: Well I've only just thought about it really, I thought what happened, because I can't remember. I know we got the deeds, and somebody said to me that (..) the deeds are here with me, with our wills. So it must be the solicitor but I don't, I can't remember who it is. [Yeah] You know so, I'll have to ur (..) if the bank handed them over, would the bank have the name of who they handed them over to?

Interviewer: (..) I guess so, but I'm afraid I'm not an expert in that area.

Gwen: No nor me.

Interviewer: I'm afraid I'm not really sure. Maybe speak to (NAME) about it, it sounds like she's probably got quite a firm grasp on everything, that's going on.

## Interview Transcript – Gwen

Gwen: Oh aye. She's the only one at home. (NAME)'s in (PLACE) and (NAME)'s in (PLACE). [Yeah] He's just been to (PLACE) for Christmas! [Oh! Yeah] (.) His friend came over, he lives over there now, he came over in June and he said come over for Christmas (NAME) and aye all right he said and he went and all. [Yeah] (.) He got back on the 10<sup>th</sup>. [Oh right okay] Had to look at the calendar (laughs), our (NAME) got me that cos I get ohh what day is it. You know so he got me that, it's got Monday 12<sup>th</sup> of January (laughs).

Interviewer: Yeah. Do you find that quite helpful?

Gwen: Oh yes (laughs).

Interviewer: Yes that is a good idea isn't it.

Gwen: Yeah. He was sick of me asking the day, so for god's sake mam stop asking! So he said I'll buy you one, so he bought the clock (laughs).

Interviewer: Yeah. (.) So is there anything else you'd like to say before I turn off the voice recorder?

Gwen: No, I think I'm alright, it's just (...) *as long* as (NAME)'s alright there and that, but if anything happens to him (.) who will come and sort me out? You know, is it (.) medical people is it?

Interviewer: Tell you what, I'll turn this off now and urm.

## Interview Transcript – Jack

Interviewer: Okay, so we're here today to talk about your diagnosis of mild cognitive impairment. Urm. So I was wondering if you could tell me what you think mild cognitive impairment is.

Jack: Urm, minor loss of memory function.

Interviewer: Yeah. Okay. And had you heard about mild cognitive impairment before?

Jack: I hadn't heard it called that, it's just called forgetfulness, basically.

Interviewer: Okay. Yeah. Yeah. Okay. And do you remember being diagnosed with mild cognitive impairment?

Jack: Yeah. Urm, I've had two sessions up at the (.) urm (PLACE). One with a a nurse, and one with a psychologist.

Interviewer: Right okay. And what prompted you to go to the memory.

Jack: Mainly because I'm forgetting things.

Interviewer: Okay, what kind of things were you forgetting?

Jack: Urm. Not turning up when I'd made appointments, urm (.) just general everyday things, short term memory mostly. [Yeah] Yeah. Urm. In my hobbies, I'm in (PROFESSION). I run a (PROFESSION) in (PLACE), and I'm also the (PROFESSION) for (PROFESSION) for the whole of the (PLACE). [Right] And I was making urm (.) appointments to be with boys for outings and things and forgetting to turn up. [Right okay] So, it was important to me that I sorted something out. [Okay] Yeah. Or if I was doing a report I would forget to put things down and then be reminded of it when I got to the meetings, which is a little bit embarrassing.

Interviewer: Okay. And was that quite out of character for you?

Jack: Ur (.) Yes. Yes. Cos it's only in the last I'd say, three or four years.

Interviewer: Yeah. Okay. And, so did you go to your GP service initially?

Jack: Yes. [Yeah] Yeah I went, well I can't remember which doctor it was now, cos there's so many of them there. But I, Doctor (NAME) is my nominated doctor, but you can, he's so popular that I very rarely see him. Urm and there I was just referred to the clinic.

Interviewer: Yeah. And what were your thoughts about being referred to the clinic, were you worried or apprehensive, or did you feel okay about it?

Jack: I was (.) a little bit apprehensive, because I really didn't know what the format would be. Urm, and my wife came with me anyway cos she wanted to know what was going on. (.) [Yeah] And it's support of course.

Interviewer: Yeah. *Yeah*. Urm so, how did you feel when you were given this diagnosis of mild cognitive impairment?

Jack: Ur it was sort of implied as th as the two interviews went on, that it wasn't a serious matter it was just a mild (.) forgetfulness that (.) to my mind age related.

Interviewer: Okay. So your perception of mild cognitive impairment is really that its age related memory loss?

Jack: Yeah. [Yeah] For me anyway, it might not be for other people but it is for me.

Interviewer: Yeah. Okay. And how does it affect you in your daily life?

Jack: Urm (.) well mostly silly things. Go and get, say to get a paper but asked to get something else and totally forget about it. [Yeah] Just get my paper and come back, where's the mushrooms or whatever, or you know. [Yeah] And oh I've forgot and I have to go out again which was annoying (laughs)! Urm and other things in in in me (PROFESSION) doing reports, and forgetting, not important bit's but certain bit's that I should've written down and I haven't cos I haven't remembered. Urm (.) arranging visits and forgetting to turn up myself. [Yeah] For visit's or events that **I'd** organised and I've forgotten to turn up for them. That's

Interview Transcript – Jack

happened twice now. [Yeah] And I've thought oh this getting a bit serious I better do something about it.

Interviewer: Yeah. *Okay*. Yeah, so urm, did you think it was a serious problem at the time?

Jack: Not really no, I didn't think it was a serious problem, but I was worried it would get worse.

Interviewer: Okay. Yeah. [Yeah] Are you still worried that it will get worse?

Jack: No I've I've sort of accepted that (indecipherable) it hasn't got any worse. Urm (.) it might do in the **future**, but at the moment it hasn't got any worse, because I've had to go about it in different ways, I keep dates on the calendar. [*Right*] I write things down, and I refer to a list of notes in the in the diary.

Interviewer: Okay. So you've made a number of kind of adaptations [Yes] to your life [Yes] to help you remember?

Jack: I mean there still are things that **I even forget to write down to remind me** (laughs)! I mean our calendar sits on the back of the kitchen cabinet door, [Yeah] it's one of those divided in half his and hers, and all my stuff goes on one side and (NAME)'s goes on the other. And I always look at it every morning. [Yeah] And that way it reminds me if anything's coming up. Urm, and if there's something I **should** be doing like writing a report or something like that.

Interviewer: Yeah. So it kind of keeps you on track for the rest of the day?

Jack: Yeah.

Interviewer: Yeah. Were urm you given any advice about mild cognitive impairment when you went to the memory clinic and you got the diagnosis?

Jack: As?



Interviewer: What it was or what to do?

Jack: Yeah I was told what it was urm and I was told that it would be better for me if I did sort of mind exercises, puzzles or word games or things like that. Well I most evenings I have a couple of hours on my laptop doing, well I play Maj Hong, this is a Chinese tile game. [Oh yes, yes] and ur, on the computer, and that you need your memory for and sometimes you know oops (laughs)! [Yeah] And ur various other games, words games and things like that. But I don't do it too long because I get bored with it quite easily. [Yeah] I'm more a do-er than a ur for instance, one of my hobbies is model railways I build model railways. [Right] And exhibit them and the layouts I've got in the club which is 25 feet long, is we won best in show at (PLACE), (PLACE) last year with it. [Yeah] A friend of mine and myself. And I've got one in the shed and I've got one round the garden (laughs)! [Right! Yeah] So I've got plenty to occupy my time even though I'm retired, I've got me (PROFESSION), me (PROFESSION), me model railways. [Yeah] So I keep my head busy, you know.

Interviewer: Yes, yeah. So has the mild cognitive impairment had much of an impact on your hobbies? So you said (indecipherable).

Jack: Not so much my hobbies no, because they're not the sort of things that you've got to remember things on a certain timescale. [Yeah] Urm, the (PROFESSION) aspect can be, as I've spoken about with the making arrangements, cos hundreds of kids are bin relying on me for these activities and outings as well as half a dozen leaders at a time. And I also am involved with their training. [Yeah] So if I forget a training event, they can't, we can't arrange it again for months afterwards. [Yeah] Everybody gets together you know. [Yeah] That's the only thing that that really bothered me.

Interviewer: Yeah. [Yeah] Do you ever worry that you're going to forget something, so something important like your responsibilities?

Jack: **Not so much now** because I've started this regime of writing things down and keeping a record of what I've decided to do, what I've arranged and how, and sometimes just the **how** you're gunna do it I have to remind myself because urm with (PROFESSION) it's such a varied thing without out outside things and indoor things there a several diff several different ways you can go about it. [Yeah] So I have remind me self which bit I've organised ur

whether it's an outside event or an inside event or a practical hands on event or a teaching event. [Yeah] I've got remind myself, *you know*. [Yeah] Lot of it is practice because I've been in scouting since I was eight years old. [Okay (laughs)] And, but I've been (PROFESSION) for 20 years, both 10 in (PLACE) and 10 here, in fact I retire here in September, that's cos I you can't do more than 10 years in one go. [Oh really?] Cos somebody else has to take over then. [Yeah] But urm (.) with all the other things in (PROFESSION), running a (NAME) in (PLACE), well I've had (NAME) in (PLACE), with (NAME), she was a leader with me. Urm, (.) its experience, and practice and you find yourself doing the same things over and over again because the kids don't remember, you know if you've done something 18 months ago and you do it again. They don't remember they've done it before!

Interviewer: No? Yeah, *okay*. Urm (.) has your life changed since being diagnosed [No] with.

Jack: Not in the slightest. [No] Apart from record keeping, but my life itself hasn't changed.

Interviewer: No. Okay. Has it changed the way that you think about yourself?

Jack: Ur (.) I think seeing me dad sink into urm (.) brain, practically brain dead, *you know*. [Right] Certainly made me think. But th the diagnosis was only a sort of urm confirmation of what I already thought.

Interviewer: What your, your diagnosis?

Jack: I already **had** this, **I knew** I was forgetting things. [Yeah] You know cos I was being reminded you've forgotten this or you've forgotten that or done this. And the diagnosis was just a confirmation of what I already suspected.

Interviewer: Yeah. Was it validating to know that there was a reason that you were forgetting things?

Jack: Yeah. Yeah. That's it, it wasn't urm (.) it wasn't going to be a tragedy (.) ur I I could live with it. [Yeah] Yeah.

Interview Transcript – Jack

Interviewer: Yeah. How how do you compare yourself, the problems you have with the problems that your father had with?

Jack: Oh well that was much more severe because I mean he'd lost all idea of who he was, who anybody else was, where he was, you know, he was just, he'd gone into senility really, *you know*. Urr (.) of course you say to yourself I don't want to be like that (.) and I still don't (laughs)!

Interviewer: Yeah. Was your father ever diagnosed with anything?

Jack: No, well I, I can't say, maybe if you'd asked his wife that question, she'd have a different answer but **I** don't know.

Interviewer: Not to your knowledge.

Jack: No. Not to my knowledge. I think, I think he was generally accepted as as needing quite a lot of physical and mental assistance. Urm when he was in the respite home *you know*. And of course (NAME) his wife, did a lot as well because I mean she used to do everything for him and remind him to get changed, an clothing an dressing and washing and *all that so. You know*.

Interviewer: So a lot more than just short term memory loss.

Jack: Oh complete loss. Yeah.

Interviewer: Yeah. Have you spoken to your family about your memory problems, it sounds like maybe your wife.

Jack: Well obviously my wife knows and my my two children. (NAME) who only just lives over the road there and me son lives in (PLACE), both with their own families. Urm they know that I forget things. Urm but anything wider than that, no.

Interviewer: *No*. (.) Do you think that they would worry about you?

Interview Transcript – Jack

Jack: I think they worry to the extent that you do with any (laughs) elderly relative. You know, I mean, my son (.) still talks to me like I'm an idiot (laughs), you know! And has done since he was a teenager! And my daughters 37 and she she's the youngest and she um, she just talks over me sometimes and I just think, will you shut up (laughs)! You know. But that's typical of your own kids, but I don't think they actively think of me of of urm going into lunacy or anything like that. *You know.*

Interviewer: *Yeah.* Do you and your wife talk a lot about your memory problems or.

Jack: Not so much now. Now we've now we've been to the clinic and it's it's sort of urm been diagnosed an and how far it's gone and everything else. I think she was more worried than anything else. [Yeah] When she used to talk about it here.

Interviewer: Yeah. What do you think she was worrying about?

Jack: Me going loopy! (laughs)

Interviewer: Yeah. And now how do you think she feels after having this diagnosis?

Jack: Well she's the one who does all the reminding when I forget things. [Yeah] Well most of the times. Because she she's very very active and brain wise she's very (.) urm **quick**. [Yeah] Quick thinking. And I'm not, I'm a slow thinker, always have been. So that probably urm makes a difference to her as by the time I've thought and made me answer from her point of view I've forgotten it. But I haven't. [Yeah] I just don't think at the speed she does.

Interviewer: Yeah. Just need a little bit more time to process and think about something.

Jack: Yeah I should've come from Suffolk or somewhere like that ur eh arr! (laughs)

Interviewer: (laughs) Urm, and have you spoken to people outside your family about your diagnosis?

Jack: Urm (.) only my (NAME), in (PROFESSION). [Right] The (NAME), he's like the boss, and I'm second down the line. It's saying that when my 10 years came up I was

stepping down [Yeah] from district level. I'll still assist in the (PROFESSION), local (PROFESSION). [Yeah] But from (PROFESSION) I'll be stepping down.

Interviewer: Right and is that because of the memory?

Jack: Because of the memory stuff yeah. [Yeah] I feel it unfair that if I'm asked to do something and I can't perform it a hundred percent.

Interviewer: Right. Yeah, *okay*. And what did he say about it?

Jack: He he was I think he was a bit surprised, he said because I've never noticed you missing things out. I'm a good good flanneler at times you know! But (laughs) he said by all means he said, that's your decision he said I wouldn't want to ur impose anything over your decision. [Yeah] Certain things obviously he has to tell me that that's the line of we're going down and doing things or urm format or something like that. But he's very much um left me to run the section, as I see things for the last 10 years. [Yeah. Yeah] So ur (.) his his actual words was I'll be sorry to see you go. [Yeah] Because with them they've got the problem of **finding somebody** else to take over which is **pro proving difficult!** Because I've already had two flat refusals when I've asked people if they will take over. [Yeah] It it's not a (.) it's not a terrifically hard job, it's just extra time. [Mmm] I mean most people in the (PROFESSION) movement are doing two or three jobs anyway. You know, I'm running a (NAME) and doing that as well. [Yeah] And I've got the visits to other packs to do. [Yeah] But it's also something I enjoy doing. I love working with kids. Really do. That's why we (PROFESSION) and that's why, I mean (NAME) used to do Childline as well. [Oh right okay] And between all the things that we used to it used to be a right gab fest in here sometimes, all talking about what we've been doing with the kids.

Interviewer: Yeah, yeah. Both very busy people.

Jack: Yeah, well there's always the old saying, if you ask a busy man to do something it'll get done, if you ask a lazy man it won't. [Yeah] *You know*. And I've always tried to keep that up, I'd rather be busy. [Yeah] I do a lot of do it yourself, I like working with wood, *hence the modelling and things, my railway modelling and all that*. Ur (.) and I'm not very keen on

Interview Transcript – Jack

decorating (laughs). [Right] I I **hate** wallpapering. [Yeah] It's it's that's one of my bug bears, wallpapering. [Right okay] I can do it but I don't like doing it.

Interviewer: No, there are other jobs that you much prefer to do.

Jack: Oh I'd rather **build** something you know.

Interviewer: Yeah. So are you still able to keep as busy as you ever have been?

Jack: Oh yeah. Yeah.

Interviewer: Despite the memory.

Jack: I mean only last week I built the cupboard over the boiler. That's a brand new boiler we've got. [Oh right!] Only last week. [Yeah] You know so that sort of things a doddle. [Yeah] It's just that the walls of the house aren't straight (laughs)!

Interviewer: (laughs) Yes that can be a bit of a problem!

Jack: So yeah I'm, I'm still as active as I can be for me age and physical fitness. Urm (.) me backs cr cracks me up sometimes as I broke my back a couple well a few years back. [Yeah] Urm (.) when I was teen. But urm (.) I had to retire early once I'd done that. [Right] I was finished when I was 50. [Yeah] Ur (.) well I'd left the sea by then, but the jobs I just couldn't handle them with me back.

Interviewer: Right okay. [Ur] And is that when you took up (PROFESSION)?

Jack: No no. Oh yeah, yeah. Once I'd packed up the sea, we couldn't really do it while I was at sea. [Yeah] Urm (.) we've probably been doing it about 30 years now. [Right, okay] Yeah [Yeah] cos we used to do it in (PLACE) when we lived there. And then moved here we sort of urm we got the upstairs converted into a bedroom so we thought well we've got a spare bedroom might as well use it.

## Interview Transcript – Jack

Interviewer: Yeah. So has having memory problems affected your ability to (PROFESSION) at all?

Jack: No. [No] Only in the, as I say just change of sort of um role really. I used to be the prime carer. Now (NAME)'s taken over a prime carer cos the prime carer has to do what they KDA's which is the daily and weekly reports on the (NAME). [Right okay] On how they're developing and how they're responding. [Yeah] Which all go into the, well you do it on a computer now, it goes into the head office.

Interviewer: Yeah. How do you feel about that change in role?

Jack: I was glad of it because I used to struggle with KDAs. [Right] Urm. I'm not a wordsmith, I **struggle** to write. I had um (.) I suppose you'd call it dyslexia with of hands really. Because I was left handed. And my teachers when I was in junior school used to hit your hand with a ruler and make you write right handed. [Yeah] Well (.) it affected my writing to such an extent if you would sayin something and I had to write it down, I'd be flummoxed. [Yeah] Because I'd start writing one way and then I'd go to capital letters, then I'd go to printing then I'd go to a scrawl. I can't keep up to the speed. [Yeah] And I don't think that's anything to do with the memory loss cos it's always been like that. [Yeah] So it was great when (NAME) did take over writing the reports. Because she puts more into them, I just do a very short scribble, [Yeah] um an but she's more fluent on what she put in the report. [Okay] Ur I mean I can do official reports because I can take my time over them, I'll sometimes sit for two hours and do a report and I'll get all the basics in as long as I remember! (both laugh) Urm but yeah, sitting at the computer using it as a word processor, because you can go back on yourself and change things and this yeah it works *alright*. [Yeah] But that was quite a relief when she took over those things because they were getting me down.

Interviewer: Yeah. And so it was getting you down, even before the memory problems? That, that's always been a problem?

Jack: Probably about the same time. [Okay] Cos it's, they've only been in about three years, these KDAs. Before that you had a diary and you wrote in a diary. And then the (PROFESSION) would come and read the diary and write off that into her official report

sheet. And I think it was to cut down their workload, they got the (PROFESSION) to do it! (laughs) You know. [Right] That's how it works. [Yeah] But it's become a requirement now, urm in (PROFESION) these reports **have** to be done because they felt that the diaries thing was more like a narrative because people were doing it day to day. And it wasn't gi **really** giving a complete ur idea of what the (NAME) was doing or urm responding to or non-responding on a lot of occasions. [Yeah] So they do them all the time now, its part and parcel of (PROFESSION).

Interviewer: Right okay. Yeah. Urm yeah so the memory problems hasn't really affected your work?

Jack: Didn't really affect it no.

Interviewer: Urm with (PROFESSION). No *okay*. Urm (.) and do you think of yourself any differently now, compared to before the diagnosis?

Jack: Ur (sighs) (.) no. No I don't. I I'm still doing the same things, more or less, (.) I just realise that I'm not getting any younger, I've got to start slowing down a little bit because sometimes (.) I I'm I'm diabetic as well and I'm **exhausted**. [Yeah] You know with some of the jobs and the work I do and things like that. I'm not saying its hard work but when I'm doing somethin something physical I can get very tired and it's a sugar burning thing. [Right] Urr you react, you flop, you just you just come to stand still literally because you've got no more energy. [Yeah] Ur and that can be anything, anything at all, it doesn't have to be physically picking up tools or lumping stone around or anything like that, it's it's more a mental thing. [Right okay] Than than um physical but it affects you physically. [Yeah] And then you've got to have a sugar rush. [Right] Urm. I used to use mars bars. [Yeah] Go and eat a mars bar, or a glucose tablet. [Yeah] Or **anything** for a quick sugar fix and then you're fine. Half hour later you're fine. [Yeah] You know.

Interviewer: So you said that it can um, it can sometimes be kind of a mental draining [Yeah, yeah] activity that you're doing. So do you think that the memory problems have increased that?



Interview Transcript – Jack

Jack: No I don't think so. [No] No I I, it's a **different** compartment if you like. [Okay] Ur it's something that affects you, and it can and it (.) if I'm in a stress situation and having to think quickly or do something very quickly, it'll it'll get me. [Yeah] Not maybe not right then, half an hour later. [Yeah] But the memory style of it doesn't get affected. [No] I mean I suppose if I ignored it and went down the slippery slope of a diabetic coma, then I'd you know be in serious trouble. But I'm at the stage that although I'm on insulin I know how to handle it, I've been on it for a number of years now and I can literally play it [Right] by my own doing my own injections, putting them up or down. I can read it. [Yeah] So it's not a problem.

Interviewer: No. No. So you haven't noticed it happening more since having [No] memory problems.

Jack: No, in fact if anything me control's got better.

Interviewer: Oh right, okay.

Jack: Yeah.

Interviewer: Why do you think that is?

Jack: Well cos I'm paying more attention probably. [Yeah] Because I know I've got to keep things on a sort of straight and narrow, like write things down, remembering things, or planning to remember things in certain ways. [Yeah] And I'm doing the same with my diabetic control. [Yeah] In the little book which I keep.

Interviewer: Okay. So it sounds like you're taking quite a proactive approach to.

Jack: Yeah I feel, I feel I have to. [Yeah] I mean it's something I've always done, it was always in my training in the (PROFESSION) as well as the (PROFESSION). It it's something that you sort of get drilled into you, you've got to organise this for yourself.

Wife: Hello! (shouts in from next door room)

Jack: Hello love! (.) Wife.

## Interview Transcript – Jack

Interviewer: Okay *okay*.

Jack: (.) So, yeah, I I don't think it's made it any worse.

Interviewer: No okay.

Wife (comes into room): Hello.

Interviewer: Hello.

Wife: Would you like a cup of tea?

Interviewer: No I'm ok thank you.

Wife: Coffee or something?

Interviewer: No I'm absolutely fine thank you. (Wife leaves room)

Jack: Oph never asked me! (laughs)

Interviewer: (laughs) Urm so urm (.) lost my trail of thought now! (laughs) Urm it sounds like the mild cognitive impairment, you've got the diagnosis but in actual fact, it hasn't really, impacted significantly on your life?

Jack: No as I say, it's just put a name to what I thought I had.

Interviewer: Yeah. And do you ever use that name?

Jack: No.

Interviewer: No, ju so when you.

Jack: Just forgetfulness.

Interviewer: You just call it forgetfulness?

Jack: Yeah cos it's too complicated that name (laughs)!

Interviewer: Yeah. Yeah. So when you went to speak to the person that's high higher up than you at (PROFESSION), you didn't say I've got this diagnosis of mild cognitive impairment?

Jack: Oh well I actually did then. Because I thought that it was important that they knew the true (phone rings - indecipherable) come on get the phone! *Yes she's got it.* Err I felt it important that they knew exactly. Ur one of the sty pens that we have in the (PROFESSION) is if you have any serious impairment you must tell *them*, I had to tell them that I was diabetic as well. [Right] Only because if I go to camp (.) I have to take all my stuff with me [Yeah] and I have to check it all meself. Normally you get somebody else to check it but as I'm running it you know (laughs)! You have to check it yourself. [Yeah] I mean th that's another thing like, you arrange at camp, and there's a million and one things you've got to sort out, [Mmm] you know like food, the menu, the camping site itself, power, water, [Yeah] gas for cooking, you know all, transport, all this sort of stuff comes under the camping licence. [Yeah] And I mean the biggest one that I've I've run was a hundred and 12 boys. [Gosh] In one camp. [Yeah] Yeah so you can imagine the logistics, I mean okay I didn't do it all meself, I had a team and we used to do a lot of organising between us, whose doing what. [Yeah] But urm that was urm five packs together. [Yeah] And we'll have another one in either June or July this year, district camp, we should probably have about the same again. [Yeah] And I've done those for years and I've lost count of the camps that I've organised now.

Interviewer: Yeah. So you're quite well rehearsed.

Jack: Yeah! (Interviewer laughs) Yeah, well-rehearsed. We have a sort of basic outline programme that we fit everything round, what the theme is, what we're going to do, the times, but the times are user, well now the times are doing activities are sorted. [Mmm] We've got this crib sheet if you like, and we work most of it from that now. [Yeah] And it's something you just develop after a while if you're doing something, I mean I must've done well over 200 camps. [Yeah] In my (PROFESSION) as a leader. But urm we do an extra one

in this district, we do one we call sixes and seconders, which are boys that are in within six months of going to (PROFESSION). [Right] And what we do, we taken them to camp, and we take (NAME) with us, (NAME), and **they** tell the boys, train the boys in the skills that they need to be a (NAME). [Right] Boys being the (NAME). [Yeah] Ur (.) with leaders, with them and (.) it makes the (NAME) so much more focused and comfortable going up into (NAME) cos they're no longer a big fish in a little pond, they're going up into a bigger pond and they're the little fish again you see. And it it frightens some boys. [Yeah] And we do these (NAME) to sort of get them together. [Yeah] (.) You making a cup of tea (talking to his wife)?

Wife: If you want one yeah.

Jack: Oh, yes please (talking to his wife). (Interviewer laughs). (.) Yeah. Yeah so we, it's things like that, it's not just urr reminding yourself all the time, we've got the system in [Yeah] to sort of I'll do that today, and I'll do that tomorrow [Yeah] next week we'll do that, all leading up to the day when you're going to the camp where you have to buy all the fresh food, I even go and get that, it's it's you know you have to go sort out whose doing it, or you're doing it yourself. Usually it's me (laughs).

Interviewer: Right (laughs). Yeah. Yeah. Urm, definitely sounds like (PROFESSION) keeps you busy, and keeps you quite active in making you use your memory as well.

Jack: Oh yeah yeah. [Yeah] And sometimes you're thinking on your feet, with the decision of what you're going to spend. Because you've only a finite finite amount of money depending on how many boys are going, or girls, we have girls as well. [Yeah] Urm. And we have to set the amount from judging what happened at previous camp got very short of money, so you put it a bit, because prices are always going up. All this sort of thing, you've got to think of you know. [Yeah] And cap fees go up as well, usually without telling you (laughs)!

Interviewer: Yeah. So do you think by keeping active and doing all these different activities, and having to use your memory, do you think that helps your memory?

Jack: Yes. Yes. I think it's kept it urm static, it hasn't got any worse. [Yeah] Urm (.) and I can't see meself stopping doing any of these activities. Maybe a lot of the camp, I won't be a

(PROFESSION) cos usually it's the ABCs that's the (PROFESSION) you see, what I'm doing at the moment, the position I'm in. Urm (.) once you step down from that you're just another (PROFESSION), with within your own section then. [Okay] You still have to do it for your own section, but it's nothing on the level of arranging a full camp. [Yeah] Cos as (PROFESSION) you're not only responsible for your own group of boys, you're responsible for the whole camp. [Yeah] So I'm I'm quite often doing two different jobs at the same time. I'm trying to answer questions from other leaders about the camp, and my leaders, my section leaders, about our own little sub camp. [Yeah] *You see* so you have to have a split personality sometimes! (laughs) I don't mean that in a psychological way (laughs)!

Interviewer: (laughs) Yeah. [So] Is there anything else that you do to try and keep your memory or make sure that it doesn't get any worse?

Jack: Not really. I think I'm busy enough. (Interviewer laughs) [Yeah]. I mean occasionally people ask you to do other things and I find I say to them I haven't got the time. [Yeah] You know. Just haven't got the time. I'm the owner of quite a large trailer and people keep asking me to move things! [Oh right, yeah] So ur just lately it's been me daughter, she moved into a flat just up the road from (.) (PLACE), which is quite down the coast a bit. [Oh right. Yeah] So we've been moving furniture, trailer loads (laughs). [Yeah!] But yeah, it's a, I think I've got enough to do at the moment, enough to keep me occupied.

Interviewer: Yeah. Yeah. And do you have an idea of what you think might've caused the mild cognitive impairment?

Jack: (.) Well I think it's just, (.) the synapse in your brain sort of break down after a while, it's (.) they say it's in your teens that your brains the best, and after that it sort of starts to wear away a bit. And I think, I just think it's that, you know, you get sort of, nibbles out of the edges (laughs). [Right!] Urm and it it just, you find that you're just not quite up to the mark you were before, thinking wise and remembering. *Ur* and apart from that it doesn't affect you physically, well *not to my mind*. [No, no] *What mind* I've got left (laughs)!

Interviewer: Yeah urm. Yeah was it explained to you at the memory service, what they thought might have caused the mild cognitive impairment?

## Interview Transcript – Jack

Jack: I don't think they had, they they came to any conclusion because the two sets of sessions that I had with the books and the cards and urm all that, they said oh you couldn't have got a better result. [Yeah] I mean can see differences between things and can answer the questions and all that. I had no problems.

Interviewer: Yeah, so you had tests looking at lots of different areas of the brain.

Jack: Lots of different ones.

Interviewer: And it was just memory that was a little bit of a problem?

Jack: Yeah. And that was the only one that they said. (.) Yeah, either that or it's going rusty (laughs)!

Interviewer: Right (laughs). Yeah. Urm how do you see yourself compared to people a similar age to you?

Jack: Well as I said before, I will always be a slow thinker, I I I don't make fast decisions mentally, I'm *just not capable of it*, **never** have been. So I do feel sometimes a little bit left behind by other people because they urm think and decide on an answer **so** much quicker than I do, if I've got the time I'll get there the same result. [Yeah] But I haven't got the speed of thinking. [Yeah. Yeah] And I don't think that's changed, I've always been like that.

Interviewer: Yeah. And do you see many differences between you and people of the same age now, in terms of memory or?

Jack: (sighs) Not really no. [No] No. Most of the most of the blokes. Thanks love (wife brings him a drink). Most of the ur blokes in the model railway club for inst, for instance, urm they're mainly in the same age group. [Yeah] Some of them some of them more bossy and cheeky than others, you and others aren't. I mean I've got another (NAME) [Mmm] and he models the layout, he does the scenery and I do the hard stuff like rails and electrics and all that sort of stuff, I mean that makes your brain think as well. [Yeah] Because its micro electrics, it's a lot of it is digital now, and and some of the affects you can get with these model railways now is amazing. [Yeah] Sounds, smoke, lights, you know. [Yeah] All this

sort of stuff. An and it's a learning curve because when I started I never thought I'd be doing digital stuff. [No] But I am now. [Yeah] And it's something, I've picked it up from other modellers in the club and they've explained it, and once it's explained you think oh yeah that's easy enough, an you go and have a go yourself. You make a complete hash of it the first time (laughs)! (Interviewer laughs) [Yeah]. But you gradually get used to it.

Interviewer: Yeah. And that's not something that you've found a problem then. [No. No] Picking up new skills and being able to learn things?

Jack: (.) I'm a great one for trying new things I like, you know, getting information and [Yeah] new skills. I mean it's wood work, soft fabrics, urm (.) like urm *what do you call it when you make things with your hands?* You know like kids do.

Interviewer: Modelling? No?

Jack: Well modelling [Yeah] yeah, yeah. *But* urm electrics, **all** this sort of thing, you're doing the scenic work, I mean on our layout, the only bit, well I even the bases have been handmade wood frames and all that. Urm. (.) The track, some of its handmade, some of its board, locomotives and rail, rolling stock, some are **kit's** that you buy and build, (.) which (laughs) I must admit the last one was a bit technical but you get there. [Yeah] Urm and (.) the end result is very satisfying, when you look at it and you see it's it's a moving picture, [Mmm] if you like, that's how I like to look at it. And if you look at the level of the the the rail track here and the scenic work there, it's a whole little world and you decide what happens in it. [Yeah] And you can stop it or start it or change or rebuild it if you don't like it, *you know*. [Yeah] It's a very very **pleasing** thing to do. And the big advantage of that hobby is if it's not going right you can put it down and walk away, it's not like being fishing. (.) If you're not catching anything you're still sat there like a lemon in the pouring rain (laughs)! [Yeah] (Interviewer laughs). You know, and you've got a long walk home when you've nothing to show for it (laughs)! [Yeah] Urr I mean some people have said arr model making that's nothing, but if they tried to do it they they'd find it, you learn so many different skills. Pain painting (.) and you think to yourself painting, what's hard about painting? Well you, sometimes you use oil paints, sometimes you use pastel shades, sometimes you use different. And a combination of all of them, to get a texture that you want. [Yeah] And we've had no formal training in it, it's just as w, as again you pick it up from other people.

Interviewer: Yeah, and trial and error.

Jack: Build yeah.

Interviewer: See what happens. Yeah. So it sounds like you get the chance to be quite creative, [Yeah you do] the chance to be quite technical [Yeah, yeah] as well so learning new skills and how to use the digital. [Yeah] Bits and pieces.

Jack: Yeah. New phrase for you. Digital (laughs).

Interviewer: Digital, yeah (laughs).

Jack: DCC. Urr what, digital command and control they call it. [Right] It's a little chip about that big that you put in them [Right, okay] and it controls everything. It can make them stop, start. Whereas the old style toy railways you'd have one train on a piece of track going round. [Mmm] With this digital you can have as many trains as you was want on the same piece of track. [Yeah] And they'll all go different directions and.

Interviewer: Yeah. So you get to have a lot of control over th.

Jack: A lot of control yeah. It's almost, it's **almost** life like. [Yeah] You know. I mean some of the some of the ones I've seen at at exhibitions nowadays, especially coming from the continent (.) they they have smoke, they have sound, they have lights, it's amazing. Working parts, like a crane, all this sort of stuff you know, lifting up model trains, all this, and all this digital control that's done it. [Yeah] And to make it work you really have to sort of, examine the subject, because the voltages are so low, urm, (.) probably three volts at tops, three volts, which is nothing, it's a lightbulb, a torch bulb. [Yeah] Power. And you're making these enormous light outs work on it. [Yeah] And I really find it, I wouldn't say fascinating because sometimes you really struggle with it and you're trying to read an article that's this is this and this is that and it's all sorts of technical terms, then you've got to go the the library to find out what the technical term is. [Right] You know, because we have our own libraries within the club with all this stuff in it, *you know*. [Oh right, okay. Yeah] Which people have brought in, when they've finished with it they put it in the library. [Yeah. Yeah. Gosh] (.)



And then there's the imagination side of it, you decide where the model is based, you know the area, the sort of countryside, the sort of erm (.) work trains were doing. It might be Cornwall, clay traffic, it might be somewhere up in Scotland pulling logs, [Yeah] tankers, passenger trains. You decide where it is. [Yeah] Or you have a conversation with somebody you're modelling with and between you you decide where it is. And some people actually model ur real locations. [Oh right okay] They have to shrink th the size down. My err I do two two scales as they call it, double O which is the ordinary table top railway. [Yeah] And O gage which my lo, well some of them are that big. [Right] You have to pick them up with both hands. That's what I've got running round the garden. [Okay then] And that's my exhibition layout is O gage. [Yeah] And it's it splits into about six sections and we have to have a car, that car, and the trailer fully loaded. [Mmm] And a box which a box which my missus (laughs) calls her coffin! (Interviewer laughs). Which goes on the roof of the car and I slide the longest section of the layout in there. [Right] It's about 25 foot long and ur. [25 foot?] And 18 inches wide. [Wow] And it all split's down. And you've got the connections and all that to plan between the boards and *this that and the other*. [Yeah] *So*, it hasn't let me down yet. Touch wood! At an exhibition. [Yeah] I mean one, we went to (PLACE) last year and won best in show. [Right. Yeah] I was very **very** pleased with that, very pleased. [Yeah] Cos there's a lot of good modellers at these shows you know. Yeah, we did one in (PLACE) just before Christmas, we do them for charity, just a one day show and we raised 680 pounds for the children's hospice. [Gosh] In one day. [Yeah. That's brilliant] There was more last year but this year there was a bit of competition because it was the (PLACE) (.) something fayre, I forget *what it was*. [Right] So we didn't get as many people coming in. [Yeah. Okay then] But it's it's useful, [Yeah] (.) we can use these models for people to enjoy **and** make money for less fortunate kids, you know.

Interviewer: Yeah. Yeah. So it's got several uses then.

Jack: Yeah well it's got our own pleasure as well, I mean we go and play trains you see (laughs).

Interviewer: (laughs) Good excuse to go and do it isn't it!

Jack: It is yeah!

Interview Transcript – Jack

Interviewer: (.) Okay, urm (.) so are there any advantages to knowing that you've got this diagnosis of mild cognitive impairment?

Jack: (sighs) Only in so much that it's sort of put me mind more at ease, with what's happening. [Yeah] I wouldn't say it's an advantage as such, but it's definitely put me mind at ease that I'm probably not going mad. I'm not gunna, get any worse for a long time. (.) You can live with it. [Yeah] Yeah.

Interviewer: Okay. And are there any disadvantages?

Jack: Disadvantages? Only when you've got to explain to somebody that **has** to know, you feel a little bit, sort of embarrassed more than anything else. [Yeah] You know that you've got to admit that your brains not working as well as you thought it should. [Yeah] And it can be a little bit (.) embarrassing when the person sort of goes *okay yeah*. [Yeah] *You know*.

Interviewer: Has anybody's reactions towards you changed since they've found out?

Jack: Urm (.) no I wouldn't say so. If if anything, it it explains to them why I wasn't doing certain things and I should've been. [Yeah] And I think they just accept it. [Yeah] Plus me age. They think to themselves, once you're over 70 you're going daft anyway (laughs)! No I wouldn't, I I shouldn't say I'm going daft cos you're not going daft, you're just slowing down. [Yeah] And I take it as that. And I'm quite comfortable in slowing down. [Yeah] *You know*, I I've got to the stage where I'll, if I'm going to do something, I'll give it two days of good looking over before I do it (laughs)! [Okay. *Okay*] Decide what I'm going to do first.

Interviewer: *Yeah*. Okay. Urm so we're coming towards the end of the interview.

Jack: Alright (NAME) (someone walks downstairs into the room, then into the kitchen).

Interviewer: (.) Urm and I was just wondering whether there was anything that you think is relevant that we haven't discussed?

Jack: That's a bit difficult because we could discuss so much. [Mmm] So we've. It's all been me so I'm quite pleased with that (laughs)! (Interviewer laughs). [Yeah] No I don't think

there's anything else really urm (.)and I and I've got a date to go, well they will let me know a date to go back to the clinic for a further check, so if anything else was going to happen I'd find out then.

Interviewer: Yeah. Yeah. So you're having regular checks then at the clinic?

Jack: They've (.) how did she phrase it? We will contact you for another assessment. [Yeah] Now I don't know whether that's going to be six months, 12 months, 18 months. [Yeah] I mean they didn't seem too particularly over concerned about it, you know. [No. No] I mean she was on the phone for a while when she gave me the diagnosis over the phone, she said I can't even see a reason to bring you back in to give you a diagnosis, because it's only a mild (.) urm (.) deviation from the norm I suppose you'd call it. [Yeah] Yeah so. [Yeah] I I can't say anything else.

Interviewer: So it doesn't sort of feel like you're just waiting for the next assessment.

Jack: No. No.

Interviewer: What's going to happen.

Jack: I mean until you'd asked me I hadn't even thought of the next (.) assessment. [Yeah. Yeah] Cos I'd forgot (laughs)! (Interviewer laughs). No I hadn't really, it just, it just hadn't crossed my mind because there was no sort of advance notice or anything like that, it was just left, left a bit in the air when they would contact me.

Interviewer: Yeah. And it sounds like because you're not particularly concerned about the memory problems now, that you're not waiting for the next appointment that it's not something that's on your mind. [Well no no] You're just living your life regardless of this diagnosis.

Jack: Yeah just carry on. [Yeah] I'm easily pleased (laughs)!

Interviewer: (laughs) Yeah. And you've got a lot of things to keep you busy as well and keep your mind off.

Jack: I certainly have yes, and a granddaughter now. [Oh right okay] Well she's two now and she's just got to that stage where she's got to be look, well played with and (.) looked after. *Handful*. [Yeah] Lovely little girl but *by heck* she's needs a lot of attention. [Right] You know. That's another one (laughs)!

Interviewer: So (.) memory problems aren't affecting you with your family, [Oh no] with, your role with.

Jack: No I don't think so no. No. And plus the fact that the older members of the family are used to me anyway. [Yeah] (.) It it's mainly (NAME) my wife, she will say to me, did you get such and such, no. Or you've forgotten and that means just means I've got to put me coat back on again and go out! Or re do it. But most times nobody else bothers. [No] I think they're more concerned with me going deaf and I don't hear what they're saying (laughs)! (Interviewer laughs) [Right okay] Oh I forgot to mention that (laughs).

Interviewer: So have you got hearing problems?

Jack: I've got hearing aids but I don't use them very often. [Ok] Because when they did the graph, they said you're going to enjoy this, the girl said, said why he said, these graphs are on exactly the pitch that your wife would talk to you and that's why you can't hear her (laughs)! (Interviewer laughs) [Oh right!] Didn't go down well with with the missus (laughs)!

Interviewer: (laughs) No I imagine not! Okay, urm do you think having hearing problems affects your memory?

Jack: Pardon? (laughs) (Interviewer laughs) (.) No I don't think so.

Interviewer: No. *Okay. Okay*. Have you got any questions for me, or anything else you'd like to share before I turn off the.

Jack: No I don't think so.

Interviewer: Voice recorder?

## Interview Transcript – Jack

Jack: (.) No.

Interviewer: No, okay. Well thank you very much and I'll turn it off then.

## Interview Transcript – Margaret

Interviewer: Okay. Urm so I'd like to talk to you today about your experience of your diagnosis of mild cognitive impairment. Urm and I was just wondering if you could tell me, to start off with, what you think mild cognitive impairment is?

Margaret: (.) *I think* (.) it's ur (.) the way it's affected me is that (.) I'm not remembering, facts from (.) from the present. There's a lot I can remember from the past, and so I'm forgetting names, even though I know the person that I'm talking to so well. And I can start a conversation and **forget** (.) just where the things going, sometimes. [Okay] And um it's very funny because my husband suffers from the same so we tell each other long stories but we can usually fill each other's gaps up! [Oh right ok] But it's very funny when there's somebody else there. [Yeah] So uh it's it's an impairment of of ones previously (.) reasonably bright intellect, it's as simple as that it it's. I used to be able to (.) go off into all sorts of detail (.) even sit exams, and yet here I am now and I'm fumbling about trying to remember words and names. [Yeah] So that's how it works for me.

Interviewer: Yeah. You urm just said a moment ago about impairment of your intellect, so is it affecting more than just your memory, are there other parts that you think it's affecting?

Margaret: Well it causes me to feel quite unhappy sometimes (.) that I've lost that edge that I think I had. You know, that I just feel that I'm a silly old woman sometimes, that I just can't, be as bright and forthcoming as I was. I've got three daughters (.) and, we used to have such lovely conversations, and we still do because they know they can fill in the bits and pieces but (.) I just think sometimes that life's got a bit less (.) urr (.) enjoyable in that sense. [Right, okay] Although they tend to talk about fashion and that things, which I joi don't join in with anyway (Interviewer laughs). They're three lovely girls.

Interviewer: Yeah. Yeah. Urm, so in what ways has it affected you on a day to day basis?

Margaret: On a day to day basis. (.) It hasn't, it hasn't really, no. [Okay] No the days come and go, there's (.) no it hasn't really affected me at all, not that side of things it hasn't. No. [Yeah] (..) And there's a constant feeling of being at the end of my life now, I'm very aware that I'm 77, and that (.) ur I've got to really enjoy every single moment of what's left, cos I'm, ha, happily married and I've got a lovely family, just keep thinking I'm going to have to

## Interview Transcript – Margaret

leave them all one of these days, sooner rather than later. **That** comes into my everyday feelings. [Okay] A lot. [Yeah] Quite a lot.

Interviewer: Yeah. So has having this diagnosis of mild cognitive impairment almost emphasised that a little bit or?

Margaret: Well in a sense it was a bit of a relief cos I I already knew that it was that I was suffering from it. [Okay] I'd read a bit about it and I already felt that's where it was going. [Okay] But um (.) so many of my friends (.) and people that I talk to, they're suffering in the same ways so it's become a bit of a joke really (laughs). [Right] *Yeah it has*. So I just tend to accept it, what can you do? [Yeah] I do lots of puzzles and read a lot and that helps.

Interviewer: Yeah (.) so had you heard about mild cognitive impairment. [Yes] before you went to the memory service?

Margaret: Oh yes.

Interviewer: Oh right okay.

Margaret: Yes I have, yes I had heard about it.

Interviewer: Where had you heard about it?

Margaret: Well (.) I suppose (.) from way back in my work and all the rest of it. You know as a (PROFESSION) I knew a lot about, when I visited the elderly I was aware of of what it was and what was going on with them. [Yeah] (.) Yeah so yes I had heard about it, I knew what it *involved*. [Yeah] Just a, just a bit, anxious about how quickly it, it proceeds. [Yeah] And how much worse it can get. (.) And that awful word Alzheimer's *looming up*. [Yeah] *All the time*. Because I had a, my grandmother on my father's side and his sister suffered from Alzheimer's, and I remember how they were and how it affected them.

Interviewer: Yeah. So is that something that's playing on your mind at the moment?

Interview Transcript – Margaret

Margaret: Urm (.) from time to time I remember it and think about it. But I try to avoid thinking about it.

Interviewer: Okay. Yeah (.) how do you manage to avoid thinking about it?

Margaret: Well (.) those sort of thoughts can make you feel quite miserable and so (.) I'm still looking at it, we go out a lot and we, we run a club for old people. [Oh right] A weekly club. [Yeah] And that takes up a lot of the interest in our lives. Urm and several of those ladies, they tend to be all ladies because it's a whist club.

Interviewer: A?

Margaret: A whist, whist drive, sort of a whist drive? You know, haven't you heard of?

Interviewer: No I haven't.

Margaret: The card game whist.

Interviewer: Oh yes, yes I know what you mean now. Yeah. Okay.

Margaret: So we run it as a little whist group, we've been running it for 12 years. [Yeah] And we've seen a lot of our (.) urm members declining over those years and we've lost a few, through death and um (.) but the ones that go are very happy to be there. [Yeah] And enjoy it (.) and we enjoy it too. [Yes] So I suppose that's one way that you're aware that as people get older, they lose that edge, you know that (.) but it doesn't seem to worry them too much we've got two 90 year old. [Oh yeah] Bright 90 year olds (.) [Yeah] So it seems to take people in different ways. I think mines the very gradual way, perhaps, I don't know.

Interviewer: Do you mean the way to d dementia?

Margaret: Yes. Yes. I think so. You can stave it off if you, you know if you keep active and all the rest of it. The newspapers are full of how to avoid it anyway, aren't they? We get lots of urm (.) advice how to avoid dementia.



Interview Transcript – Margaret

Interviewer: Yeah. Do you do any of those things that you've read in the papers?

Margaret: Well yes, you know it's all about diet and exercise, and getting out and about and meeting people and having lots of interests. Yes we do, we do do all those things.

Interviewer: Is that in an active effort to, as you said, stave off dementia or are those things that you would just do anyway?

Margaret: I think they're things we would do anyway aren't they. [Yeah] So yes (.) but you know we were talking about, see this whole (.) what's it called again?

Interviewer: Mild cognitive impairment?

Margaret: Yeah it's not that so much, but what (NAME)'s been doing, this mindfulness. [Oh right] Yes well I try to use that when I start getting these urm feelings and unhappy thoughts. [Yeah] Urr but I don't find that it helps all that much sometimes. You know I try to concentrate on my breathing and all the rest of it, but it works for a few minutes and then it all comes back. Best thing for me is to get in my in my car and go to (PLACE) or somewhere. [Yeah] And talk to everybody. And that gets rid of it.

Interviewer: Yeah. Yeah. So getting out and about?

Margaret: Definitely is it's the best policy for me. [Yeah] And that's why it's so hard for people who are housebound, it must be dreadful.

Interviewer: Yeah (.) so what prompted you to go to the, was it the memory clinic or was it your GP to start with?

Margaret: Yes it was the memory clinic. Because (.) I'd noticed that my memory was getting worse and worse (.) so I asked Dr (NAME), about it and she referred me. [Right] So I've been going for a while. I really enjoyed it.

Interviewer: Yeah. What did you enjoy about going to the memory service?

Margaret: Well, meeting quite a lot of other people with similar problems, that was at the meetings, but chatting to (NAME) when she came, you know that was quite reassuring really. [Yeah] I think um.

Interviewer: (.) Is that the mindfulness group that you went to?

Margaret: Yes we went to 2 or 3 of those. [Okay] Of the mindfulness group. [Yeah] And you know, that was interesting. But I've done a lot of ur meditation in, in my life. [Okay] Urm we did a lot of it in the, um (.) psychology degree that I did. [Yeah] We we tried different varieties of meditation, and then I went to India urm with a little family that I got to know. And had a couple of weeks in an Ashram and learnt the (.) the Indian route (.) with the, you know with the 5 special words and the (.) found that very (.) difficult *really*. I got ill while I was there so (.) after two weeks of living on melon juice it was (.) *anyway* it was a very good experience while it *lasted*. [Yeah] And *I'm trying to think now* (.) the other meditation that everybody did (.) with the Maharaji and the Beetles, what was the one they did? (..) Concentrate on a mantra anyway and keep repeating that. [Okay] So that was helpful, for a while I used to, mediate every, every day, you know, before I went to work, and I found it helpful. [Yeah] But (sigh) (.) I read a couple of books on mindfulness. I just don't seem to be able to get it to work for me very well. [Yeah] (.) The simple things, you see something and you start to concentrate on your breathing and you start, really sort of, focussing (clock chimes) you can get rid of it perhaps urm (.) but for really major things, if they come into your mind, and it just doesn't seem to work *very* well.

Interviewer: (.) Yeah okay. Urm do you, has having mild cognitive impairment affected your ability to do mindfulness do you think or to do meditation, has it impacted on that?

Margaret: Oh no. [No] No it hasn't at all. [Yeah] No *that doesn't work that way at all*. [Okay] I think we tend, I think sometimes we meditate more often than we realise, you can you can perhaps just sit down and look out at the garden and perhaps just drift off into a meditative state you know, (.) so I think we do more of it than we realise. [Yeah] But (.) the anxiety thing, it doesn't seem to work. [Yeah, *okay*] (.) As we're doing this chatting thing (laughs) I'll, I might as well just say that one of the worst things for me is animal cruelty, I can't bear it. And often when you're out and you see a dog perhaps being (.) badly treated and (.) it absolutely gets me (.) and then I try to use the mindfulness thing. If I can't intervene, and

Interview Transcript – Margaret

usually you can't, (.) cos it's across the road from you or something, that's one of the worst things for me.

Interviewer: Yeah. Yeah. So if some things really get to you.

Margaret: Yes very badly.

Interviewer: And you try to use mindfulness and sometimes it helps and sometimes it doesn't.

Margaret: Yeah that's right. Yes. It does.

Interviewer: Yeah (.) okay. So do you remember being told about your diagnosis of mild cognitive impairment?

Margaret: Yes, it was (NAME) that told me. [Okay] Yeah (NAME) told me, the doctor didn't.

Interviewer: No. So you had the assessments at the memory clinic?

Margaret: Yes.

Interviewer: So you had some tests to do.

Margaret: Yes I did. [Yeah] She (.) I was quite amazed at what it showed, because one the major things was that there were four pictures. And you to, look at those pictures and then explain (.) what the people in the picture were doing. I **couldn't do it! I just couldn't do it! I couldn't even remember who was in the pictures!** [Yeah] Except that I ur I recognised was a family and a dog there. [Yeah] So that **amazed** me, that I couldn't do that (.) but I can remember ur lists of words, and I can, I can do that. [Yeah] So that was a **real shock**.

Interviewer: Okay, so did you find out that different parts of your memory were affected or weren't affected?

Margaret: Yes. That's right. Yes definitely, there were bits that *were* and bits that *weren't*.

## Interview Transcript – Margaret

Interviewer: Yeah. Urm what was it like being told that you had this diagnosis?

Margaret: (.) Urm.

Interviewer: If you can remember?

Margaret: It was a little bit, shocking I suppose in a way (.) but just a month ago I was told that I had cancer, so. [Oh gosh] You just think to yourself, which is worse you know. It's all part of old age. It's the old vehicle, you know (.) having problems in its different parts I suppose. [Yeah] So (.) compared with **that** diagnosis, the mild cognitive impairment one, ur wasn't quite in that league.

Interviewer: (.) What do you think the differences are between the two diagnoses, why whys it changed your opinion?

Margaret: Well its urm (.) well its whether it involves lots of treatment and constant visits to the hospital, and feeling that you know (.) definitely on the way to the end now. I suppose with mild cognitive impairment, there were things that you can do, you can read, which I love reading an, and watch (.) dramas on television. (.) It doesn't feel as severe, as Alzheimer's yes it would be. We've got a friend, younger than us, and his wife got it and he's lost her completely. She doesn't know who he is and they were such a happy married, couple. [Yeah] And, terrible grief that has affected him. He's lost her, he feels completely (.) whereas with the diagnosis of cancer then, the chances are that you still retain a lot of your memories you know an (.) and you recognise your family and that stuff, I suppose.

Interviewer: Yeah. I guess it doesn't affect you as a person, what your personality is, [That's right] it doesn't affect you intellect?

Margaret: Yes that's what it is.

Interviewer: You still stay the same person.

Interview Transcript – Margaret

Margaret: You do. [Yeah] Well I think you do, I haven't been there yet quite but I think you do. [Yeah. Yeah] It's just this awful long haul down to (.) old age isn't it and death (.) you sort of think how nice it would be if you could just sort of press a button and say right that's it I'm going, and there's a lot of that of course in, in the press isn't there. [Yeah] When I was, a lot younger I didn't think along these lines. But now I've reached (.) this age (.) I suppose (.) *I think about it quite a lot.*

Interviewer: Mmm (.) yeah. Do you ever speak to your family about this?

Margaret: Urm (.) a little bit but (.) *no* I'm far too busy listening to what they're telling me. But a little bit *I suppose*. My youngest daughters a (PROFESSION) and she and I talk about these things quite a bit.

Interviewer: Okay. Yeah. (.) Urm with your youngest daughter being a (PROFESSION), did she suggest that you should go to your GP about the memory problems?

Margaret: No. No. [No okay] No, she didn't.

Interviewer: Do does your family, so your daughter's, do they know about your memory problems?

Margaret: Yes they do.

Interviewer: Your diagnosis?

Margaret: Yeah. [Yeah, okay] It doesn't seem to make any difference to them at all.

Interviewer: No?

Margaret: Because we we don't dwell on things like that. You know. [Yeah] (.) *We have lots of other interesting things to talk about.*

Interviewer: Yeah, okay. So were they not surprised when you got this diagnosis? Or was it just I've got this diagnosis and that's that and moved on from there?

Margaret: Well the diagnosis of this, its minor isn't it. Its its, you know, I mean the chances are that it's not going to get any worse because (NAME) did a, when I first met her she did a uh the test and then a year later she did the test, and she said if anything it's got slightly better in parts. [Okay] So that was reassuring. So I don't see that diagnosis as really being anything to **worry** about. [Yeah] It's just, it's just something that happens as you get older. [Yeah] And lots and lots of people live with it, and there are all sorts of ways of dealing with it. So no, I don't see it as a, as a major problem.

Interviewer: No, no. Do you know what the urm prognosis is for mild cognitive impairment, so what the outcomes might be in the future?

Margaret: Well no because I haven't had that conversation so I don't know. I'd be quite glad if you'd tell me actually (laughs).

Interviewer: Yeah, I'll tell you what, I'll tell you towards the end [Towards the end] of the interview. [Okay] Yes I will go through. [Yes] I will go through that with you.

Margaret: And how to spot when things are going worse, because I don't think I know that really.

Interviewer: Yeah. So have you been tested twice then by the memory service?

Margaret: Yes. [Okay] Yes and I think they're going to test me again, a year from the last time. [Yeah] I'm hoping they will anyhow.

Interviewer: Yeah. My guess is that you probably are on that waiting list to be reassessed in a year's time.

Margaret: Yes I think so, yes I will be. [Yeah] That's common is it to be tested every year sort of thing?

Interviewer: *Yeah*. So how do you feel about being just put on this waiting list to just be tested every year?

## Interview Transcript – Margaret

Margaret: It's reassuring to know that somebody's keeping an eye on you. [Yeah] It means that you know, at some point you're going to be shown (.) whether you're just as you were or you've you've got worse. [Yeah] So it's sort of an official recognition of where you are.

Interviewer: Yeah. So you don't feel worried about the testing coming up, you know when you get the appointment letter through?

Margaret: No, absolutely not. I quite enjoy it (laughs)! (Interviewer laughs) [Oh okay!] *Yes I do.*

Interviewer: Yeah. And have you spoken to people outside your family, so friends, about this diagnosis of mild cognitive impairment?

Margaret: I've not actually mentioned the diagnosis, just simply, just simply chatted (.) generally about what a pain it is when you can't remember names and (.) especially in our little club, we're always talking about it, but they can all play a good game of whist! (laughs) So you know that are a few there that sort of say oh I can't remember what I was talking about and I'll say well that's just how I am, **we're all the same** you know! And that gets over that, that's fine. It's like a sort of urm supportive little group in that sense. [Yeah] While they're busily playing cards they're telling you all these things that affect them, so that by sharing it it helps a lot. [Oh okay. Yeah] So sharing worries. But we don't use words like mild cognitive impairment. [No] No. We don't use those words.

Interviewer: What words do you use?

Margaret: (.) Just we, I can't remember so and so's name when I meet them, and you know (.) I I went to the shops and I couldn't remember what I'd come for and I go upstairs and I get to the top of the stairs and I can't remember what **on earth it was I came upstairs for**, things like that.

Interviewer: Yeah. So you talk about how it practically affects you. [Yes] In your day to day lives. [Yes] So you know, the things that you forget.

Interview Transcript – Margaret

Margaret: And it so doesn't matter. You make lists more than you used to. Lists are very useful aren't they?

Interviewer: Yeah. So is that something that you do then to help you with your memory problems?

Margaret: Yes, we've got a notice board in the kitchen which tends to have all the bits and pieces on it that we need to remember, an. [Yeah] You know, although I've just been to see what the doctors su (.) what practice my doctor is in and I can't even find that on the board so that must've been thrown away at some point.

Interviewer: *Yeah*. So is there anything else that you do to help with your memory problems?

Margaret: Urm (.) yes I do crosswords. [Yeah] And urm (.) I don't do them because of that, I do them because I enjoy doing them so (.) I don't think I've got too much to worry *about at the moment*, its it is very mild *whatever it is*. [Yeah] I know it's probably going to get worse, but *so what*, you know. There is, there are various things they can do aren't there, aren't there medications, medication that you can take? [Urm] That might help?

Interviewer: Yeah there is for Alzheimer's, yes. [Yes] *Yeah* (.) Urm (.) it won't nes it won't make it better but it can stop it deteriorating as quickly.

Margaret: Yes. And you sort of wonder, at what point, you know you've got Alzheimer's rather than you know a bit of senile dementia, what where is the cut-off *point*.

Interviewer: Yeah, what do you think the cut-off point is?

Margaret: *Well I don't know, I don't know* really. (.) Now that would worry me, that would worry me very much. (.) I'm not sure (.) perhaps there isn't a cut of point, perhaps there's a gradual deterioration, *I don't know*. (.) I'll ask you at the end (laughs).

Interviewer: Urm and what do you think has caused the mild cognitive impairment, do you have an idea of what you think might've caused it?



Interview Transcript – Margaret

Margaret: I think it's just part of getting older. [Yeah] We're all living a lot longer now aren't we? But also the fact that it's in the family as well. [Right] It seems to be in the female side of my father's family I think. [Yeah] Because he was as bright as a button when he went and so was my mum. But it might be the female side, so I'm in direct line aren't I from Granny to Auntie to me. And so I start thinking along those lines. There's a lot being written about it, and I tend to read it if I see it in the, particularly in the newspapers you see, articles about it, I read those (.) but I try not to think about it too much.

Interviewer: Yeah. *Yeah.* (.) *Okay*, and how did you think about yourself before the diagnosis of mild cognitive impairment? How would you have described yourself?

Margaret: Well (.) just quite capable of (.) of remembering facts and (.) holding a decent conversation without having to think now where did I see that or whose name was *that or*. It's harder now to chat with people, especially when you don't know them too well (.) although I'm not doing too badly with you, am I? (laughs).

Interviewer: No, not at all (laughs).

Margaret: No, so it hasn't really made that much difference. (.) *There's so many other things* to worry about.

Interviewer: Yeah. Do you think of yourself any differently now, compared to before you had the diagnosis?

Margaret: (.) Yes I think do. I used to be able to whizz through my life, you know whizz through the housework and go to work, and see the family and now everything slowed down very much. [Yeah] But that might be because there's an underlying depression there too I think. Which, I've got tablets for that, (.) I but think everything's slowed down *so much and* (.) arthritic pain doesn't help either (.) it's the tendon (.) *um.* (.) You're much less efficient at things, even (.) cooking, you know, becomes an absolute (.) burden sometimes, you know, but I've got a husband who enjoys cooking and he's just made 18 pans of marmalade (laughs).

Interviewer: Gosh! (laughs) That will keep you going for a while!

## Interview Transcript – Margaret

Margaret: (laughs) Yes well we give a lot of it away. But he loves doing things like that, that's a great blessing. He's out walking at the moment, he's the same age as me, 77 and he's got a walking friend and he's got a friend he goes to air shows with and, he's very positive, and (.) [Yeah] he makes everything a lot easier. [Okay] Yeah he does.

Interviewer: Yes, so he's quite supportive?

Margaret: **Very** supportive. Yes, he's fantastic. [Yeah] So lucky. And *how long have we been married now* (.) urm, *I think its* 35 years now we've been married. [Yeah, wow] And urm I'm just so lucky to have him. [Yeah] (.) His ears'll be burning!

Interviewer: (laughs) Yeah. Urm, so, do you talk to him about the mild cognitive impairment?

Margaret: Yes, yes, sometimes. But his his way of looking at it is, don't worry about it, it's fine. [Yeah] You know, we'll deal with it, its fine, and that's his way of looking at everything really. [Yeah] He does worry about things like the garden. See I used to love the garden, when we moved here 25 years ago, I had greenhouses full of tomatoes and I had a lovely vegetable garden, and , and now it's it's really hard work to do it, so I've filled it up with shrubs and lawns and trees. [Yeah] There's half an acre out there you haven't seen have you?

Interviewer: No. Gosh.

Margaret: And it's a big garden. We had hens when we came here. [Yeah] And we thought of having a goat (.) and it's all gone now, you know. And you see now our children have those sort of ideas. And *you think to yourself* life goes so quickly so get on with yourself, go do it. Do it while you can. One of them's just, she's got two horses now. [Yeah] And (.) she's filling her life up with animals, she's like me.

Interviewer: Yeah, very much taking after you then on the animal front?

Margaret: Well. Yeah, I think with all three of them they're all very different personalities but (.) I can see me in lots of things that they do. [Yeah] (..) I think that's, I think somebody

who was perhaps alone and didn't have family and friends, they would suffer terribly as they began to lose (.) names and (.) places, but (.) it's it's so different when you've got a fairly full life. [Yeah] They're all coming next Saturday (.) we've got **10** coming for dinner. [Yeah] In this little bungalow! (Interviewer laughs) So we're going to make it easier, cook a few chickens and do a load of oven chips, that'll sort them out (laughs)! [Okay, yeah!] A few trifles, and that will do won't it. [Yeah] But it's lovely that they're all coming, it's it's for (NAME)'s birthday. So (.) see my daughters are in their 50s and I think oh *goodness*! [Yeah] *Can't believe it.* [Yeah] So I'm looking forward to that.

Interviewer: Yeah. Urm so it sounds like being busy and having lots of things to do, keeps you going?

Margaret: It does, [Yeah] it does. And you can switch off as well in other ways, is if you've got a really good book on the go you know you can get into that and stop worrying so much. I'm trying to wade through Wolf Hall at the moment. [Oh right, yeah] Because of the, because it's on the television. [Yeah] And urm it's fairly hard going but I like the way she writes, Hilary Mantel. [Mmm] (.) See I'm remembering things aren't I? There you are you see. Bring up the Bodies is the next one, I've got that as well to read. (.) I suppose really you know when you look at how your children's lives are, and how busy they are and stressed they get (.) we're very lucky at this end of our lives because we can (.) we can enjoy a lot of things that there isn't the time for earlier. I remember being so **rushed** all the time, [Yeah] and you don't have to be **rushed** anymore.

Interviewer: No. Is it quite difficult though adjusting to [It **was**] not being quite so rushed?

Margaret: Ahh when I first retired (.) I I went from somebody who, you know, I felt, was important in life, well not important that's the wrong word (.) capable and (.) and then all of a sudden you wake up one morning and you're just plain old Mrs so and so, OAP. [Yeah] That's I think why we started this group because it was a chance to give back a bit of that. Because in work I I used to be involved with groups. [Yeah] So it was a nice way of giving that back. And there are so many, very lonely old people out there (.) but it's sometimes difficult to get them to join a group, you know. [Yeah] They tend to be (.) you have to really find them, or someone else finds them for you.

Interview Transcript – Margaret

Interviewer: Yeah, yeah I guess if they're quite isolated. [Yes] They won't know what's going on, [No] they won't have the [And they're] the *social contacts*.

Margaret: And they're a bit suspicious about things, not sure they want to be involved with a group. [Yeah] But we've got 18 members, which is quite a lot really.

Interviewer: Yeah. *Yeah*. So it sounds like in the past you, kind of defined yourself by this job, you had responsibilities. [Yes] You had, you had a role, you know, there was meaning wasn't there.

Margaret: Yes and I had the opportunity to go and really help somebody sometimes you know. Just like you're doing now, sitting talking, I used to do a lot of that. Because after a while they'd start to tell you about the things that were really worrying them. [Yeah] And um sometimes you could help a bit, or even just listen, that was the important part of it. [Yeah] And I always felt, you're there to do a (PROFESSION) and (.) and they'd finish up telling you what a, you know, a sad life they were having with their marriages or whatever. (.) *Sometimes you could do something and sometimes you couldn't but you could listen*. I enjoyed that part of the job, I really did. [Yeah] Really enjoyed that. I did miss it, in a way I did miss it. [Yeah] Not as much *now*. (.) The job has changed a lot anyway. [Right] I don't think they go out visiting as much as we did. We used to try and get in about 5 or 6 visits a day. [Yeah] And (.) I suppose all the check, (PROFESSION), the clinics, and the (.) and the paperwork. So it was very busy. [Yeah] (..) [Yeah] So.

Interviewer: (.) Yeah, so it sounds like things changed quite significantly then when you retired.

Margaret: They did, yes.

Interviewer: Um, almost a bit of shock, not to be working anymore.

Margaret: That's right. Yeah.

Interviewer: And then did that change again when you had this diagnosis that, of mild cognitive impairment or did things just stay the same?

Margaret: Just stayed the same. [Yeah] I can't honestly say that I think about it very much. [No] You know, I don't see it as a problem. But then again I haven't gone into what its likely to become in the future, I don't know enough about that part of it (.) urm (.) so I (.) I think the other diagnosis has probably given me more [Yeah] cause for worry, you know. Although they've been very reassuring about that as well so (.) (laughs). [Yeah] (.) No, I'm not worried about not worried about this other thing at all.

Interviewer: No. Okay. So do you think there are any advantages to knowing that you have mild cognitive impairment?

Margaret: (.) Urm. In a way yes. In a way it sort of **helps** to have a diagnosis doesn't it. When things aren't going (.) quite right and you're thinking why on earth can't I remember like used to be able to, it's it's good to have a diagnosis you know where you're going, you know what's happening to you. [Yeah] And, it's a common thing isn't it, so many people, *of my age* have got (.) a bit of it, or a lot of it. [Yeah] So it's not something I'm worried about really.

Interviewer: No. No (.) urm you said earlier that your husband also has some memory difficulties.

Margaret: Yes he does.

Interviewer: Occasionally and you end up finishing each other's stories.

Margaret: (laughs) Yes yes.

Interviewer: Um, does he have a diagnosis?

Margaret: No he hasn't.

Interviewer: No. Okay.

Interview Transcript – Margaret

Margaret: (laughs) The chances of him having one are remote because he's the sort that would say oh no I'm fine.

Interviewer: Yeah. So he wouldn't go to the GP and talk about having memory problems, no.

Margaret: No I don't think he would. And urm I don't know where he is in relation to mine, but I'd say that perhaps mine's worse than his. [Right] You know. (.) I tend to put things in strange places sometimes you know. Because I'm thinking about other things, I'll just put something down, I **loose** things constantly, that's one of the biggest things about it. I can't find things, I spend hours looking for things. [Yeah] And ur so I try to get really tidy. But (.) the trouble with that is I put things away very carefully (laughs). And then I can't remember where I've put. [Yeah] So I've chucked out all my boxes that you can't see into and I've got these plastic boxes now so that I can see right away what's in them. [Yeah] I do a lot of craft. [Right] And urm (.) so I've got wool (.) I could open a shop the amount of wool I've got. And material an. [Yeah] And I make things and that's another lovely part of the week. We have a little sewing club on a Wednesday morning, and, just a very small group but I really enjoy that little group. [Yeah] I think that's one of the answers, just to get out there and join little groups. [Yeah] And I'm, just, get involved *with things*. [Yeah] You know.

Interviewer: Urm (.) are you ever self-conscious that you can't do things as well as maybe you used to be able to do maybe 20 or 30 years ago?

Margaret: Yes, I can't I can't thread needles like I could. And there's a lot of arthritis in my hands that when I knit, I can only knit for so long then I have to give up. So I'm aware of that (.) but (.) not to any great extent. [No] You sort of, you adapt to what you can do. [Yeah] You know I paint as well, I love watercolours so I do those. [Yeah] And urm (.) that's not too difficult, you can hold a paintbrush and you can get on with that. [Yeah] So no, I just find that time is going so quickly, the weeks are just hurtling by. [Yeah] And you feel you want to really cherish every moment really. That's the feeling. [Yeah] (.) And the thought of having to leave family one day, that's fairly horrific as well.

Interviewer: (.) Yeah, so it sounds like there are more pressing things on your mind, other than this [Yeah] diagnosis [Yes] this is only a very small part of your life.

## Interview Transcript – Margaret

Margaret: Yes it's a very minor part. It, because it's not at the level yet. If it got worse, and (.) say I couldn't drive my car that would be a, that would be a big problem because I just love that independence. [Yeah] So ur yes. I jus. As things are, if they would stay as they are, that would be just fine. [Yeah] That would be lovely, I can deal with that, I can live with that.

Interviewer: Yeah, yeah. (.) Urm are there any disadvantages to having this diagnosis of mild cognitive impairment?

Margaret: Well (.) not if you try to put it out of your mind. You just try not to think about it. [Yeah] You just um get on with it. I can do just about everything I want to do and need to do. [Yeah] And (.) so I can't really see any massive disadvantages. [No] You, you can't tell stories about things like you used to be able to, but I mean it's, you know, you go somewhere enjoy a film or you enjoy a play (clock chimes) and you try to recoup back to somebody else and you **can't** because you can't remember the blummin details you know (laughs). [Yeah] Can't remember who was in it and urm, bits of the story aren't always there and (.) so (.) that's how it works. [Yeah] (.) I think really I'm probably, only a very mild case of it you know. The only thing that worries me is what's going to happen (.) down the line, in a years' time. [Yeah] In two years' time, is it going to be very much worse? (.) *I wonder.*

Interviewer: Okay, shall I answer your previous question about what the prognosis is.

Margaret: Yes please I'd like you to do that.

Interviewer: For mild cognitive impairment? Yeah.

Margaret: Thank you.

Interviewer: Urm. So there's no way of definitely being able to say exactly what's going, you know what's going to happen for **you**, urm but research has found that about a third of people stay the same, okay? So urm a third of people that diagnosed there is no change, okay it stays the same for the rest of their lives. Urm about a third of people convert to dementia, okay, so they do go downhill with their memory and they do get a diagnosis of dementia. Urm and then the last third of people urm actually the mild cognitive impairment gets better. And goes away.

Interview Transcript – Margaret

Margaret: Really?

Interviewer: Yeah.

Margaret: Well isn't that wonderful to know. I didn't know that! [Yeah] (.) That's so, so good to know, that it actually goes away.

Interviewer: Yeah, so that's in about a third of cases. [Yes] Yes so it's quite an equal split between people who get better, stay the same and get worse.

Margaret: So what happens if you're if you're actually going down towards dementia and Alzheimer's, what are the sign posts of that?

Interviewer: Urm well to get the diagnosis of mild cognitive impairment, you only have difficulties in one area of thinking, so it sounds like for you its memory problems, okay?

Margaret: Yes.

Interviewer: But it's not really affecting your day to day life. [No] Okay so that is the diagnosis of mild cognitive impairment. But for a diagnosis of dementia it needs to be affecting two areas of your thinking, okay so it might be like memory problems and language problems, okay, so significant word finding problems.

Margaret: **Significant** word finding?

Interviewer: Yeah. And it needs to be affecting you in your day to day life. [Yes] Okay so it needs to be stopping you doing things that you would normally be doing.

Margaret: Like?

Interviewer: Urm like, if you, if you were the cook then, and if you couldn't remember your recipes anymore, you couldn't follow the instructions, urm, that you'd be leaving pans on the hob all the time, things like that. [Yes] Or getting lost in familiar places. [Right, yes] So



## Interview Transcript – Margaret

places that you know really well, actually getting quite lost in those areas. [Yes] Urm, not being able to do the social groups that you do. [Yes] You know, for whatever reason, you know or (.) urm not being able to drive. [Yes] It's those kind of things. [Yes] So it needs to be affecting you in your daily functioning.

Margaret: Yes. And then going onto Alzheimer's, that's?

Interviewer: Well Alzheimer's is a type of dementia.

Margaret: Oh I see of course it is, yes. So you get to the point that you don't recognise people and.

Interviewer: Yeah, some people get to that point, yeah. Urm I think with everybody it's slightly different, you know, the, the, what exactly happens.

Margaret: Yes. Okay. It's such a cruel thing to happen *isn't it*. You sort of feel that, that, mind you my brothers got Motor Neurone Disease, and (.) he's paralysed, he's got to be fed by a tube, he can't speak. But his intellect is fine. [Yeah] You know like Stephen Hawking, he's a typical example. [Yeah] (.) I I think that must be torture when (.) *everybody else*. The longer I live the longer I realise, the more I realise that most of us have got nightmare-ish things going on at some point in the future. It's just part of it. Although some people seem to live, golden lives don't they. [Yeah] Although do you know I think it's all down to attitude as well, if you can sort of say oh right that's happening, so what and go and do something else, you can avoid it. It's **dwelling** on it that's the problem. [Yeah] And that's why I don't dwell on it, I try to, you know (.) avoid it if I can but take any advice. [Yeah] *Is it still switched on?*

Interviewer: *It's still on yes*. Urm, so (laughs)

Margaret: That's the elephant into the room! (laughs).

Interviewer: The voice recorder, yeah (laughs).

Margaret: Oh, dear!

## Interview Transcript – Margaret

Interviewer: Urm so, we, we're coming towards the end of the interview urm I was wondering whether there's anything else that you think might be relevant but that we haven't discussed?

Margaret: Urm (..) well you know you were talking about forgetting where you're going (.) all my life I've found that problem! [Okay] (Interviewer laughs). That I can get lost in a town quite easily (laughs). [Yeah] So (.) I think that's happening now. I can't I can't visualise ur a route and I just wondered if that's something that's part of you anyway?

Interviewer: Have you ever been able to do that very well?

Margaret: Urm no (laughs).

Interviewer: No, well.

Margaret: So there you are that's that isn't it.

Interviewer: Yeah, it needs to be a **change** in your abilities.

Margaret: A **change**, that's right.

Interviewer: Yeah, so if that, if that was totally normal for you and it has been for most of your life then.

Margaret: I don't need to worry about that too much. [No] No and one of, and one of the girls has got exactly the same problem (laughs). [Yeah] (Interviewer laughs). So when she and I go out together it's (.) **who** knows where we'll finish up (laughs)! [Yeah] (Interviewer laughs) (.) Oh that's good that was a thing I wondered about. But I don't think it's getting any worse. He tends to do the driving which is a pity really, my cars only done seven thousand miles. [Yeah] And I some, he likes to drive and that's part of him so that's why I've been beetled off sometimes when he's on one of his treks, like today. [Yeah] Or later on I've got a friend lives round the corner and I'll ring her up, come on (NAME), we're going for a wander. [Yeah] Don't know where we'll finish up! [Yeah] But you know all those things you can do them so long as you can still do those things. [Yeah] *I think* that's the answer isn't it.

## Interview Transcript – Margaret

[Yeah] But thank you, you've made things a lot clearer. [Okay] I'm delighted to know that one in three of us actually gets over this, I can't see it happening, but if, I think I've had mild cognitive impairment all my life (laughs)! (Interviewer laughs) I can memorise facts pretty well, or I used to be able to but. [Yeah] It's part of my personality (laughs) (.) it makes for quite an interesting life. [Yeah, yeah] (.) And also it makes you very compassionate for people who are clearly going through something, you know, I often go to (PLACE) ur (PLACE) market, have a wander round there and I go in that little tea room that's there and, sometimes, the people in there you can tell that they're struggling an. Desperately sorry for them, *you know*. [Yeah] (.) All we can do is just (.) well, kindness is the big thing I think. [Yeah] I love my little group, and even, you know even on Boxing Day they wanted to meet because so many of them are so lonely (.) all I've done is talk about my group haven't I, instead of talking about what this means!

Interviewer: No no that's okay!

Margaret: (laughs) Oh good.

Interviewer: Okay (.) so is there anything else?

Margaret: No [No] there isn't. [Okay] I've found this really helpful. [Okay] Very helpful.

Interviewer: Okay so I'll turn this off now then.

## Interview Transcript – Simon

Interviewer: Okay. So I'd like to talk to you today about when you were told about your diagnosis of mild cognitive impairment. [Yes, yeah] So um I was just wondering if you could say what you think mild cognitive impairment is?

Simon: (.) Well, I'm not really sure, but I think it's to do with urm (.) memory (.) not remembering things. [Yeah] And (.) but you do remember things but (.) not entirely, if a if you understand what I mean. [Right okay] Urm (.) some thing's I forget altogether. [Right] Urm. I don't know how they can come up with **mild** when its, what's the difference? [Yeah] You know mild dose of it or (.) fully blown I don't know.

Interviewer: Yeah. Yeah. So urm, would you say that your problems are mild?

Simon: (.) I would but I don't know whether the wife would. [Right okay] Urm (.) she says it gets on her nerves sometimes when I'm (.) talking about something and I I just go onto something else. [Yeah] Urm (.) but you don't remember, you just don't remember.

Interviewer: Yeah. Yeah. Had you heard about mild cognitive impairment before you came?

Simon: I have yeah.

Interviewer: Oh right okay.

Simon: I have heard of it, yeah.

Interviewer: Where had you heard about it or why?

Simon: I don't know I I picked things up just reading like, I've heard it said. [Right] (.) But I didn't really know what it meant [No] sort of thing, (.) *but now I do mm.*

Interviewer: Yeah. Okay. When were you diagnosed with mild cognitive impairment?

Simon: (.) Just (.) I'd say last month.

Interviewer: Last month?

## Interview Transcript – Simon

Simon: Yeah. [Right] In this very building. [Right okay] Urm what it was, I had a bang on the head (.) in (PLACE) and ur, ur a piece of wood fell off the scaffolding, I was walking under it and this piece of wood fell off and it hit me head. [Right] End on and bounced off me head. Anyway I went to see a few doctors, one in (PLACE), and me own at (PLACE), and urm, next minute I'm sort of here I am, sort of (.) I don't know if that's part of it [Yeah] urm (.) or if if anything happened when this hit me, I dunno.

Interviewer: Yeah. So did you only notice the memory problems after you got hit on the head?

Simon: I think it's got worse.

Interviewer: Worse, okay.

Simon: Yeah. Ur.

Interviewer: (.) Yeah. So what did you come to this memory service expecting?

Simon: (.) I don't really know. [Yeah] I mean obviously I can't see there being a cure or whatever. Just urr, I think it was to help you out, if you're studying. [Yeah] And someone said that I fit the bill. [Yeah] But ur you could interview.

Interviewer: Yeah. Urm so why did you refer yourself to the memory service? Or why do you think the GP referred you?

Simon: Probably because of that bang on the head I had. [Yeah] Because it really did knock me. [Yeah] Urr (.) I went dizzy and sick and all that. And I had x-rays and stuff like that. [Yeah] Urm (.) I don't know, it's just an ongoing sort of thing. [Yeah] For me.

Interviewer: Yeah, okay. And, do you remember who told you that you had this diagnosis?

Simon: (.) *No I don't know. [No] I can't remember her name.*

Interview Transcript – Simon

Interviewer: No, but do you remember being told about it?

Simon: Yes, yeah, yeah.

Interviewer: How did you feel when she told you that you had mild cognitive impairment?

Simon: (.) I thought I hadn't. [Okay] I thought I'm alright like, nothing wrong like. [Yeah] Urm, I still sometimes think that. [Yeah] But when, when I (.) look back on things I do (.) I don't do silly things, but, I don't finish anything off. [Right ok] Urm (.) I lose interest in things which I've never done that before. I've always started a job and finished it. [Yeah] (.) And it's just them sort of things you know, it's (.) it's just strange in a way. [Yeah] I can't seem to concentrate.

Interviewer: Okay. Yeah. So there's a part of you that knows that you have some memory problems and find it difficult to concentrate at times, and there's another part of you that doesn't really think that there's anything wrong, because presumably you're still the same person?

Simon: Yeah.

Interviewer: Yeah, yeah.

Simon: *That's right, yeah.* [Yeah] Strange it is to be honest (laughs).

Interviewer: Yeah? Okay, and (.) what does it mean to be diagnosed with mild cognitive impairment? Has that changed your life at all?

Simon: No, no it's not affected me as such. [No] (.) Only like I say, the wife she gets annoyed when I (.) silly things or whatever. When you do something and you don't finish it, *like I say*. It doesn't sort of bother me, I'm easy going.

Interviewer: Yeah. Yeah. So how would you have described yourself before, before you got hit on the head, before you got this diagnosis?

Interview Transcript – Simon

Simon: I just, going about my life. You know urm (.) you know, it's urr (.)

Interviewer: What kind of person were you? *Would you have said that you were?* (.) You said easy going?

Simon: Easy going yeah [Yeah] Got a lot of patience, that's one of my faults I think (laughs). Urm (.) yeah I'm just ur mild mannered an (.) never get aggressive. [No] And I've I've I've had cause to but I never rise to it. [No] No. [Yeah] It's it's, it's the thought of it, really (.) I don't know what damage you can do (indecipherable) you know or whatever, and I'm surprised people still do it, you know always will I suppose. [Yeah] But I urrr it's jus, just me.

Interviewer: Yeah. And has anything changed since having the mild cognitive impairment?

Simon: (.) No, not really.

Interviewer: *No. No.* How would you describe yourself now?

Simon: (...) I don't, cos I sort of feel, there's all sorts of things cos I feel tired all the time an (.) I don't know cos it's hard to, answer that.

Interviewer: Yeah, is the tiredness part of the?

Simon: I don't know, that might be the tablets I'm on. [Right okay] For my diabetes so I'm not sure. [Okay, yeah] There's one tablet I was taking, in the day time and told me doctor and (.) they went through it all and he said start taking that one at night, because that was, well one of the symptoms makes you yawn. [Oh!] And I was forever yawning all the time. [Yeah] (.) Once I yawn I was, yawning all the time. [Yeah] So he said take that one when you go to bed. [Right] Which I said well that makes more sense (laughs).

Interviewer: Yeah. So did that help with the tiredness?

Simon: No. [No, okay] To be honest, no (laughs)!

## Interview Transcript – Simon

Interviewer: Yeah (.) yeah, okay. Urm (.) ur so has being told you have mild cognitive impairment influenced your life?

Simon: (.) (sighs) No it's not stopped me from doing nothing. [No] No (.) uurm (.) I don't think about it really. [Yeah] (.) Urm (.) It's just I don't, it's something that if you're diagnosed with something, obviously it's something that's wrong *with you*. Which, that is a disorder. But it's not affected me really in any sort of bad way. [Yeah] Ur (.) I mean I know where I'm going when I get in the car and stuff, I don't go the wrong way. [No] Anything like that, but urm (.) like you say it's just mild. [Yeah] But will it get any worse?

Interviewer: (.) Is that something that you wonder?

Simon: Yeah.

Interviewer: Whether it's going to get any worse?

Simon: Yeah.

Interviewer: Yeah. Do you have any idea bout urm (.) I guess the prognosis, or what might happen in the future with mild cognitive impairment?

Simon: (sighs) (.) How do you mean? Do you mean tha, any treatment or?

Interviewer: Well treatment, or urm whether it will get worse, or get better, or the same?

Simon: Well I do worry if it gets worse. [Yeah] Urm (.) I wouldn't want to end up like they say a cabbage (.) you need your faculties don't you in life (.) urm (.) *that's* (.) I try not to think about it really. [Okay] Cos you know (*indecipherable*). [Pardon?] Just hope it doesn't go worse. [Yeah] (.) Just plod on.

Interviewer: Is there anything that you do to try and help with the memory problems?

Simon: (..) Only reading and just to keep my mind occupied you know. I don't really watch a lot of television. [No] So I'm always reading or (.) quiz books or things like that. (.) Just try



## Interview Transcript – Simon

and keep yourself occupied you know. [Yeah] Your mind occupied. [Yeah] Cos I like gardening as well.

Interviewer: Okay. Yeah. So, do you think that these things might help with memory problems or?

Simon: Um (..) I dunno, it's hard to say that urm. I mean I don't know the technical names for flowers and things like that, I know some of them but you can't remember them all (laughs). [No] (Interviewer laughs). But I do try to learn. [Yeah] Yeah, yeah.

Interviewer: So do you try and keep your mind active then?

Simon: Yes, oh yeah, yeah. [Yeah] Yeah.

Interviewer: So do you think that that might help or?

Simon: Yeah (..) you know, you can always learn, there's always something to learn. Ur.

Interviewer: Yeah. And do you find that you are still able to learn?

Simon: Yeah I pick things up yeah. [Yeah] (..) I I mean I'm for (..) if that was broke, I'd want to fix it.

Interviewer: Yeah, the hole punch, yeah.

Simon: Yeah, anything if something was broke, I'd take it apart and fix it. [Yeah] Urm (..) and now with havin to wear glasses, it's difficult, you know, cos you've gotta (..) close up for anything that's closer you've got to put glasses on. [Okay] And sometimes I'll put them down, and I'd go somewhere and come back, come back and I can't find my glasses, not that I can't see them, but, I might have put them on pile of tools or something like that. [Right] Or something an (..) it's annoying. You sit down and pick that up and ah my glasses. It's annoying, if, you need your glasses all the time. [Yeah] And I forget, forget sometimes to take em out with me. [Right] Which is annoying as well (laughs). [Right yeah] Yeah.

## Interview Transcript – Simon

Interviewer: How long have you had the glasses for?

Simon: Not long.

Interviewer: No. Cos you've said that you got the glasses, because. [The diabetes] Of diabetes. Yeah, which you were not diagnosed with that long ago.

Simon: No, four years now I think.

Interviewer: Four years.

Simon: Something like that.

Interviewer: Yeah. Yeah, so that's something new.

Simon: Yeah. (.) Before me eyes were great. They're all right now really but, I just need them for close up.

Interviewer: Yeah. So it sounds like maybe there's been several changes then in your life over the past year or so, so including the mild cognitive impairment, but also the diabetes and [Yeah] the glasses.

Simon: And then when I had that piece of wood on my head that was ur sort of knocked me a bit. [Yeah] That's still ongoing, it's with urm the solicitor, and they're waiting to get me, me medical notes. [Right] Urm (.) the scaffolding firm, in (PLACE) they want, some solicitor of theirs wants my notes for some reason. And they're having difficulties getting them. [Right] And my solicitor keeps pushing and pushing but, they say it takes months. [Right okay] *Yeah*.

Interviewer: Yeah. So this is the case because of presumably the head injury that you've had.

Simon: Yeah. [Yeah] Yeah. And all this, all this (.) mild cognitive, you know disorder, that's, I think that's come about because of the bang on me head and they just wanted to make sure, it's not caused anything.

Interview Transcript – Simon

Interviewer: Right, yeah. So have you had a brain scan, as well?

Simon: Yeah. Well a CT scan.

Interviewer: CT scan, yeah. Yeah. Urm and did you find out the results of the CT scan?

Simon: No. [No okay] *Don't know why.*

Interviewer: Yeah (.) So urm, when you were told about the mild cognitive impairment, so that you were having memory problems and concentration problems, urm, did they, did they give you strategies to use or any information about the diagnosis?

Simon: No. *No not really.* [No] No. (.) Nothing to ur, I did a few tests. [Yeah] Paper tests and that was quite difficult [Yeah] to be honest. And then they show me a pattern, well different patterns on a, A4 sheet, and urm (.) but she showed them me and then five minutes after she pushed me a piece of paper, and said I want you to draw what you saw on that paper five minutes ago I I said you're joking (laughs). [Yeah] Anyway, she said oh take your time. Anyway, I got, I remember it's funny in it that you can remember, I can see the lines, I didn't get it all but (.) got most of it. [Yeah] Yeah. And different things like that. Sums. [Right okay] (.) And there was a a (.) there was a sentence (.) and it involved a fire engine, and a house on fire. And you sort of had to relay that back. That was another thing she left for about 10 minutes (laughs). She read it out to me and said I want you to say what I said. [Yeah] And that was quite difficult. [Yeah] **Even though** she said it a few times. [Right okay] Just couldn't grasp it all.

Interviewer: Yeah. And are these things that you think that you would've done a bit better at [Oh yeah] before, before the head injury?

Simon: Yeah, probably, yeah.

Interviewer: *Yeah* (.) urm (.) so did you, I don't know, did you find out whether there are parts of your memory, that are maybe more affected by the mild cognitive impairment than others? So maybe visual memory, is a bit better or? (.) So hearing things is more difficult, looking at things is easier to remember?

## Interview Transcript – Simon

Simon: (.) Well (.) it's funny that you should say that, this ear, when I talk I can't hear out of this ear, for some reason. [Right] It's li like an echo. [Yeah] Don't know what that is. But not this one. [Right] Urr.

Interviewer: How longs that been happening for?

Simon: For last couple of weeks that's been like that, yeah.

Interviewer: Yeah. So it's quite recent then.

Simon: Yeah (.) (indecipherable). [Pardon?] It's like I'm **falling apart** (laughs).

Interviewer: Right yeah. (.) Like one thing after another?

Simon: Yeah, like an ongoing thing.

Interviewer: Yeah, how how is that you know, one thing after another?

Simon: (.) I just look at it as if it's (.) there's other people worse off (.) you know. (.) Try not to complain really. [Yeah] Cos obviously get things the older you get.

Interviewer: Yeah (.) urm and will you be reassessed by the memory service?

Simon: I don't know. [No] Nobodies said nothing. Like next time I hear (.) it's like a letter through the post, urm to say can you come in for (.) whatever interview or (.) [Yeah] That's, that's more or less the first, unless you go to the doctors with something, makes appointment (.) [Yeah] Or sometimes they'll say ur they'll send you a letter in a couple of weeks (.) [Yeah] (.) *and that's it really.*

Interviewer: Yeah so you're not sure whether or not. [No] You're going to have any more assessments [No] in the future?

Simon: No I don't know.

Interviewer: (.) Okay yeah. And do you talk to your family about your memory problems?

Simon: Well there's only the wife really. [Right] Urm (.) me mother passed away about three years ago (coughs) *got a tickle in me throat* (continues coughing) *about three years ago now* (continues coughing).

Interviewer: Would you like a glass of water?

Simon: Yeah, please.

Interviewer: Okay I'll just pause the tape recorder. (Pauses tape recorder).

Interviewer: (un-pauses tape recorder). Okay so you were saying, urm, that ur with your family that it's just your wife?

Simon: Yeah cos urm (.) we're from (PLACE) originally. [Oh right] And most of, well most of my side stayed there. [Yeah] Urm, her mother came up here (.) and she lives in (PLACE). So she's 86, so she's got **her** health problems, I don't really **talk** to anyone about **mine**. [Yeah] There's only the wife really to say things.

Interviewer: Yeah. Yeah. So do you speak to your wife [Yeah oh yeah] much about your memory problems?

Simon: Urm (.) not particularly about that. [No] No. (.) She never asks so (.) [Okay] Don't say (laughs). There's nothing to say really, you know. [Yeah] Cos she knows that I don't (.) she must know I'm not the same. [Right] Urm (.) because I've always started a job and finished it. [Yeah] And I do all the hard work and don't finish off like, I'll burn the paint off and I'll sand it all down and fill it in and I won't paint it (laughs). [Right. Okay] Things like that, I'll do all the hard work and not finish things off. Strip the walls and won't paper them, I'll line them and everything and not put the final paper on. [Right] It's it's weird (.)

Interviewer: Yeah. How do you feel about that when you realise that you've got half way through a job and.

## Interview Transcript – Simon

Simon: I've just not got the, what's it to carry on and finish it (.) [Yeah] If you like, what's, I don't know what the word is. (.) I want to finish it but I don't (.) I dunno it's just weird. I don't, I got all the tools and everything (.) and I **can** do it, but I don't know why I don't do it.

Interviewer: Yeah. Do you get distracted and then forget about it?

Simon: Yeah (.) if I'd have put two of th, if I'd lined the walls or whatever with paper. [Yeah] And we we were going away on holiday, and then we went away on holiday and then come back to finish it after me holiday, I would have put all the tools away by that time and I wouldn't want to get them out again, and carry on. [Okay] It's just weird it is.

Interviewer: So you wouldn't want to get the tools out?

Simon: No.

Interviewer: Right.

Simon: And she's tired, I mean still got to do it now. [Yeah] (laughs).

Interviewer: And is that quite unusual for you?

Simon: Yeah. Yeah. I've always carried on and finished. Yeah.

Interviewer: Yeah (.) you like to see a job finished?

Simon: Oh yeah, yeah. It's like when I was (PROFESSION), I used to do a job as you find it, leave it. You know, no mess or anything like that. [Mmm] Urm (.) I see some (PROFESSION) and I think ophh terrible. [Yeah] But I I do a job and leave it as I found it, not, just the job that you've done, and everything else is clean. [Yeah] (.) That's how it should be really. [Yeah] Ur I see some of them mixing on the side, on the con, you know on the pavement and then they don't wash it down, then it dries there and it's **awful**. [Yeah, that's true] And I, I do think like that but I wouldn't forget to not do that. [No] I'd always do

Interview Transcript – Simon

that, get a board and mix it on a board, but (.) I just haven't got the (.) I don't know what the word is (.) to carry on and finish a job.

Interviewer: Like the motivation?

Simon: Yeah. Yeah. [Yeah] Yeah I **did** do at one time, I wanted to finish a job, start it finish it. [Yeah] I just (.) I dunno it's weird. [Yeah] Is that this disorder, I don't know.

Interviewer: (.) Yeah what do you think?

Simon: (.) I think it's something, it's jus, I just haven't got the (.) (sighs) *I dunno* (.) I want to do things but I (.) you just **don't** if you know what I mean. It's strange.

Interviewer: Yeah, so it's not forgetting to do the job?

Simon: No.

Interviewer: Or getting distracted? It's [Yeah] but you want to do it. But [Yeah] you physically can't do it?

Simon: I dunno it's just.

Interviewer: You can't start doing it?

Simon: I just want to sit there and (.) you know read a book or something. [Okay] Other than doing the job. [Yeah] And I mean, my doctor did say to me concentrate on one thing, don't start on another job, get that job finished and then start on another job. [Right] Urr but that didn't work (laughs).

Interviewer: Oh didn't it, no.

Simon: No.

Interviewer: So you tried that out then. [Mmm] And what happened?

## Interview Transcript – Simon

Simon: It just didn't work (.) cos, I'd start something else you know urm (.) *I dunno*.

Interviewer: Yeah. So do you have several jobs on the go. [Oh yeah] At the moment in the home?

Simon: Yeah. Yeah.

Interviewer: Yeah. And are any of them nearing being finished?

Simon: *No*. (.) No. Urgh [No] (.) No urrr, no haven't got it. [No] I've got loads to do.

Interviewer: Yeah (.) is that quite overwhelming having so much to do?

Simon: Yeah. Yeah. She said she'd get somebody in to do it. I said no you know I'll do it, I'll do it, well get on with it then you know. (sighs) (.) Like when she's in work all morning I could do something then. I do **my** jobs, I do little jobs urmm, and by that time it's time to go and get her. [Yeah] Urm (.) (sighs).

Interviewer: And so urm, has this only happened since the mild cognitive impairment?

Simon: Yeah, yeah.

Interviewer: Since the bang on the head?

Simon: Yeah. Yeah.

Interviewer: So do you think they're related in some way?

Simon: (.) I don't know to be honest. [Yeah] It was heck of a crack on me head. Weren't a big piece of wood but it was urghh about 8ft 10ft long. [Yeah] One of these struts of these slating, (indecipherable) slater, one of them it was. And there was a bloke on the top of the scaffold and I'm sure he went like that, and aimed it at me cos it hit me **bang** on the head there. [Ouch] **Bounced** off me head. [Yeah] Rolling around the ground, in (PLACE) there



## Interview Transcript – Simon

was a witness there, had blood pouring down me head here. [Yeah] And urm, this witness is one of the (.) security guards, on the camp that we're on. [Right] Urm so he said how can help, be a witness or anything, and he took me to the doctors in (PLACE). [Yeah] Well ever since then it's been sort of urr (.) *I dunno* (.) just been funny (.) (sighs) It's not, I wouldn't say much has changed me. [No] I wouldn't say that, no urm. (..) No I dunno what it's done to me but it's done something but (.) cos it makes you think, if there was a spike on the end of that, it would've stuck in me head. Or if there was a baby in a pram say, at the shop window, or a woman say (.) it would I think it would've ur (.) done more damage. [Mmm] Must have a hard head, literally bounced off my head! You know you get a piece of wood and go like that on the floor. [Yeah] You can hear the wood, it did that on me head.

Interviewer: *Gosh. Yeah.* So nothings particularly changed, your personality hasn't changed or anything like that.

Simon: No.

Interviewer: But you get the sense that something is different?

Simon: Mmm. Yeah.

Interviewer: Something you can't put your finger on?

Simon: That's it yeah. I was just gonna say that, yeah. (.) It's (.) you get these little pains down me head, on top of me head, you think to yourself is that gonna go worse? (.) Which I never had before but.

Interviewer: *Yeah.* Yeah. (.) So it sounds like there's a lot of unanswered questions?

Simon: Mmm well it's still ongoing, might end up in court yet. [Right. Yeah] Well they've admitted liability.

Interviewer: Okay. Yeah (.) *I guess that's good start* (.) Okay, so you don't really speak to your wife [No] about the memory problems?

Interview Transcript – Simon

Simon: No.

Interviewer: It sounds like she does notice though?

Simon: Yeah.

Interviewer: And, you said earlier that urm, she might think that your memory problems are more severe than you think that they are?

Simon: Yeah (.) mmm.

Interviewer: (.) Why do you think that is?

Simon: (.) I just, I mean she doesn't, she must be easy going as well, because urr (.) she'll have a go at me, and then she'll forget about it, if I don't do anything (laughs). [*Right*] So (.) sort of a joint thing. [Yeah] (.) I'll have to, have to start doing things, it's not fair. [Yeah] Cos now we've got a little two year old grandchild, so (.) she's into everything now urm (.) I'll have to start (.) really doing things to be honest. (.) Which I try, but I just haven't got the, get up and go.

Interviewer: Yeah. Yeah (.) Is that related to the being tired more easily than you used to be?

Simon: Could be, yeah it could be [Yeah] *yeah*. (.) I'm always tired like.

Interviewer: Yeah, okay. Do you ever speak to your friends about the mild cognitive impairment or the memory problems?

Simon: No. No.

Interviewer: What do you think that they would say?

Simon: Not a lot (laughs).

Interviewer: No (laughs).

## Interview Transcript – Simon

Simon: Don't bother really. [No] No.

Interviewer: Is there a reason you haven't spoken to them?

Simon: No, no. I'm not ashamed of it or whatever. [No] (.) Just it doesn't really bother me [Yeah] but it might do other people.

Interviewer: What do you mean, it might do other people?

Simon: Well it sometimes someone can tell you something and urr (.) you can say you know you haven't told me that, and then they can say yeah I did. And, cos I've got two boys, two lads, and (.) it happens with them. (.) And I say no you haven't told me, haven't told me and get in an argument then. [Right] But ur (.) Not arguing as such sort a thing, but it's it's, yeah.

Interviewer: Yeah, a bit of a disagreement.

Simon: Yeah.

Interviewer: Yeah. So have you spoken to your two boys about memory problems, or, do they know anything about it?

Simon: No I don't think so, no (.) but they think they think there's something, something not right. [Right] Yeah.

Interviewer: Yeah. What do they, what do they think is not right?

Simon: (.) Well (.) cos I've always done things and carried on and finished them. [Yeah] And now I'm not. Urrm it's just not me really.

Interviewer: Yeah. *Yeah* (.) So they've noticed the subtle changes even though you haven't explicitly told them anything about the mild cognitive impairment?

Simon: Yeah, I don't think I've mentioned that to them.

## Interview Transcript – Simon

Interviewer: No. Is there a reason that you don't [No] don't want to tell them?

Simon: No

Interviewer: (.) Some people maybe don't tell friends and family because they don't want them to worry about them.

Simon: Yeah I, yeah. Well I don't want people to worry anyway but. [Yeah] That might be why. [Yeah] Everyone's got problems and (.) just plod along. [Yeah] (.) As long as I don't go worse *or you know*, end up in (.) in hospital.

Interviewer: Yeah. Why, why do you think, what do you think might happen to make you need to go into hospital?

Simon: Well it's with diabetes as well (.) I've urm, I've collapsed a few times with that, and I've ended up in hospital. [Yeah] Urm (.) just with sugar levels and that. [Yeah] (.) And I think they obviously worry about that.

Interviewer: (.)Yeah. (.) *Yeah*. So maybe you don't want to give them another thing to worry about?

Simon: No, no, no.

Interviewer: Although obviously might not worry about it, I don't know.

Simon: (.) But urr yeah. There was nothing wrong one time from ur, just going out for a quick pint, I hadn't even got to the chippy and apparently I fell on the floor and banged me head. Next minute I woke up in hosp, in ur ambulance. [Really] On the main road. [Yeah] And the wife had gone home, just slightly earlier, well she'd gone to get some chips (indecipherable) and I was gunna meet her at home. I I never got home and she come out looking me for me, and found me in the ambulance.

Interviewer: Right. Yeah, and was that because of the diabetes?

## Interview Transcript – Simon

Simon: Yeah. [Yeah] It's that as well you know that really, everything (.) this mild cognitive thing the diabetes and (.) it's everything gets on top of you, you know.

Interviewer: Yeah (.) Does it, does it worry you at all?

Simon: (.) (sigh) Um (.) no. (.) No. Just got to be accepting like you say but (.) the diabetes does. [Yeah] (.) Cos you've got to manage that haven't you, make sure you eat the right things.

Interviewer: Yeah. Yeah so the diabe, the diabetes has much of an impact on your daily life [Yeah] than the mild cognitive impairment does.

Simon: Yeah. Yeah. Oh yeah.

Interviewer: (.) Okay (.) Urm, are there any advantages to knowing that you've got mild cognitive impairment?

Simon: (.) Mmm. (.) In, in what respect like?

Interviewer: Urm, are there any benefits to knowing and having this diagnosis [No] of mild cognitive impairment? (.) There might not be any, just curious.

Simon: Mm (.) Suppose it puts (.) a word to (.) what's happening, you know, to you. (.) It sort of describing why I'm not doing this and doing that. [Yeah] Urm, yeah [Yeah] (.) cos obviously that that's the, (.) what's it called? Cognitive disorder. [Yeah] And you then you know then that that's what you've got then so (.) you (indecipherable) through it cos that's it.

Interviewer: Yeah. Okay. Are there any disadvantages to knowing that you've got mild cognitive impairment?

Simon: Umm (.) No.

Interviewer: No (.) No downsides to having [No] the diagnosis.

Simon: No. [No] (.) I suppose there's different levels of it (.) *like*, it's mild what I've got. (.) I mean what's someone look like or sound like that's got, a severe case of it. Are they urrr, (.) would they be hospitalised or? *I don't know*. [Yeah. Yeah (.) Urm] Or in a home or whatever. [Yeah] I mean I don't want that to happen to me. If, will mine go (.) worse *or what*?

Interviewer: (.) Yeah (.) Do you spend any time thinking about that?

Simon: No. No, I try not to.

Interviewer: Yeah, yeah okay. (.) I guess we're coming towards the end of the interview, so I was just wondering if you wanted me to answer that question about what happens after a diagnosis of mild cognitive impairment?

Simon: Yeah.

Interviewer: What the, future could look like?

Simon: Yeah. Yeah.

Interviewer: Well I think the thing is that it's uncertain. So, research into people who've got this diagnosis of mild cognitive impairment shows that about a third of people who have the diagnosis stay the same for the rest of their lives. [Right] The impairment doesn't get any worse, doesn't get any better, stays exactly the same. Urm and then another third of people who have the diagnosis, end up having um having dementia, *okay*, converting to dementia. And then the last third of people who have this diagnosis actually get better, *okay*, and the problems go away for whatever reason. [Mhm] Okay (.) Umm so, is that what you were expecting? [Yeah, yeah] Is that what you thought might happen?

Simon: Yeah. Yeah. (.) But, I mean how quick would it progress, or is it different with everybody?

## Interview Transcript – Simon

Interviewer: It's different with everybody. And it might be different because it sounds like your mild cognitive impairment has come from a brain injury, so from having been hit on the head, rather than um another cause.

Simon: Yeah. *Right*.

Interviewer: So the diagnosis, there's not set route that could happen. [Mmm, yeah] *Okay*. Is that more, I dunno, is that urm, I dunno, (.) urgh made things.

Simon: Clearer?

Interviewer: Yeah, clearer?

Simon: Yeah I think so yeah. [Yeah] You've answered everything. [Or has] I don't think there's anything else to (.) sort of add to it.

Interviewer: Yeah, I was just wondering if my explanation, how it how that made you feel? Me explaining about a third of people staying the same, a third of people converting to dementia, and a third of people getting better. How does that make you feel?

Simon: The odds, the odds are not too bad I suppose. Is it a, is it a common thing?

Interviewer: Urm (.) I don't know, I don't know what percentage of people end up with this diagnosis, but (.) I guess it's probably a little bit more common than people realise, because not a lot of people have heard of mild cognitive impairment. But you said that you had before.

Simon: (coughs) *Excuse me*. It's probably because I worked at (PLACE) as a (PROFESSION). [Oh okay] So that's probably where, that might be where I've heard it.

Interviewer: Possibly yeah. (.) Yeah. Did you have sense of what mild cognitive impairment would look like, in a person?

Simon: Urm (.) Can you actually tell if someone's got it by just looking at them?

## Interview Transcript – Simon

Interviewer: *No*. No. I don't mean the way that they look, I mean how somebody.

Simon: How they behave?

Interviewer: How they would behave, yeah. [Urr] Or what they would do? What problems they might have. Did you associate mild cognitive impairment with memory problems?

Simon: No. [No] No. But when I hear something I got, I suppose I shouldn't really, medical book. [Yeah] I shouldn't really because you become a hypochondriac (laughs).

Interviewer: Yeah (laughs) (.) So did you look up [Yeah] mild cognitive impairment?

Simon: Yeah

Interviewer: Yeah. Do you remember what it said in there?

Simon: No. [No] Can't to be honest. [*No, no*] I know I looked it up.

Interviewer: Yeah, was that before or after you got the diagnosis?

Simon: That was before.

Interviewer: Before?

Simon: Yeah. Like I say I was a (PROFESSION), if any, if anyone was going for a scan or whatever and I didn't understand what it was I used to look it up. [Right, okay] And urr, cos a couple of healthcare workers said you're in the wrong job. [Yeah] I should be healthcare.

Interviewer: Yeah. So you're quite curious about different problems people might have and. [Yeah] Yeah. Medical kind of side of things.

Simon: Yeah.



Interview Transcript – Simon

Interviewer: Yeah (.) you didn't think of becoming a.

Simon: No I didn't no (.) No, *it's not a* job I could've done. Mmm.

Interviewer: Okay, so is there anything that we haven't discussed that you feel is relevant?

Simon: (.) Anything we haven't discussed?

Interviewer: Yeah.

Simon: No not really.

Interviewer: No, you think we've pretty much covered?

Simon: Yeah, a whole spectrum of it (.) yeah.

Interviewer: Yeah, okay, well thank you very much.

Simon: Well I hope it helps you.

Interviewer: Yeah.

## Interview Transcript – William

Interviewer: Right. Okay. So I'd like to talk to you today about your diagnosis of mild cognitive impairment, okay. [Right] Urm, so I was just wondering if you can say what you think mild cognitive impairment is.

William: Well, urm (.) it's loss of memory (.) and I suppose loss of concentration levels. [Right] Tha tha that's how I understand it.

Interviewer: Yeah, yeah, okay. And, had you heard about mild cognitive impairment [No] before?

William: I'd never heard of it before. [No] No.

Interviewer: Okay, and can you tell me a little bit about when you were told that you had mild cognitive impairment? Can you remember, *being told*?

William: Ur yes it was in (PLACE), yeah. Urr (.) what do you wanna know?

Interviewer: Urm, so, can you remember the process of the assessment, what you had to do?

William: Oh yeah, it went on for weeks! [Pardon?] It went on for weeks! [On for weeks] Doing all these tests and everything yeah.

Interviewer: Oh right, okay, and why why did you go to (PLACE)?

William: I just found that I couldn't remember things. [Yeah] And I was, as I say my concentration was completely gone. [Yeah] (.) **Completely** gone. [Okay] I love football, but I couldn't sit down and watch a whole match, I just got **bored**.

Interviewer: Right, and that was quite unusual for you?

William: Oh that was yeah, that was **unheard of** (laughs)! [Right] (Interviewer laughs). (indecipherable) glued to the tele. But I I'd just get up and wander round because, like, it **bored** me.

## Interview Transcript – William

Interviewer: Right, okay. And so you went to (PLACE) with memory problems and concentration problems. [Yes] Okay, and then you did lots of assessments, and then urm you did you meet with somebody at the end who told you about the diagnosis?

William: Yes. Yes.

Interviewer: Yeah. And what was that experience like, being told?

William: Actually it was a relief. [Okay] Because I thought it might've been something worse.

Interviewer: Like?

William: **Alzheimer's** or something like that. [Right] But when I was told it was mild cognitive impairment, that, that was a relief. [Okay] Because it's not **that**, well I believe it's not **that** serious. [Yeah] So that re, that was, I didn't think I was going, I found out I wasn't going mental. [Okay] That helped a lot!

Interviewer: Yeah. Okay. And, did they urm explain to you what mild cognitive impairment was?

William: (.) Urm (.) all they said was (.) there's a white matter and grey matter in your brain and my white matter's beginning to atrophy.

Interviewer: It's beginning to atrophy?

William: Yeah. [Right] Which I haven't got a clue what that means but there you go! [Okay] (Interviewer laughs) As far I know atrophy means decaying.

Interviewer: Yeah, it's like urm your brain shrinking.

William: Ah, oh right! [So] So that must be the cause of it, as far as I know.

## Interview Transcript – William

Interviewer: Yeah, okay. Urm, so (.) urm what what does it mean to you to be diagnosed with mild cognitive impairment?

William: (.) Urm (.) it means I've got to be very careful about remembering things and writing things down. [Yeah] And it's **very** frustrating, when you're trying to remember a word or somebodies name, and it just won't come to you. [Yeah] Then six hours later you can be sat here watching the television and the name will pop into your head. And you think what's all that about, it's the name I was trying to think of this morning. [Right] That's, that's annoying that its.

Interviewer: Yeah, yeah. And so what are the kind of problems that you have because of the mild cognitive impairment? Can you give me some examples?

William: Well as I said, me concentrations gone. [Yeah] Urm (.) I love reading. I can read (.) a few pages of a book (.) and then the next day **completely** forgot about what the books about, I just read them again. [Yeah] It might take two or three times for it to sink in that I read it. [Right] And I'll look forward to watching a film on the television. Three quarters of the way through I realise that I've already seen it. [Right] But I didn't, didn't know I'd seen it when it first started. [Yeah] And it's **just the little things like that**. It's very annoying.

Interviewer: Yeah, and how long have you been noticing these problems for?

William: About two years.

Interviewer: Yeah. Okay, and when were you diagnosed, how long ago?

William: Last year.

Interviewer: Last year?

William: Yeah. [Yeah] I'm due for assessment, (.) next month I believe.

Interviewer: Right, okay, so you're going back to (PLACE) [Yes] to be reassessed, yeah. And do you know what that's for?

## Interview Transcript – William

William: No.

Interviewer: No?

William: No.

Interviewer: Um. Is it to see there's been any changes?

William: They might've told me but I don't know.

Interviewer: Not sure.

William: No (.) Sorry (laughs)!

Interviewer: So you're going to turn up and see what happens (laughs)?

William: Yeah going to turn up and see what happens yeah (laughs)!

Interviewer: Right okay. How does that feel, just turning up and seeing what happens?

William: I'm not worried about it! [No] No (.) I've been through major heart surgery, so going there and answering a few questions is nothing. [Right] So. [Yeah, yeah] No it doesn't bother me. I'm not, now I know it's something not serious, I'm not worried, at all.

Interviewer: Something not serious?

William: Its, I don't believe it's serious. [Yeah] From the information they give me it can go, lead to more serious things but I don't think it will so I'm not going to worry about it.

Interviewer: Yeah. Okay. Urm. Yeah, what more serious things do you think that it could lead to?

## Interview Transcript – William

William: Well it's in the package they give me it's early onset, Alzheimer's and all this, and I thought well that's not going to happen to me. (.) So I'm not, **I'm not going to sit here** worrying about it, I know a lot of people would. [Yeah] Well let it get on with it, if it happens it happens. [Yeah] I won't know will I (laughs)!

Interviewer: So you're, you're kind of living your life regardless of this mild cognitive impairment?

William: I try not to let it affect me. [Yeah] But obviously it does. But nothing I can do about that (clock chimes).

Interviewer: Yeah. Yeah. How does it affect you, in what way?

William: Urr (.) a lot of times, (.) cooking. I'll put something in the oven, come and sit down think oh this looks good on television and I completely forget it's in there and it burns to a crisp. [Right, okay] Or I'll make a cup of tea, leave it in the kitchen, and I'll later think god I'm still thirsty. Then I'll go and find I haven't got my cup of tea. Little things like that.

Interviewer: Yeah, yeah. So everyday little tasks. [Yes] Forgetting about them, forgetting to do them, getting distracted, those kind of things.

William: Oh eas, very easily distracted. [Right okay] I never used to be, I used to be focussed on what I did, but now I can, as I said to you earlier, I can be pulled off on a tangent at any time.

Interviewer: Yeah. So even in conversation as well?

William: Oh in conversation definitely, yes. [Yeah] We'll start off talking about one thing and end up talking about something **totally** different, then I'm trying to figure out what we started off talking about and we don't know.

Interviewer: Yeah, yeah, okay. And urm (.) how did you think about yourself before the mild cognitive impairment? Can you describe yourself to me?

## Interview Transcript – William

William: I was more outgoing, (.) confident. [Yeah] Which I'm losing a bit of my confidence now because, of the memory thing. *But* that's about it. Gregarious, how's that for a word!

Interviewer: Okay, gregarious yep (laughs)!

William: (laughs) When you come to type that up you've got to learn to spell it (laughs)! No um I was life and soul of the party, but now I tend to withdraw a bit.

Interviewer: Right, okay. And is that because of the diagnosis, because of the mild cognitive impairment?

William: I think it has yeah because I forget. (.) We'll make arrangements to do something at the weekend, and I'll forget about it and I'll turn up at the pub for a drink, whatever's happening is happening and I'm thinking (.) I don't remember this, whys, why hasn't somebody told me then I find out later that yeah you were invited or whatever. So I tend to, stay back a bit now.

Interviewer: Right, okay. So it has impacted on your confidence then.

William: Oh definitely yeah.

Interviewer: Yeah. Have you spoken to friends or family about the mild cognitive impairment?

William: All my friends know about it. [Right] They all make allowances for me, they're very good like that.

Interviewer: Yeah (.) so when you spoke to your friends about this mild cognitive impairment, did you call it mild cognitive impairment?

William: No, just that I'm losing my memory.

Interviewer: Okay, so you said that you were losing your memory.

Interview Transcript – William

William: Yeah.

Interviewer: Right, okay. And how, what was their reaction?

William: Oh the usual thing, it's your age, things like that you know (.) nothing (.) derogatory or nothing, they all understood. [Yeah] They're a very good bunch. [Yeah] *So yeah*, (.) yeah I've had a lot of support from them.

Interviewer: Yeah, yeah. And, are they worried about you at all or?

William: Urm (.) I wouldn't say worried. If I don't turn up somewhere they tend to phone up find out where I am to see if I'm alright. [Right, okay] And I say oh am I supposed to be out? And they go **yes**. Okay I'll be there in half an hour like, you know.

Interviewer: Yeah (.) so they act as a bit of a prompt for you.

William: Yes.

Interviewer: A bit of a reminder.

William: Yeah, they wouldn't just say oh (NAME)'s not out, leave it, forget it. [No] Well somebody will phone up and say are you alright, you're supposed to be out. That's it like, you know.

Interviewer: Yeah. And do you think they do that because you told them that you've got these memory problems?

William: (.) I should imagine so, yeah.

Interviewer: Yeah (.) so maybe if they didn't know that you had the memory problems.

William: They wouldn't bother. [No] (.) No. Plus, as I said, I've got a heart condition. So if I'm not seen, or heard from for a few days, they worry about that. [Yeah] So I think they group it **all** together, and make sure I'm alright.



## Interview Transcript – William

Interviewer: Yeah. Yeah, so you have the sense that they're looking out for you.

William: Oh yeah! Yeah, even the landlord at my local, will phone up if I'm not out on a Saturday night, they'll phone up, are you alright oh oh I didn't feel like coming out, oh no that's alright as long as you're alright. You know, things like that. [Yeah] (.) So yeah I've got support, I'm happy with that.

Interviewer: Yeah, okay. Urm and (.) have your friends said anything else about the memory problems?

William: Apart from the jokes, no. (laughs)

Interviewer: Okay, so do they do they make jokes to kind of make light of it?

William: Yes. [Yeah] They'll tell me you borrowed a tenner off me last week can I have it back, things like that, you know (laughs)! But it's all, if I got oh did I, I go to give it, they go noo you didn't, only messing around (laughs).

Interviewer: Yeah, yeah so they're quite honest.

William: Oh yeah, (laughs) yeah.

Interviewer: Friends, yeah. Yeah, that you know they aren't going to take advantage.

William: Oh they might **take** the tenner, then give it me back an hour later! [Yeah] You know, they're just messing around. [Yeah] I don't take it in a nasty sense, cos they don't mean it in a nasty sense (clock chimes). [No, no] So, yeah, it's just (.) one of them things in life in it. [Yeah] Nothing I can do about it. Not unless you've got a new brain there in your bag, that would be handy (laughs)!

Interviewer: Yeah (laughs). Urm okay, and what about your family, have you spoken to any.

William: I don't get on well at all with my family. [Okay] (.) I've very little to do with them.

## Interview Transcript – William

Interviewer: Yeah. Okay, they're not aware of?

William: Oh they're aware but (.) I don't see them very often. [Yeah] There was a massive family argument years ago and we've never got on since, so I just just leave it.

Interviewer: Yeah okay. So your friends are your support network [Yes] then rather than your family.

William: Yes.

Interviewer: Yeah, okay. And urm (.) in what other ways has the mild cognitive impairment impacted on your life now?

William: It's hard to say really, cos things always seem about the same even though I might be missing something. But I can't though, there's no one major event or anything like that that's changed. [No] It's just very very small things which change and they're the most annoying ones. [Yeah] But no, there's no (.) no there's no major events or anything like that that's changed as I said, little things.

Interviewer: Yeah, yeah so the little things that you forget to do around the house and those kind of things.

William: Yeah

Interviewer: (.) Yeah, has it impacted in your, on your life in any other kind of way?

William: Only with me confidence.

Interviewer: (.) Yeah, tell me a little bit more about that.

William: I can't play darts anymore. [Right] Cos I just, I stand in front of a dart board with me darts in a league match and I just can't throw them.

## Interview Transcript – William

Interviewer: Why?

William: Cos I don't think I'm going to hit the board. [Okay] And (.) I used to be a reasonably good darts player, but now no, I don't bother now.

Interviewer: No. And how's the mild cognitive impairment had an impact on that, because playing darts, that's, it's not your memory but it seems like it's affected your confidence.

William: No **I** think it is memory.

Interviewer: In more global.

William: Its muscle, muscle memory. [Right, okay] (.) Cos you know where your arms got to be, and everything but I just haven't got the confidence now, because I don't, nothing feels right. Before I'd (indecipherable) the dart, I'd go to throw it, it felt right. Now nothing feels right, so (.) [Right, okay] I put that down to that. [Yeah] Pointing at one's head (laughs).

Interviewer: Urm (laughs) (.) so urm, it's affected your, do you think it's affected then your memory of what your body is supposed to do?

William: In a way yes.

Interviewer: So skills that you've learnt, like playing darts, which you used to be able to do very naturally, I'm guessing. [Yeah] And now it just doesn't feel natural anymore.

William: And driving.

Interviewer: And driving, okay.

William: I got into a car the other week (.) and I sat there and I thought I haven't got a clue what you do with **any** of this. [Right] (.) I had the key in my hand and I thought I don't know what what do I do? [Yeah] And it took me about a good **10 minutes** to figure out, ah got it now and got on alright then. [Yeah] But everything just looked (.) alien. I I didn't know what I was supposed to do with it.

Interviewer: Yeah, and when was the last time that you drove?

William: Urr well I drive, quite a bit actually, well I used to, but I don't drive as much now. [Yeah] (.) But that was very strange, I was sitting in that car not having a **clue** what anything meant. [Yeah] You see the little symbols on the switches, didn't have a clue what they meant. [Yeah] **Didn't have a clue!** (.) **Didn't know** how to start it or anything.

Interviewer: Is this a car that you've driven in the past?

William: Yes, my mates car! [Okay] I I used to drive it **regularly**. [Yeah] If I needed needed a car, I'd ring him up can I borrow your car, yeah come and get it. [Yeah] But no, **didn't haven't a clue**.

Interviewer: Yeah. And how, how did you feel?

William: Frightened (.) [Yeah] I actually felt **frightened**, I thought no I can't do this. And I sat there and had a cigarette and things came back. [Right] Then all of a sudden I knew **exactly** how to drive the car so I was happy then.

Interviewer: Yeah. Yeah. So it was in there?

William: Just some time to come out. (.) [Yeah] And I'm, I've gone lousy with directions. [Okay] (.) Going somewhere I've been a thousand times, sometimes I think am I going the right way? (clock chimes). I don't recognise that bit there. [Yeah] You know, it's places I drive, used to drive to very very often.

Interviewer: Yeah. Yeah, so that, that was, that's quite unlike you then?

William: Oh god yeah I used to be very good at directions. [Yeah] But not anymore no. [No] Everything looks, something, not **all** the time, but sometimes things look, I don't remem, I might've, must've passed it a thousand times and I've never noticed, I think, I don't remember that (.) and that feels a bit weird.

## Interview Transcript – William

Interviewer: Yeah. Yeah. Urm, so (.) urm (.).

William: *Turn it off* (laughs).

Interviewer: Urm. So it sounds like, that maybe, there are several parts of your life that are being affected by the mild cognitive impairment, to a gre greater or lesser. [Yeah] Extent, yeah. So you said about the driving, and the darts. Is there any other kind of areas that it's affecting in your life?

William: Not that I can think of offhand, no.

Interviewer: No, so they're the main areas and. (indecipherable).

William: And I read things and don't remember what I've read and that's about it.

Interviewer: Yeah. Yeah. And how do you feel when urm when you can't do something that previously you.

William: Frustrated, very frustrated. Cos I know I can do it. [Yeah] So it, gets on your nerves. (.) It's like trying to think of somebodies name, you know you know it, it just frustrates you cos you can't remember it. [Yeah] So it's **frustration** more than anything. [Yeah] I have been known to get angry. [Okay] (.) With me (laughs). [Yeah] (.) I feel a right fool because I can't remember somebodies name.

Interviewer: Yeah, can you give me some examples of that?

William: Urr (.) there was somebody I went to school with, and known him for (.) 50 odd years. Met him in town the other day, could **not** for the life of me remember his name. [Yeah] Could **not**! Took me three days to remember his name. I was sitting here and thought **oh! I know who it is now!** And there's a woman who lives at the bottom of the road. (.) I've spoke to her every day since I've lived here for 20 years, and I **haven't** got a clue what her name is. [Yeah] Not now, **haven't** got a clue. I'm not going to ask her. (.) I'm not going to, make a fool of meself going I can't remember your name.

Interview Transcript – William

Interviewer: Right, is that how it would feel then if you were to go and ask her?

William: Oh yeah, I'd feel a, I'd feel a fool. [Yeah] Cos I should be able to remember somebodies name. And I can't so. Like I haven't got a clue what your name is and you told me when you first came in. [Yeah] **Haven't got a clue** (laughs)!

Interviewer: Okay, my name's Sian.

William: Yeah (laughs).

Interviewer: (laughs) Yeah.

William: I think if I just hear it once or twice, cos we spoke on the phone, that that wouldn't register. [Yeah] (.) If I'd known you a few years, I'd know who you were. (.) I'd recognise your face for a start. [Yeah] So that's a good thing. But just hearing a name a couple of times, no haven't got a clue, doesn't stick.

Interviewer: Yeah so it takes a lot more effort to get things to stick.

William: Yes.

Interviewer: *And stay.*

William: You really got to try. [Yeah] You got to make yourself try and remember it.

Interviewer: Yeah. What kinds of things do you do to try and help with your memory problems?

William: Write things down. [Okay] I write everything down. [Yeah] (.) Then being, (.) it's the it's the actual act of writing it down. I can throw the piece of paper away after but after I've written it down, I'll never forget it. [Right, yeah] (.) I can write it down, throw the piece of paper away, it's the act of writing it down makes you remember it. [Right] Does that sound, that sounds stupid really *doesn't it*. But it's true.

## Interview Transcript – William

Interviewer: No, I think it makes sense. Why do you think that is? Why do you think it sticks when you write it down?

William: Because it's a physical thing. [Yeah] It's not, (.) a brain thing, you've written it down. You've **manually** did, done, did it. And it, you remember it better. [Yeah] When you're told something, well **I** don't take that much notice. [Yeah] (.) But if I've read something **I'm alright**.

Interviewer: Yeah. Yeah, so visually your, you find it easier to remember things than if you hear it.

William: Yes. [Yeah] Yeah, definitely.

Interviewer: Yeah, so the, the hearing part, the verbal memory, that's more affected than the visual memory, yeah?

William: Yes, things I hear that in one ear and out the other. [Yeah] Haven't got a clue. [Yeah] (.) And I used to ha, I used to pride myself on having a good memory. [Right] When I was younger. [Yeah] *But no, not anymore.*

Interviewer: Yeah. What kinds of things were you able to remember when you were younger?

William: We used to do, quizzes **every** week (.) and we always used to win because my memory was great. Once I'd read it I'd never forget it, that was it. [Yeah] But now I couldn't do a quiz if you, if you paid me.

Interviewer: Right (.) Yeah, so the general knowledge aspect, is that what you were, you were very good at in the past, yeah?

William: Yeah. I was very good at general knowledge in the past, yeah but not now.

Interviewer: No, so the general knowledge that you've learnt in the past, has kind of (.) disappeared?

## Interview Transcript – William

William: Yeah, the trivia gets filtered out first. [Right] Which as you know quizzes are about trivia. [Yeah] So that's why I'm no good at them anymore. [Right] Get rid of the trivia, I don't need it. That's what me brains saying, **I think I need it**, but.

Interviewer: (.) Yeah, yeah. So do you still go to pub quizzes?

William: No. [No] No.

Interviewer: Is that because of the mild cognitive impairment?

William: It's got something to do with it, yeah. (.) Cos I don't want to sit there and look an idiot, so I don't bother.

Interviewer: Yeah. Yeah, do you, your friends still go to the pub quizzes?

William: Yes. [Right] Yeah they're all asking me to go but no. *I'm not, I'm not going*. [No] (.) Ask me a simple a question and you don't know, you look, feel like a fool don't you. [Right, okay] Well I do *anyway so*.

Interviewer: Is that because of how good you used to be?

William: Yeah. (.) Yes. (.) I think it is yeah. (.) It's all very (.) things don't always make sense (.) *that sounds* bad. I think it's because I can't associate it with something else. (.) It's something that's there by itself. (.) [Right] If I had something in my memory that I could associate it with, I'd be alright, but now, now and again things just don't make sense. [Yeah] It's a it's a stand-alone thing. [Right] It's not associated with any other part of my life. But it ur **it might've been**. [Yeah] But now it doesn't mean a thing so. (.) *I'm going to get locked up* (laughs).

Interviewer: *No. No.* (William laughs). Do you, do you then, worry then about what people think about you?



## Interview Transcript – William

William: Ur. (.) When I first started getting it, yes I do, did. [Okay] Now I'm not too bothered [Right]. I'm a bit worried what strangers think. (.) But when I'm with my friends they **know** what I'm like, so they don't take any notice. [Yeah] Which is good. [Yeah] It's when you're with strangers and (.) are there any, if you're doing something official and you can't remember your date of birth, and they all look at you daft like you know.

Interviewer: Right, okay. Yeah. So little things like that. [Yeah] Not being able to remember your date of birth. Yeah.

William: It'll come back to me you know, in a couple of hours but that's no good then (laughs).

Interviewer: Yeah. Yeah, so do you ever avoid going to places where you might be put on the spot [Yes] with questions like that?

William: Yes.

Interviewer: Yeah. How do you get round it?

William: Urr, any way I can (.) I don't apply for things and so I I'm not going to get questioned by anybody so I just don't bother. [Right. Yeah] I was a witness to an accident (.) but I wouldn't say I'd be a witness cos I know damn well I couldn't remember half of what I'd seen. [Right] (.) But when the police, somebody had given them my name, they come round I couldn't just couldn't remember a thing. Ur it was only a young policeman, and he was looking at me, I don, don't think I believe you. [Right] You know, but I knew I couldn't remember it, and he was thinking no I think you're *covering something up* you know. [Oh right, okay] I didn't like that.

Interviewer: No, no. Did you, did you tell the police about the [Yes] mild cognitive impairment?

William: Yes, the Sargent who came with him, an older gentleman, he (indecipherable) straight away (clicks his fingers). [Oh okay] But the young one he was bit *ohh I dunno*. [Yeah] But the Sargent, if you can't remember you can't remember, as simple as that.

Interview Transcript – William

Interviewer: Yeah. Yeah. So did you actually tell the police then that you have memory difficulties?

William: Yeah. Yeah.

Interviewer: Okay, and did you tell them you have a diagnosis, or?

William: Yes, I showed him the letter.

Interviewer: Oh did you?

William: Yeah.

Interviewer: Oh right, okay.

William: I keep that just in case.

Interviewer: Right. Do you find that letter helpful then in explaining your problems?

William: Yes, it's better than me trying to explain it. [Right] I say, you read that, and everybody knows then.

Interviewer: Yeah, so urm what does the letter say?

William: (.) I'll tell you the truth, I've not got a clue. (Goes to find the letter) (...) (Passes Interviewer the letter).

Interviewer: Oh right okay, thank you. (.) Okay, so information then from the Alzheimer's society about mild cognitive impairment. And, some information on how to improve your memory.

William: (.) And the diagnosis is in there as well I believe

Interview Transcript – William

Interviewer: (.) *No I don't*. No I don't think it is.

William: (...) Nope cos it's still here (laughs).

Interviewer: Right, okay so this is the letter then.

William: Yeah this is what I got from (PLACE) yeah.

Interviewer: Okay. Do you mind me reading this?

William: Oh god no!

Interviewer: Are you sure, okay. (...) Okay then, yeah. So the letter just says that urm that you met with (NAME).

William: That's her name yeah.

Interviewer: And, you talked about how you have got some difficulties with your attention and your delayed memory.

William: That's what I wanted to, I've got to ask her about that. [Right] What is delayed memory? [Right] Cos I don't know what **delayed** memory means. [Okay] So next time I see her.

Interviewer: What, what do you think it?

William: I don't know, [No] if you can't remember something, you can't delay it and remember it later. [Yeah] But I don't know, don't know what she meant by that phrase delayed memory.

Interviewer: Right, okay, yeah. Yeah so that's something worth asking when you see her soon. Urm and (clock chimes) she's written that you've got mild cognitive impairment urm and that she's enclosed some information. So have you had a look through the information? No, okay. Why is that?

William: (sighs) (.) Ur (..) I think I'm a bit scared about what I read in case, I start off thinking worse things. [Right. Yeah] (.) So she's told me what it is and I'm quite happy to leave it at that. [Yeah] (.) I know that sounds strange. But if I start reading that about Alzheimer's and **I know** I will start worrying then, [Yeah] because it's in writing.

Interviewer: Yeah. Does it worry you, or how do you feel about it, the information that you're given being from the Alzheimer's society?

William: I was a bit worried at first. Then I realised, that they are the obvious people to give the information.

Interviewer: Why?

William: Cos they (.) **deal** with this sort of thing all the time. [Yeah] And mild cognitive impairment, to me, is a stage **down** from Alzheimer's. (.) So I I if I read that I'm a bit worried in case they might say well in five years you're going to get Alzheimer's. [Yeah] That's why, that's why I've never read it.

Interviewer: And what if it doesn't say that?

William: (.) I don't know. [Yeah] I honestly don't know. But I won't read it just in case it does say it.

Interviewer: So to protect yourself [Yes] you're not going to read it, but it's there just in case you [Yes] ever want it, you've obviously kept this letter in a safe place, to be able to refer to it if you.

William: I I give it to other people so it [Yeah] explains to them.

Interviewer: Yeah. So who else have you given this letter to? Or shown it to?

William: Oh all all sorts of people, the council, things like that, you know.

## Interview Transcript – William

Interviewer: The council?

William: Yeah.

Interviewer: How, how come the council?

William: Urm. (.) I went through a stage where I was forgetting to pay my rent. [Okay] And they thought ohhh he's not paying rent we'll take him to court and all this. [Yeah] I showed them that and they went ohh right right. That letter must account for something and they were very very good then. [*Right okay*] Once they seen that they went right we can work with you.

Interviewer: Okay. So they recognised it as a as a difficulty that [Yes] you had and made exceptions for you?

William: They actually called it a disability. [Right] **I** don't call it a disability, but they did. [Okay] (.) Which made life a lot easier. [Yeah] Once I showed them that, I mean obviously if you're not paying rent they're going to wonder why. [Yeah] So I said look I keep on forgetting, showed them the letter, oh great, we know what to do now, we can work with it. [Yeah] So, it's brilliant.

Interviewer: Yeah. Okay, so in that sense it's been quite helpful to have the diagnosis in the letter.

William: **Yes! Yes!** Cos if you say to someone oh I can't remember, they think oh yeah course you can, but if you can show them there's a **reason** why you can't remember (.) they understand more.

Interviewer: Yeah. Yeah, so it helps with other peoples understanding [Yeah] of what you're experiencing as well.

William: Yeah. Changes their whole outlook on you.

Interviewer: Yeah. And do you think it, was it the diagnosis, so having this term mild cognitive impairment that made a difference?

## Interview Transcript – William

William: Yes.

Interviewer: Or just having the assessment?

William: I think having a diagnosis made the difference.

Interviewer: Yeah (.) Yeah. Cos I'm wondering what would've ha, what do you think would've happened if you'd have turned up with a letter that just said that you've got some difficulties with attention and delayed memory but we're not going to give you a diagnosis?

William: I don't think they would've taken any notice. [Okay] (.) It's like pull yourself together when you're depressed, you know it's one of them things. [Right] **We** know you can't do it. [Yeah] But everybody says yeah you've got to do it. [Yeah] **But when it's got a name** (.) people could go, oh it's real, it's got a name.

Interviewer: Okay. Yeah, so just having a label for it, having a name for it [Yes] makes it real in other people's eyes.

William: Yeah.

Interviewer: So that they're able to understand a bit better, and?

William: **Yes**, they can see, th th **there is** something wrong. [Yeah] You're not just making it up, **there is** something wrong. [Yeah] It's a medical condition. (.) [Yeah] So that makes it a lot easier.

Interviewer: Yeah. Yeah. Okay, urm and (.) they, you said that they called it a disability.

William: Yeah the council did yeah.

Interviewer: Yeah, urm, but you wouldn't call it a disability?

William: No. [No] No.

Interviewer: What do you think the difference is in the council's perception and your perception of, of it being a disability?

William: Well I am disabled, because of me heart and lungs. Which is a **physical** thing, (.) me hearts had it, me lungs are completely gone, so, that could be seen. (.) That can't be seen. It's not a disability it's a, it's a condition. [Right] (.) Does that make sense?

Interviewer: Yeah. *Yeah*. Okay, so the fact that you can't see this mild cognitive impairment, that (.) urm (.) that means, that makes it different to you, to the heart and the lungs, problems?

William: I can understand how people with severe mental illness (.) get ignored. Because nobody can see it. [Yeah] (.) You can't see inside your brain and see what's going on. So I sympathise with people who are really mentally ill. They're all, you're fine hurry up you know, I can understand that, they don't know what's going on.

Interviewer: Yeah, yeah cos you look normal.

William: Exactly. [Yeah] Yeah. So that's why I don't think of it as a disability. [Okay. Yeah] It's just something I've got. And it's only **mild** so. (.) [Yeah, yeah, okay] Is there a next stage from mild? [Urm] Getting worse (laughs)?

Interviewer: Maybe that's something we could talk through at the end [Yeah] if you want to find out a little bit more about.

William: I'd I'd love to know yeah.

Interviewer: Yeah. I guess probably what I'll be telling you is probably in the Alzheimer's society information (laughs).

William: Yeah but I'd sooner hear it from you (laughs)!

Interviewer: *Okay* (laughs). Yeah. Okay. Is there something different then to hearing it from somebody compared to reading it?

## Interview Transcript – William

William: If you read it it's real isn't it.

Interviewer: Okay. (.) Whereas if you speak about it?

William: I can think oh it's only her opinion, *it doesn't matter*. [Okay. Yeah] I know, it's just the way I deal with things.

Interviewer: Yeah. (.) *No that's fine*.

William: I I I'm mental, I can't help it (laughs)!

Interviewer: Everybody deals with things in different ways.

William: You've got to, you've got to have your own way of dealing with things.

Interviewer: Yeah. Okay, and urm so I think you've probably already covered this a little bit, but, urm, what are the advantages of knowing that you have mild cognitive impairment?

William: Well apart from having a name for it, which you can tell people what it is, there's not really any more advantages. [Okay. Yeah] (.) You can prove, by the name, a label as you said which I agree with, that it, I've got it. But that's that's the only advantage. [Yeah] People will (.) tend to treat you slightly differently when they can see, what it is. That's the only advantage.

Interviewer: Yeah. Treat you differently?

William: In a good way. [Okay] They understand more.

Interviewer: Yeah. Yeah so you're experience has been that people have been more understanding.

William: Yes definitely.



## Interview Transcript – William

Interviewer: Because you've been able to show them that you've got this [Yes] diagnosis. Okay. And are there any disadvantages to knowing that you've got mild cognitive impairment?

William: Urm (.) from my point of view? [Yeah] Well apart from the forgetting and the concentration, no. [No] No I'm not going to worry about it.

Interviewer: Yeah. Yeah, are there any disadvantages to knowing that you've got the diagnosis of mild cognitive impairment?

William: (.) I wouldn't say it's a disadvantage, only thing is I'm worried that it's going to get worse. [Yeah] Cos I can't see it getting better. So that's the only disadvantage of it getting worse. I'm a bit, **very** worried about that. [Yeah] (.) But no I can't, I can't see any disadvantages really.

Interviewer: Yeah, okay. So we're coming to the end of the interview, would you like me to tell you what the outcome is of mild cognitive impairment, kind of what happens in the future?

William: I'd like to know, yes.

Interviewer: Yeah. Can I just quickly ask what you think might happen in the future?

William: Urm. I'm hoping things will stay the same (.) and I can live with this. But I'm scared of it getting worse. [Yeah, yeah] I know people with Alzheimer's, I've seen what it's like, it's not nice, and I don't want it. [Yeah] (.) I don't think I'd be able to cope with it. But that's that's it.

Interviewer: Okay. So urm, and I'm probably just going to be saying what's in the information sheet (William laughs) because I have read that. So, research has shown us that people have this diagnosis of mild cognitive impairment, that about one in three people, so about a third of people who have the diagnosis, will stay the same. Okay so it won't change. Okay. And that'll be the same for the rest of their lives, okay. [Yeah] And then the next third

## Interview Transcript – William

of people, will end up deteriorating into dementia, and will have some form of dementia, okay. And the last third of people will actually get better.

William: **Oh!** Excellent, I want to be in the last third then!

Interviewer: (laughs) Okay so actually, with this diagnosis, we can't say what will happen in the future. [No] Okay, so it may get better, it may stay the same, urm and things may get worse. So, yeah it's quite uncertain really, the future of it, what could happen.

William: It must be a (.) very difficult thing for a psychologist to try and figure out (.) cos as you say, things are so uncertain. [Yeah] It's not like having a cold, you can have some pills and it's gone. [Yeah] This, you know, this is not one of them things.

Interviewer: No, no, exactly, and there isn't a tablet that you can take.

William: Exactly.

Interviewer: There isn't one thing that you can do [No] that will necessarily make things better. So it is, it is difficult.

William: I I should imagine it must be. And the one thing, there's one phrase which **has** worried me since I've been told, is about this, *grey or white matter*, one of them, atrophying. [Right] Now to me if something atrophy's, it's going to carry on atrophying. (.) Cos it's breaking down, going and in the end it's going to stop working. [Yeah] That's my, how I understand the word atrophy. [Yeah] I could be **totally wrong**. But that's how I understand it.

Interviewer: Urm. (.) Well I don't know the answer to that (William laughs). But, urm there is research to show that people can have, can be. That people have looked at peoples brains when they've passed away, and they've had a lot of atrophy, but they've not presented as having any difficulties in their lives.

William: Does it matter where the atrophying is, in the brain?

Interviewer: Urm, I'd imagine that probably would [Yeah] have an impact on it, but.

## Interview Transcript – William

William: That that sounds sensible to me.

Interviewer: Yeah. Cos different parts of the brain do different things.

William: Exactly.

Interviewer: But people can have global atrophy, so atrophy that affects the whole brain, and it doesn't necessarily mean that people are going to have problems in their day to day life.

William: Uh, well case in point, people who smoke for 60 years never get anything wrong with them. [Yeah] Exactly the same thing isn't it.

Interviewer: Yeah, exactly. That just because there are these changes in the brain, it doesn't mean that definitely that things are going to get worse.

William: Well that's what I'm, hoping for. [Yeah] Cos I don't I don't want dementia (.) *you know, I'm still young.* (laughs) (.) No. We'll see how it goes anyway.

Interviewer: Yeah. Yeah. Okay so is there anything that we haven't discussed today that think is relevant?

William: No I've learnt a lot, than, from what you were saying, thank you.

Interviewer: Okay (laughs).

William: I've picked up little things you've said. [Right] I've come together and made sense of things I've been thinking about so, that has helped.

Interviewer: So what are the bits that you've found useful from what I've said?

William: What you've explained now about the third, third, third. I didn't know, I thought once you've got it that was it. [Yeah] End of story. That, **that** makes me feel better now. I

## Interview Transcript – William

could be in that third that get better, great. [Yeah] You, you've said a lot which, made me feel a lot better about it.

Interviewer: Right. Okay. Yes, so it's the bit that we've just spoken about, the bit towards the end?

William: And you've got, you've got a way (.) of getting rid of the stigma an all. [Right] Because now I feel, you feel like you're the only one this is happening to. [Right] And you've told me it's common so. I feel better now. [Yeah, yeah, okay] I suppose with any mental thing, you think you're the only one. [Yeah] (.) Cos it's **your brain**.

Interviewer: Yeah. Does it surprise you then that this isn't uncommon?

William: Yes, I am quite surprised yeah. [Yeah] I didn't think, well I didn't think it was (.) non-existent, I knew it happened, I didn't think as much as what you said. [Right] Which has made me feel a lot better. That there are thousands of people out there that are exactly the same as me, that that makes me feel better.

Interviewer: Yeah. I mean I don't know the exact numbers.

William: Oh no! It doesn't matter about the numbers! But there's a lot.

Interviewer: It probably says in this letter (laughs).

William: (laughs) I'll pluck up the courage and read it one day.

Interviewer: Oh here we go (reads from information sheet) 'different studies suggest that between five and 20 percent of older people have mild cognitive impairment of some form at any one time'. Yeah, so about, well between five and 20 percent of the population (.) well of older people will develop mild cognitive impairment.

William: Well I don't consider myself an older people.

Interviewer: No that's true, yeah you're a bit younger.

## Interview Transcript – William

William: I was 62, so I'm not **old**. [No] I still act like a fool (laughs) when I go out I still have a good laugh. [Yeah] Well I, when you say old people you think of people with Zimmer frames and things like that, you know. [Yeah] I suppose I am an old person to some people. (.) [Yeah] If you're 15, I'm an old person, *you know*. (.) It's all relative really.

Interviewer: Yeah. Yeah. Okay.

William: No, I'm quite happy. [Okay] And I hope I've been of some use to you.

Interviewer: Yes, yes thank you very much for taking part in the interview.

William: Oh you're welcome, if it helps other people. That's great yeah.

Interviewer: Okay, have you got anything else that you'd like to say or any questions for me?

William: No cos as I say, I've got an assessment next month. [Yeah] I can talk things over with (NAME), [Yeah] now that you've reminded me of her name (laughs) so urr. It was, she, she contacted me on your behalf.

Interviewer: Yes, yeah, she would've done yeah.

William: So yeah I'm quite happy to help you, if I have helped, I might've talked a load of rubbish, I don't know!

Interviewer: No you have been very helpful, thank you. I'll turn this off then.