

Interview 4, “Mary”

Date: 25.3.2019, Duration: 90 mins; Setting: participant’s home

I = Interviewer, P = Participant

I: Ok, so can you erm tell me a bit more about your caring situation?

P: Erm, I care for an uncle who has vascular dementia who is, he’s in his own home, he was in hospital for six months erm he lost his son due to a massive stroke who used to be his carer, so when he died we sort of took over the caring role. I mean the role we were involved with in before you know not to sort of we agreed we are sort kind of involved with him now erm he was in [Hospital 00:33.1] for six months erm then he got erm sort of like released into the community, there was a bit of confusion about whether he could actually make decisions in sort of like living on his own and there was a wee bit of err controversy shall we say because erm two doctors said that he couldn’t make erm decisions and then erm it was then, you know so he could make his decisions so he wanted to go home which was fine, good enough. We had to erm renovate his house because it wasn’t suitable for him to live in erm he was a hoarder so you couldn’t get in for, for stuff erm so we had erm let to [Name1, 1:17.0] do that, we had to put in erm sort of like a new erm shower room because he couldn’t get into the bath, we had to basically renovate the whole house before he could actually move in. He moved in in August 2018 with a package of four carers a day. We erm found very quickly that that wasn’t enough, so we sort of had to top up the care erm if not every day, every second day we would be down, sort of like maybe once a day, sometimes maybe twice a day erm depending on like how he was, sometimes we’ve had to go erm in during the night if he’s called to us say you know that’s he’s feeling unwell or erm anything like that erm, we have had him in hospital erm sort of like different times sort of like check-ups because he’s not been well etc., he’s had erm two hospital stays in for sort of like various things erm it’s been sort of a, it’s been a strange sort of like both physically and mentally because erm you know we’ve got sort of like erm work full time erm, I’ve got my own business which I’ve had to sort of, I mean it’s a lot easier I suppose erm because I do have my own business so I can sort of you know try and move things about to actually go and help him but sometimes you know there’s days when I can’t go down to visit so I’ve had to sort of like speak to him on the phone which I do every day erm sometimes twice, sometimes three time a day, maybe more if you know that’s needed. Erm at weekends we go down erm to sort of like to see him help him, we do, we don’t do all the housework, we have a cleaner in that does the housework for us, we do his shopping, erm we make sure that he’s sort of like ok erm, sort of like that he’s washed and dressed and you know things like that erm it’s just been really, really hard, sort of just going in sort of because sometime you’ll go down and he’s really, really good and other times he’s just very, very sort of disorientated, he thinks he’s somewhere else, he’ll go for wanders, so you lose him, you don’t know where he is and then you’ve got to sort of like try and find out where he is. It’s just been really, really quite hard, so actually I feel as if we’ve had to put our life on hold because if we had gone out anywhere for any reason you know sort of like for an overnight stay or away on holiday, we’ve actually got to try and arrange... so

42 somebody's there just in case you know sort of like something happens outside of the time
 43 when the carers are there.

44 I: So, you talked about topping up the care that he's getting (yes) during the week, what would
 45 you do for him?

46 P: We'd go down, and sort of like give him emotional support, we'll erm go and get erm like his
 47 prescriptions, we'll go and sort of like do shopping whether it be you know sort of like for just
 48 milk and bread or you know sort of like if you have to go to the shops seeing if he's run out of
 49 something or you know sort of like if, if he's got like a doctor's appointment, dentist
 50 appointment, opticians appointment, hospital appointments, you know we've had to sort of
 51 err just so we do, we do that, I mean don't get me wrong, carers are absolutely amazing but
 52 they're not there long enough. I mean they're basically in and out within about within about
 53 20 minutes to half an hour which is not enough time to you know actually sort of attend to all
 54 of his needs, and you know it's just not, it's not enough time. I think sometimes he's really,
 55 really lonely and I mean he's sort of quoted on occasions "I don't want to die alone" I mean
 56 that's actually quite upsetting for sort of like us as a family because you know we can't be
 57 there 24/7, I mean it's impossible to be there for 24/7 and just recently he's been phoning his
 58 neighbours upstairs also in the middle of the night (oh dear) erm which you know is not, it's
 59 not a good idea I mean he phoned about 2/3 weeks ago and he says to me "I've had a stroke"
 60 and I says to him "no you haven't a stroke" I says "you're phoning me you've dialled my
 61 number, you haven't had a stroke" I says "are you not feeling well?" "no I don't feel well" "so
 62 right fair enough, I'll come down" and I mean when we, I think he had actually had a dream
 63 and he actually thought it was real but he he keeps on saying there's men in the house, there's
 64 people in his house and we're not, we're not 100% sure where that's coming from, we don't
 65 know if that's part of the dementia or, or what but he keeps on saying it and he gets frightened
 66 because there's people in his house. So he'll phone and say "there's a man in my house" so
 67 I'll say to him "right go and let me speak to the man then, let me talk..." "no he doesn't want
 68 to talk to you" so I say to him "right well just you tell him that he needs to go out you know
 69 he's not to come into the house he needs to go out" "ok, fine, fair enough" but you know it's
 70 just, it's hard some, sometimes you just need somebody to say well "is this normal?" you know
 71 somebody to say "well is this normal, is this part of the process or you know is there something
 72 else you know sort of going on?"

73 I: Yes, so you said you took over the caring role (yes) from your cousin (cousin, yes) when about
 74 was that?

75 P: OK, erm that was a year past February (ok) a year past February.

76 I: And since then you are the main carer for your uncle?

77 P: Well there's three of us, there's myself, my husband and erm another cousin.

78 I: Another cousin?

79 P: Yes, so erm I mean well erm because I can sort of my husband sort of like works full time as
 80 well, so he, he doesn't sort of like take on as big a role as what I do because obviously sort of
 81 erm I'll go down during the day when, when I have time etc., but I mean it's mostly myself and
 82 erm sort of like the other cousin, but she's just erm, she's just back after being in Australia for

83 six weeks so it's basically been ourselves erm well sort of mostly me for the last six weeks, you
 84 know sort of like looking after him so, yes.

85 I: And how would that work between the three of you, how do you co-ordinate?

86 P: Well usually what erm like today he won't get any visitors so like at hospital I'm going to go in
 87 tomorrow, she'll go in on Wednesday and then I'll go back in again on Thursday, she'll go in
 88 on Friday and then at the weekend we both take a day at the weekend, so she'll go in one day
 89 and then we'll go in the next day, so basically he's got visitors.

90 I: So, you are in close contact (yes) sort of (yes) saying who is doing what (yes)?

91 P: So there's erm another erm, my sister in law, she's stays down South so she's, she came up
 92 erm for sort of like two weeks here and sort of gave us a wee bit of a hand to sort of go and
 93 you know but obviously it's more difficult for her because she's down South so (yes) but you
 94 know obviously we keep in touch with her and she'll sort of like whenever she can she does
 95 come up give us, to give us a hand.

96 I: How far away does your uncle live?

97 P: About half an hour away.

98 I: By car?

99 P: Yes, about 20-25 minutes.

100 I: Ok, how do you personally feel about the care that you provide for your uncle?

101 P: Erm I don't know, I mean I'm quite happy to give him that, I would do, I would do anything for
 102 him because I, I get on really, really well with him and he's lovely, he's really, really nice you
 103 know but I just, just feel sometimes like we have been left on our own just to...because there's
 104 family about like, it's like you know we, "there you go, you know he's home, he's your
 105 responsibility now" you know and I just feel that there should be more erm you know like help
 106 for people who are caring for you know sort of like elderly relatives with you know sort of like
 107 dementia or you know other, other erm. I mean I think there should be a booklet which sort
 108 of says you know if this...these are the people to contact, this is the what you know what you
 109 can do, these are the things that are available to yourself when we left [Hospital 0:09:06.0],
 110 we were told within four weeks there would be erm you know sort of like people come out
 111 and tell us you know sort of like occupational therapists and they'd be erm sort of like a social
 112 worker or a care worker that would come out and it took from the August until the end of
 113 October before anybody got in contact with us.

114 I: Really?

115 P: Mmm and I had to push for that I kept on phoning and saying you know I kept on phoning
 116 social care direct and saying "you know when we, when we, when we left hospital we were
 117 told that you know there would be a place four weeks to you know let them know what help
 118 was available in the community." There was nothing, not a thing and then I found out erm
 119 after talking to friends that were like a care assistant erm she said to me "I was only allocated
 120 to him for a very short time" so I was saying "well why, why were you only allocated to him
 121 for a very short time?" you know and basically I got in contact with VOCAL and they were an
 122 absolutely amazing resource they are just, they're so so good, they have been, especially, I

mean this has been absolutely amazing. She has sort of pointed me in the right direction for everything and she said “well have you done this, have you done that, have you done...?” “no” I mean because I didn’t know what to do, so if there’s a booklet there that you know that sort of said ‘well if you’re caring for somebody with dementia or whatever, these are the resources that are available to yourselves’ which would make life a lot easier and also sort of like people checking in on you to make sure you’re ok, to make sure that you’re coping and I just, I just feel that you know, but when you do have relatives, you just basically left “there you go, get on with it!” You know and that is, it’s horrible, it is because I mean if you’re having a really a day and you didn’t know what to do for them you know you’re just sort of like well what do we do? How can I help them, you know you want to try and help them and you don’t and I mean I’ve been back and forward for some the doctors and because you know we don’t, we don’t know I mean whether he’s ok or not, you know been complaining, he had erm sort of like pains in his arms, he had pains in his legs, you know he wasn’t well so we phoned a doctor, had the doctor out, he had erm cellulitis on his ear on his foot, he had it sort of down below, so had to phone a doctor with regards to that. We’ve actually; and I mean he’s been back and forward to the hospital, he was in between Christmas and New Year because he wasn’t well at all, but I mean the thing is, you know if he’s not well during the night, then you know we get the phone call so you know we’ve got to sort of go down and deal with it which its fine, it’s fair enough you know but I mean that has an impact on sort of like the next working day, you know you’ve still got to get up and you know go to work because people are depending on you so you so you know if you’re up in the middle of the night and you’re having to take him into hospital you know it’s got an impact on work the next again day, its these things, I just feel there’s just not enough help out there for carers who are caring for you know sort of like relatives.

I: You mentioned to me that you have also been caring for your mother (yes) who is living with dementia?

P: Yes she had dementia as well she had it as well, she had it for five years until erm eventually she erm became, she became quite she became very, very aggressive which and I mean we just, we couldn’t do it anymore, my dad got no help whatsoever with erm so I mean there was a family, there was myself and my brother and obviously my husband and his family and when we had to go down at night to give erm my dad a hand, we asked for if somebody could come in and he could and maybe sit with my mum, for maybe like an hour a day or maybe an hour and half a day just to let my dad go out and they said no, that was that, you know so my dad was basically a prisoner in his own house until such times a like when one of us went down to let him out because my mum couldn’t be left on her own I mean she would let people, she would let people into the house so like she moved in, one day my dad erm wasn’t well, he went to the doctors, she was in bed when he left and when he came back she’d actually gone and taken tablets which were in the cupboard so erm we had to phone a doctor and you know I mean she just couldn’t, she couldn’t be left at all, I mean she was very and I mean eventually the last ?? she had, she had erm she had carers and she threatened to throw coffee over them one day and I mean it was just, it got...we had her back and forward, we’d get respite you know we’d be far better maybe a week or so and she’d back and we’d think fine, we’ve had a bit of a rest lets you know sorted out and we had her back five times erm and then eventually

166 the last time we just, we couldn't, I mean my dad was lifting her because eventually she lost
167 the power of her legs and...sorry (crying).

168 I: Its ok.

169 P: And she couldn't do anything for herself and we just, we we, she had to be lift, she had to be
170 lifted or hoisted erm and that was fine when the carers were there because she could be
171 hoisted but after there was only my dad or sort of like myself you know we, we couldn't do it
172 and at this day she needed the toilet and my dad lifted her and took her I mean she was very,
173 I mean she lost a lot of weight and he took her from, he carried her from the living room where
174 she had a bed and the toilet and then he did his back in and then I got a phone call at work to
175 say to him, you know he said to me "can you come", he says "I can't move", he says "mums
176 on the toilet" he says "I'm on the floor I can't move" you know so I mean it took me from I
177 was at work [??] so had to come home and erm right down to my mum and dad which took
178 me about an hour and a bit and in all that time he was, you know sort of like on the floor and
179 she was on the toilet. You know and I just feel that there should be, there should be something
180 there that you know if you're struggling then at least you can get help but a lot of the time it's
181 sort of like sink or swim, get on with it and its really, it's hard, it's hard, it's really, really hard
182 work, you know it's just, it's exhausting more than anything else and you know when I don't
183 think people understand that you know what, what you're actually doing, I mean there's a lot
184 of people worse off than what you know what you are but when you're in that situation,
185 you're in it is you know you just like 'what do I do', you're sort of trying to, you're trying to
186 keep things together but eventually we had to erm make the decision of sending my mother
187 into a care home, which we didn't want to do and it was horrible, it was really, it was just you
188 know you're thinking well why can't she stay at home but we just couldn't cope not even with,
189 not even with the carers and eventually we had to send her to a care home and I remember
190 sort of like a long, long time ago having a conversation with my mum and she said to me never
191 ever put me in a care home and I had to actually and that was horrible (crying) and I didn't
192 want to do but we had to, because we just, we couldn't, we couldn't cope cos I mean she was
193 very violent in that way, she used to hit you or she would try and bite you or whatever and I
194 mean before, before that came along I mean she was a, she was a, she was a very, very quiet
195 person and to see like her, she would put, I mean she would hit the nurses and you know she
196 would just and she would swear at you and things like that and you know that was really hard
197 to see the person that you know, sort of like it wasn't, it wasn't like it wasn't my mum you
198 know it was just, just like as if she'd changed completely and it's horrible, it's a horrible,
199 horrible disease and it actually you know it sort of, it makes you scared and you know are you
200 aware cos you think what you can't do anything you are, I mean they are just sort of they keep
201 coming out with these things and then in some of the things she used to say was like was
202 horrible, I mean like really, really horrible but you knew that you know obviously that wasn't,
203 that wasn't her and I mean she used to, she used to belt you, she used to slap you, you know
204 and I mean you'd have to go with her. She'd say horrible things to you, so you just sort of like
205 try and pull yourself together, go away and then come back, and I think that's why I'm finding
206 it really hard now because when my mum died, it sounds awful but it was like, it was like a
207 relief, you know we knew fine well she was at rest, she wasn't, she wasn't you know like in
208 pain anymore, because I mean sometimes she used to, you used to see her and it was horrible
209 to see her like you know she was just wasting, she was wasting away and I don't think I grieved

for my mum then I think that you know in a way it was like oh well she's at peace you know sort of, she's fine now, it's everything and obviously you know sort of I grieved a bit but I think you know on the whole you it's like sort of she's not in pain anymore she's not how she is and then to be you know sort of like less than a year later you know all of a sudden I'm having to go through it again and I think you know that's, it's brought up lots and lots of like emotions and I think, I think I've actually sort of, I think I'm grieving now sort of like for her but also, I know what's happening and that's frightening I'm just, I'm just finding that really hard because every time that you know you see something happening, you think I know what's happening next and it is is horrible but I mean just you know they don't, they don't under, you know you say to them well you know what, you know what is there any sort of like help is there anything, but you just feel as if you're sort of like, you know get on, show you have to get with that. And I mean he's lovely he's really, really nice, but since December, he's gone downhill a lot you know and he said to me one day "I just want my life to be back to normal, do you think if I go to sleep and I wake up it'll be gone?" you know and how do you, how do you answer that and I said to him, I had a little think so I says "I don't think so" I says "you know it's never" he says "but I don't remember things now" he says, "my head" what did he say? "My heads like a time bomb" and I said to him, "what do you mean by that?" He says "I just feel as if its bubbling" and I says to him "I don't understand what you mean" well he says "well sometimes" he says "I want to say things, but it's just all jumbled and I feel as if it's ready to explode" and I thought Oh, it was sort of quite actually quite like graphic what he, what he was saying, but since December he's gone downhill a lot he went out at the beginning of December and he got lost and he didn't know how to get back and he was missing for two and a half hours and we didn't know where , we didn't know where to look, we didn't you know, what, what to do and anything and eventually he managed to sort of get back, somebody had obviously, sort of recognised him, knew who he was and then brought him back but I mean since then he's gone for a wee wonder and I can't say erm he went across to the bank and drew a large amount of money at the bank erm and then he kept going and as we were coming down he was coming back out of this taxi and we said to him where he's been and you know "I've been here and this is the amount of money that I've taken out" you know so we sort of sat him down and said that "you know please you know you could have been like mugged, you could have you know sort of like somebody could have taken the money from you, if you need money then we will take you to the bank to get money, but you know sort of do not do it on your own again" but I mean he's never, he's never sort of did it since, we just took him there and then and put the money right back in the bank again. We did have, we've got power of attorney now, so what we do is we erm we sort of look after his finances so we'll tell him, you know we'll say to him "right what do you need, right this is it, this is what we're doing" so we both, all the three of us have got a card for his account, so if we do shopping we'll get it on his erm card and then we'll bring it back, show him like his receipts, so we keep sort of like a log book of receipts and all the money that we're sort of like spending and he can see what we're like spending on, on the account erm so I mean we've, we've put that in place, erm we've sort of tried a neighbour upstairs she's not too bad, she'll sort of try and keep an eye on him sort of like with wanders, but one day one of their the cleaner who comes in is a friend of ours, erm he wandered off up the street erm and it was pouring buckets of rain, he just had a pair of slippers on and I searched, he'd gone for a wander up the street but I mean it's just, it's getting to the stage now, where he's not, he's not safe, he's not, he's just not safe at all and he's

255 falling, erm we found him one day when we went down actually he managed to get himself
256 wedged in between the unit and the and erm the wardrobe, we don't know how, we don't
257 know how he got there, really don't know, he doesn't, he can't tell us, can't tell us. I says to
258 him "did you fall, did you get up and stumble, did you black out?" but he can't tell us, he can't
259 tell us what happened so we don't, we don't know and that's, he isn't, he isn't safe in his own
260 house, but he's quite determined that he wants to stay in his own house and obviously you
261 know, we're sort of, sort of from my point of view you know thinking you know, how would I
262 feel if somebody said to me, "well that's it you're going somewhere you're not going back to
263 your own house". I would feel really, really bad so we've sort of tried, you know to sort of
264 facilitate that we will you know keep you in your own house as long as possible as long as it's
265 safe you know, the minute you're not safe then you know obviously we need to sort of try and
266 think about other things so I mean I don't know, I really don't know whether he isn't I mean
267 he's not, he's not safe. Like yesterday when we went up, we got a phone call at 7.30 yesterday
268 morning from the nurses to say that they had found him with a big gash in his head erm they
269 don't know how, how he managed to do that, they don't know whether he's fallen out of bed,
270 whether he's actually got out of bed and sort of like then stumbled and fallen, I don't know if
271 that's when he told me he'd been up on a roof and put a bell on the chimney stack [Carer
272 0:23:46.2] so he said I mean it is, it's just you know but there's nobody to turn round and say
273 well this is what you should do, you know we're, we are sort of thinking, well he didn't want
274 to go anywhere, he doesn't want to go into a care home, he doesn't want to go into sheltered
275 housing you know but he's not, he's not safe anymore so what, what do we do? You know
276 there's all, there's all, there's all these things, you know there should be sort of like somebody
277 there to say "well you know have you thought about like doing A, B, C or maybe you should
278 start off with A then if it doesn't work, then maybe be B or C".

279 I: So, something like a case manager?

280 P: It's just yeah, there's nobody, there's, you speak to the doctor but the doctors don't have the
281 time and that's you know so for appointments so I mean, so if he's in with something there's
282 no, no the doctor can't talk to you, you you know, well I think this or this, but there's nobody
283 there that will say "oh well maybe you could you know speak to so and so and then they'll
284 maybe advise you" I mean we've now gone down the road of actually getting a social worker
285 erm, we pressed for a social worker whereas they you know they're saying "well why do you
286 need a social worker"? I says "well I feel it's got to the stage now where we do need a social
287 worker, we need to sort of like speak to them, so they can advise us you know what to do long
288 term you know" so the wait we have you know on the day that the social worker was supposed
289 to come, that's when he ended up in hospital so we haven't met the social worker yet, but
290 he's been very, very good he's kept in touch and said that you know once he's feeling better
291 then you know he will come and actually have certainly have a meeting with nursing staff and
292 also ourselves and then that way we can sort of try and think of what we're, what we're going
293 to do.

294 I: How does that make you feel?

295 P: Erm I feel, I feel in a way I feel relief but in a way I feel really bad because I'm certainly going
296 against his wishes and I don't, I don't want that (crying). I don't want him to think that we
297 want sort of like 'here you go just go into a care home' and we don't want that, we want him

298 to we want to be you know be as independent as possible but I mean I don't, I, he's not, he's
299 not safe anymore and every night you know sort of like I got when he was in the house, I'd go
300 to my bed at night thinking am I going to get a phone call in the middle of the night, you know
301 is he safe, what happened if he gets up in the middle of the night, what happens if he wanders?
302 It is, it's just you're mental health it's just, you get up in the morning you know and I mean
303 that's the first thing I do in the morning you know sort of like phone him to make sure that
304 you know he's alright and I also care for my dad as well, my dad's 89 but I mean my dad's very
305 fit which you know is a relief because I'm thinking, if he, if he's too ill I don't know how, I don't
306 know how you know how I would do it I don't know how I would look after him you know sort
307 of like and also [Uncle 0:26:47.1] so erm it keeps things you know on an even keel but it's just,
308 it's just really, it's quite hard and I mean you're send, you're sending him into you know sort
309 of like if you do go into a care home you're you know, you're going you see, you see so many
310 things about care homes you know about how they treat people and things like that and then
311 you know you're thinking is he going to be safe you know, is he going you know, are we just
312 sort of taking him from sort of like somewhere he's not safe just now, you know, sending,
313 sending him there you know sort of, I mean the price of care homes is absolutely extortionate
314 you know and I mean we knew that when we sort of put, put my mum in sort of in a care
315 home and it was extortionate. The one she was in was absolutely amazing they were so so
316 good, I mean really, really, really good, erm and they were very, very supportive of you know
317 sort of like us as a family, and they sort of like helped us and they were very good with my
318 mum because I I mean I had a; I was sort of dug my heels in thought that she's not going to a
319 care home, know we will, we will, we will sort of do it, but we got to a stage and we just
320 couldn't do it erm and in the beginning I said to my dad "no, I'm not going, I don't want to go,
321 I'm not, I'm not putting her into a care home" and then afterwards I thought, why did I, why
322 was I like that, why you know, why did I, why was I...? But I just remembered sort of like my
323 mum having this conversation and I'm thinking I'm putting her in there, she has nowhere to
324 go (crying).

325 I: It is a big decision.

326 P: It's horrible, I mean it is it's just because you, you've you know you're just sort of, you're
327 deciding what, what's going to happen like to them and I mean it's not, I mean he is sort of
328 quite adamant that he wants to stay in his own, own house and I mean if he can, stay in his
329 own I mean we would obviously do it but I mean he needs care during the night as well and I
330 mean they don't provide you know sort of that and I think if that is the case then we need to
331 sort of like look down the line or sort of try to get somebody in erm to look after him during
332 the night but I mean this time nurse would have to, like he's got two bedrooms in his house
333 just now but I mean the other bedroom is just sort like a storage area where erm, we, because
334 there is so much stuff that you know, that we didn't obviously want to throw out because it
335 wasn't ours to throw out, but we threw out the stuff that we thought you know wasn't any,
336 any good so I mean so that sort of like a storage area if that's the case in we're going to have
337 to sort of like decorate that bedroom you know sort of try and find places for this stuff that's
338 there you know it's a..you know it's just at this moment in time I just feel my heads just a bit
339 like; I don't know what to do for the best, you know do we just sort of try and get him back
340 into the house and then you know maybe one of us sort of goes down like you know we'll take
341 our turn each night and you know sort of like sleep down here but I mean the thing is that

342 obviously has an impact on like work a few are, working again the next day you know and
 343 you've been up sort of like half the night so you know you've got that as a big impact
 344 (absolutely). It'd be easier that if you didn't you know if you didn't work but you know sort of
 345 like nowadays you've got to sort of like work to survive you know so.

346 I: Can you tell bit more about your work?

347 P: Err I'm a childminder erm so I work full time, so I work sort of like sometimes from erm like
 348 on a Wednesday, Thursday I work from 7.15 to 6.00 erm on Monday I start erm I've got the
 349 morning off erm so I don't start until 2.30, a Tuesday erm I start at 12.00 Wednesday erm I
 350 start at 7.15 and then that's me until 5.30 and then on a Thursday I start at 7.15 and that's
 351 through till 6.00 and a Friday I start at 12.00 and that through until 6.00 on a Friday, so...

352 I: So, you have got fixed times (yes) for you (ah ah) to (yeah) to where do you work exactly?

353 P: I work erm from the house.

354 I: From the house?

355 P: Yes, I work from home ah ha so I work, I work from home.

356 I: OK. But they are fixed times?

357 P: There are fixed times ah ha, out with those times, erm you know sort of like I only did to
 358 basically go down to see [Uncle 0:31:24.9] I can't do it you know, I can't do it, I couldn't do it
 359 I can do it by phone, but I can't actually sort of physically go down to sort of like to see, to see
 360 him.

361 I: Is it possible for you, when you are at work to for example take a break when you need to to
 362 make a phone call?

363 P: Yes, what I would do, what I would do is if I was sort of erm, needed to make to make a phone
 364 call get the children sort of like in here and I would actually you know sort of always keep the
 365 kids in my sight, because obviously you know I got to keep an eye on them so you know if for
 366 any reason I had to make a phone call erm I would erm do it here with the children here.

367 I: And you can have an eye on them?

368 P: Yes, yes, (ok) so I mean it's not, it's not too bad and I mean the times that I'm not working I
 369 can actually you know sort of go in you know sort of see him but I mean there's a couple of
 370 times that I've actually had to sort of like take holidays and just of sort say to parents look I'm
 371 really sorry about this I need to...But actually they're really really good they're quite
 372 understanding as well, because you know obviously they know the situation because I've had
 373 to sort of like tell them erm and they're really, really good erm I've also got a backup
 374 childminder which erm there's two of us like that are erm like work, we don't actually work
 375 together in the same house but you know we'll meet up and we have this erm understanding
 376 that if anything happens then if she's got space then she can, you know sort of like look after
 377 the kids that I've got and vice versa if anything happens then you know like an emergency, we
 378 just, we just do that which is really, really quite good.

379 I: Yes, that's really good. How many kids are you looking after?

380 P: Erm it varies from day to day, it varies from day to day. Like today erm I've got, I had three
 381 this morning, erm well I had two this morning because one of the wee girls was off and this
 382 afternoon I've got three erm tomorrow morning I have erm three in the morning, and then
 383 I've got seven in the afternoon (Seven?) yes because I had to get a variation because one of
 384 the, one of the wee girls that I look after she's been coming here since when she was a baby
 385 and she was nine months and she's three and a bit now, erm she was erm she went down to
 386 nursery; her grandparents were looking after her but they're just finding it you know kind of
 387 a trail back and forward, so I put in for a variation erm so I can actually look after, but just for
 388 a Tuesday, I can actually have her from erm from sort of like 3.00 until 6.00 so I have seven
 389 erm on a Tuesday, on a Wednesday morning I have four in the morning and then I have five
 390 in the evening on a Thursday morning I've got four in the morning and then I have five in the
 391 afternoon and then on a Friday morning I just have one in the morning and then later in the
 392 afternoon I have four (wow) so yeah. I love it, so it's just all. They range I mean the youngest
 393 one I've got is 18 months and the oldest one is eight.

394 I: Eight?

395 P: Yeah, they're actually really, they're really really good, they play together really really well,
 396 they're really really good. One of the, one the children that I look after, he's my grandson, he
 397 actually stays here with us erm that's my youngest daughter and her partner that was so ???
 398 That's her partner and her wee boy they stay with is in the house, so that quite good, he stays
 399 with us in the house, so that's quite good, this is his house but he loves having other kids about
 400 if erm if there's nobody here he'll go "erm why is there nobody here today?" "Well this is a
 401 family day and this is a Saturday or a Sunday" "but I like it when my friends come, I like when
 402 they come to play with me"!

403 I: So sweet, it's so good.

404 P: Yeah it is good, it's actually really good because it keeps you grounded you know sort of like,
 405 when they come in, you know everything else just sort of goes to the you know back, you
 406 know and they, they just keep you going because you know we do sort of like arts and crafts
 407 or go for walks and we lots of things so...

408 I: Keeps you busy?

409 P: So whilst they're about you know you don't think of that, it's when you sort of like oh that's
 410 when you know, they keep you going so I think if I didn't have that I think it would be worse
 411 because you'd sort of sit and think about things, the worse thing about it, it's really really good
 412 it just keeps you, keeps you going.

413 I: So, in case something was to happen you would have to make a phone call for example and it
 414 turns out that your uncle needed help, erm how would you be able to manage that then?

415 P: If I've got kids? If I've got kids erm like depending on how many, how many children sort of
 416 like if I had for instance there was only two and the other childminder had three so then I
 417 would phone her and say "look you there's an emergency, are you ok to sort of like take
 418 them?" I would then phone the parents and and ask them for "are you ok to erm you know
 419 sort of like if we up into erm you know, they know, they know who [Childminder 0:36:19.8]
 420 who is", so they're ok, they're ok with that and it's not, you know she's done it before, erm
 421 there was one time we were on holiday and one of the parents was des- desperately needing

422 sort of like child care so I just said to [Childminder 0:36:33.1] "are you ok for that?" And she
 423 said "yes", so I mean the parents know who she is as well so it was quite good, I've got that,
 424 I've got that back up which is good, but I mean if for any reason she wasn't able to do that
 425 erm and I did have to do that and there was an emergency I would phone the parents and
 426 they would sort of, they've got a thing that they, if there's an emergency they would just sort
 427 of come home. (ok) so we've got that, I mean I've only have to had to do that once when my
 428 mum was really, really poorly and I got called for erm you know I had to sort of like phone the
 429 parents and they were fine with that, they were really really good we, I actually dropped him
 430 off and they were fine they fine or they'd just come up and pick them up depending you know
 431 sort of like what's the quickest so.

432 I: That sounds good, Erm so we talked a lot about support that you receive and so you said
 433 you're receiving support from part of your family, there's some family members that are
 434 helping you, there are some carers that are coming in, erm you get some support from VOCAL
 435 (yes) are there any organisations like VOCAL that are helping out?

436 P: No nothing at all.

437 I: So, what about technology, does technology play a part in, in your support in caring for
 438 example, helping you to care or staying in contact with people?

439 P: Mmm I used like, I use my mobile, I use my mobile, I use my mobile phone a lot (yes) you know
 440 obviously to sort of keep well, whilst, whilst, he' in sort of like hospital just now obviously to
 441 phone on the land line but if I'm going down there you know sort of like for instance he really
 442 sort of quite like uptight erm or something happened I'll keep in touch with them but
 443 obviously like put them on hands free and I'll talk to them whilst I'm on my way down erm
 444 sort of like to, to him, you know I'll tell him, I'll say to him "look I'm down, I'm coming to you
 445 know, it'll only take me like five minutes, it'll take me like 10 minutes you know, just keep calm
 446 you know I'm on my way down" so I use my mobile, I use my mobile phone a lot to erm you
 447 know sort of like keep in, keep in contact with him yeah.

448 I: Erm and how about erm your husband and your cousin who are also caring for your uncle, is
 449 that something that for example the phone that you are using to keep in touch with each
 450 other?

451 P: I, I will, I will phone and we give each other updates erm say for instance like yesterday erm
 452 my husband and I we went up to the hospital to see [Uncle 0:38:56.5] a bit after what had
 453 happened I mean we were going up anyway but you know sort of like we were going up that
 454 wee bit earlier so when we came back after you know sort of like speaking to the nurse etc.,
 455 we then sort of like, we then phone everybody and let them know, you know sort of basically
 456 what's, what's going on (yes) so we do it that way.

457 I: Do you have anything erm like a telecare technology so devices there?

458 P: [Uncle 0:39:21.2] has telecare in his home, he's got one of these erm the bracelets that when
 459 he fell the last time and he managed to get himself, cos I said to him "why didn't you press
 460 the buzzer"?, he says "it wouldn't let me" (ok) and I spoke to like the person there and they
 461 said it wasn't, when we pressed it because he said you know press it but it wasn't picking up
 462 so we got one that was a bit more sensitive (ok) but we also put in the erm the alarm, erm
 463 their movement, no, not the movement erm, I can't remember what it's called, like if he got

464 out of his bed and he wasn't back in his bed within 30 minutes then you know they would
465 actually put like sort of say to him like erm sort of like where are you you ok, etc., etc. and
466 then they put the mat on the floor as well so that's that's after he had the fall, we spoke to
467 them and erm we've got that. They were saying that the erm like the wrist thing should have
468 actually you know picked up he had had a fall but it didn't for some reason so she doesn't
469 know what had happened but we did renew that erm afterwards (ok) they did, they did do
470 that so he has got the tele care sort of like in his house.

471 I: So apart from that one episode where apparently it didn't work what would you say, are you
472 happy with the technology or...?

473 P: Erm yes it's quite, it is it's quite a handy, it is really handy cos at least that way sort of like if
474 anything he presses a buzzer we can you know sort of like say to him you know what is wrong
475 and then you know with like.... but the thing is he doesn't he doesn't do that, you know he
476 automatically just phones us, he will like you know because sort of like erm we've him on his
477 phone, we've got our numbers, so we'll say to him look you know if you need us this is it and
478 we've got our number on the notice board erm so you know, he'll phone us rather than sort
479 of doing...

480 I: So, does he also have a mobile phone?

481 P: He does have a mobile phone, but he doesn't use it.

482 I: He doesn't use it, ok?

483 P: He doesn't use it; it just lies on the shelf! But we thought that would be really quite good
484 because if he did go for a wander at least that way he would have you know sort of like a
485 mobile phone with him and then we could sort of like get in contact with him, but he wouldn't,
486 he wouldn't use it. We did actually erm, there was talk about getting him, you know sort of
487 like erm a like a tracker, a tracker type thing and I can't remember why we didn't get it, there
488 was some reason, reason, why, why we didn't get the tracker, I can't, I can't remember why
489 we didn't say it wasn't available? I can't remember anyway erm when we spoke to the OT at
490 [Hospital 0:41.59] I can't remember anyway they just said that you know sort of, it wasn't
491 viable or something. I can't remember why but we didn't get him a tracker but I mean that
492 day that he went my son I mean that was awful you know and we didn't, we didn't get onto
493 him, we just said to him "look you know you mustn't do that, you know if you're going out
494 phone us and let us know that you are going out", I said "that's fine" I says "we're not saying
495 to you you have to stay in the house but just phone us and tell us that you're going out and
496 where you're going to be and I says and then if you do get lost at least that way we know sort
497 of like try and get you" but he never did this day. He's got a Christmas card and it wasn't his
498 address, so he thought he knew where he was going and then when somebody completely
499 and utterly different. And he didn't know how to get back but that; he did have a car erm and
500 when he was, whilst he was in hospital we, we then found out he we had this conversation
501 with him and he says to me "I used to go and drive in my car but sometimes I don't know how
502 to get back" and I said to him "pardon"? He says, "I don't know how to get back" I says, "well
503 how did you eventually get back"? He says, "just a process of elimination", and I was like Ok
504 fine and I says, "how often is that happened?" "Oh quite a few times" I says "alright, ok, fine"
505 so anyway erm we decided very quickly after that conversation that it wouldn't be safe for

506 him to go out in the car, so that was another so we got a mobility car taken, taken away,
507 because erm yeah.

508 I: How did he react to that?

509 P: He was alright occasionally he sort of said "oh it'd be really, really nice to go and drive", but I
510 mean I've taken him out you know sort of like just for a drive round about, sort of like familiar
511 places but he doesn't have a clue where he is like yesterday it was actually quite frightening,
512 yesterday erm like he said, he says to me "I can't see you", I says "well have you looked in the
513 mirror", yeah but I can't sort of, "so I tell you what else I can do I'll take a picture on my mobile
514 and I'll show you it, is that ok?" "yeah that's fine" so anyway he's sitting there so I took a
515 picture of him and I showed him, and I says, "oh who's that handsome guy?" and he says, "oh
516 I don't know who that is". (oh dear) I says "that's you" "that's not me" I says "yes it is" "yes
517 that's you, look I've got your head" he goes "I don't know who that is" I says "but it's you,
518 that's who you are" but he didn't recognise who he was and I was like "oh", you know but we
519 had the erm doctor erm the now what was it, the memory, memory clinic, the doctor from
520 the memory clinic you know for the elderly and he came in and unbeknown to us he has
521 actually seen him five years ago (mmm) he'd seen him five years ago and erm I couldn't,
522 couldn't actually erm attend that meeting because erm I was but I was busy, I had sort of like
523 kids so my husband took the day off and he went down and erm met with the doctor but erm
524 you know sort of did like obviously sort of like some cognitive test just to try and find out
525 where you know where he was and things like that and he said he has deteriorated more than
526 50% from when he had actually seen him five years ago. And so he said he had actually you
527 know gone downhill, you know I've seen, I've seen a big big difference in him since erm since
528 just before Christmas I mean beforehand you used to be able to have a conversation with him,
529 you had lots of lucid moments or you would have conversations, you would talk to him about
530 erm you know sort of like things that happened sort of like in the past and you know you
531 would sort of just tell him about different things "do you remember when did this, or do you
532 remember when we did that" and he'd go "oh yeah, I remember that" you know but now you
533 didn't you don't get that conversation you know you're just trying to have a conversation with
534 him. Yesterday sort of like when we were talking about erm you know sort of like when we
535 lived at [Place 0:45:52.3] and [Name2 0:45:54.9] says to him do you remember when you
536 stayed in [Place 0:45:57.2] and he's gone "I didn't live at [Place 0:46:01.1]" "yes you did" "you
537 know this is when we stayed in [Place 0:46:05.0]" and "well that's a long time ago" and we
538 says "yeah it is a long time ago you know" but he just, he just didn't have any, any recollection
539 of you know sort of like staying and one day the carer actually did take him to outside to his
540 house to show him because he was in his house and he didn't know, he didn't know he was
541 in his house, he didn't recognise anything at all. And then we didn't, we didn't change anything
542 in the house and we got new carpets but I mean he was sort of like part of that process of you
543 know, we said to him you need to get new carpets because the ones that you've got before
544 are sort of like past their best so we'll get new carpets so he was erm you know part of that
545 process erm I mean everything we did in the house you know we got him to, we showed him
546 what we thought you know "do you want to do this, or do you want to do that or are you ok
547 with that?" "yeah, yeah" he was fine he was fine, he was fine with that and got him new sofa,
548 erm two new sofas so we showed him where, yes he was quite happy with that and he just,
549 he just didn't have you know sort of like a clue just didn't know that was a day he told me he

550 was in a stately home in Blackpool and one of the carers phoned me and says to me "he's
 551 really really confused today", I says "I know" I says "he's phoned me and told me he's in a
 552 stately house in Blackpool" and she says he says "he's not in his house" I says "do you want to
 553 sort of take him outside, like show him the garden and sort of show him the door and maybe
 554 you know sort of?" She says "yeah, I'll try, I'll try that", but it just, but thought he was
 555 somewhere else he's not (mmm) and I mean recently you go down and he's sat in in and I
 556 mean the heat in his house is roasting, he puts it up to 32 degrees and you're absolutely stifling
 557 when you go in, and he's sat there in a dressing gown on and his clothes and I says to him like
 558 "oh my goodness me, it's roasting in here, let us open the door and get some air in" and he
 559 says "oh no, it's cold, I'm really cold" "but how can you be cold" I says "it's up to 32 degrees,
 560 I says "it's really roasting in here" I says "that's not healthy for you" I says "you know that's
 561 what breeds germs you need to even open a wee window then just to get..." but no he used
 562 to just sit there and I mean recently he's refused to do anything and I'm not.. beforehand
 563 he'd make you a cup of coffee like and if you went he'd say to you "do you want a cup of
 564 coffee?" "I'd love a cup of coffee" I says, "are you going to make it?" "yes" I says "well if you're
 565 making it for me so you know so right, just sit down and I'll go and make you a cup of coffee"
 566 so he'd go and make you a cup of coffee and he'd bring you a biscuit, erm but recently, just,
 567 just, just since Christmas time he doesn't do anything at all he just sits in the chair. I used to
 568 take him out on a Friday morning and we used to go to the shops and then we'd go for a
 569 coffee, erm so he just wasn't; we got him into [Place 0:48:47.4], which is you know in the
 570 morning they do like exercises just to sort of obviously to keep them on the move and prove
 571 that they're moving etc. and then in the afternoon they would have a discussion about erm
 572 you know sort of like different things maybe different topics, maybe like politics or something
 573 just to sort of like try and get their memory. So the first day he went and he came home that
 574 night, I went down to find out how he got on and he says to me "I was helping all the patients
 575 today" I says "Helping all the patients, what do you mean?" he says, "Oh I was helping them
 576 all, I was helping them to do stuff" and I says "but where" I says "did you go to [Place 0:49:20.3]
 577 today?" "yes" I says, "but that's not what you were there for" I says, "you were there you
 578 know sort of like to be part of it" I says, "did you do some exercises?" "Ah ha" I says, "That's
 579 really good, but help to patients?" I says, "but you help the patients to do what?" and he
 580 couldn't tell me, he didn't know what he, you know was there so when I spoke to [Name3
 581 0:49:42.0] and I said "does." "She says he's alright" She says he wasn't, you know very sort of
 582 enthusiastic, but he did sort of like do, do some stuff. So anyway, the next week erm, he says
 583 to me on the Sunday night "I'm not going", I say "why?" "I don't want to help all these patients
 584 again", I says "no", I says "it's to help your mobility to keep you know, sort of like more
 585 mobile", and I says "it'll help you with your memory" I says "they talk to you about different
 586 things" I says "it's really quite interesting" I says "there's a different topic every week". "No
 587 I'm not going", and I says "well I'll tell you what, I'll phone you in the morning and we'll talk
 588 about it then", I says "it'll be really quite good to you know go, I didn't like it", I says "but
 589 you've only been for one, one day, how about trying it again and then if you don't like it then
 590 you don't have to go back", I says "you ok with that?" "Ok that's fine then". I says, "right ok,
 591 right that's fine", so anyway I says, "I'll phone you when you get back", "ok that's fine then",
 592 erm. "I had an appointment down the [Place 0:50:41.6]" I was literally just down there, he
 593 must have been in 20 minutes and then I got a phone call from [Name3 0:50:47.1] she says
 594 "oh we've had to phone for an ambulance erm to take him to hospital", I says "alright, ok", I

595 says "can you tell me know what's wrong with him?", she says "Oh", she says "he's
 596 complaining about erm pains in his erm arms and his legs and he's got a sore back", I says
 597 "well I spoke to him at 9.00 this morning and never mentioned anything at all", I says "he was
 598 quite you know sort of like ok about it" I says "he did say last night, he didn't want to go, but
 599 I said to him to try it again" and I says "he was quite happy to do that" so she says "well I really
 600 need to phone the ambulance" she says "and you know obviously take him to hospital", so I
 601 says "yes that's fine, that's fine enough", I says "right" I says "after my appointment I'll sort of
 602 like head up there so anyway", I can't remember what happened...Oh I know what it was one
 603 of the mums, one of the mums phoned in and said "look you know I've got to do something
 604 can you take you know sort of the wee one" and I says "right ok fine" anyway so I phoned the
 605 hospital and I said to erm "look I'm not going to be able to make it right just now but I will
 606 do later on", "yeah, yeah its fine he's not here yet", I says "right that's ok, that's fine" so
 607 anyway erm I phoned later on and they said "oh well he's just waiting to be seen by the
 608 doctor, we'll phone you and let you know what's happening", "right fine", I says "I'm working
 609 now until 6.00" I says "but" I says "I can come up you know once I've finished work" "yeah,
 610 yeah that's fine, that's fine" so anyway they phoned me about 3.00 and said "oh he's fine he's
 611 alright but he's just gone for a wander", I says "right, ok, fine, good enough for us", I says,
 612 "what do you mean he's gone for a wander?" "oh, he's just walked out of the hospital", she
 613 says "but we managed to sort of like bring him, get him back in again" I says "alright, ok, good
 614 enough for us", she says "can you come and pick him up"? I says "look I'm really sorry but I
 615 can't, I says "but I'll come up", I says "as soon as I've sort of like you know finished work" but
 616 and as it was erm [Name2 52:36.5] was in a meeting so he couldn't, he couldn't go so erm he
 617 phoned me again about 4.00 and said to me "what about patient transport erm we're just
 618 sending him home", I says "alright, ok, fine, fair enough but there's not going to be like
 619 anybody in the house", I says "the carers are in at 5.00", I says "or I can come and pick him up
 620 whilst, you know after I finish work", "alright, right, so you can't come and pick him up now?"
 621 I says "no, sorry I can't come and pick him up now". "Oh alright, ok fine, fair enough", so
 622 anyway, they're phoning me again, they're phoned me again at 5.30, "when are you coming
 623 to pick him up?", I says "well the last time I heard", I says "you know there was to be patient
 624 transport", I says "so I take there's no patient transport"? "No, no patient transport" says "will
 625 come and pick him up", I says "Yeah I'll come and pick him up", I says "yeah", I says "but the
 626 earliest I can be there is probably about 6.30-6.45". "Oh, right you can't come any earlier"? I
 627 says "no, sorry but I'm working", "Oh right, right, ok fine fair enough". So anyway, we went
 628 and picked him up, I picked him up about 6.45, my sister in law was up at the same, they
 629 picked him up about 6.45, so I asked sort of like what was going on and they just said that he
 630 had palpitations. But when I got home I said to him "you know if you didn't want to go this
 631 morning why didn't you just tell me when I phoned you, why did you wait until you went there
 632 because obviously you were just a wee bit uptight" I says "but if you had just phoned me and
 633 said you didn't want to go" I said "rather than going you know if you didn't really want to go"
 634 so but after that we just decided that you know that he wasn't, he wasn't going to go back so
 635 we didn't but I mean he's just he just refuse, I mean he does, he does nothing at all he's
 636 socially, he's socially isolated, he'll do, he'll do nothing, he won't go out any more like we've
 637 tried to get him to sort of come with us even so this time even just before he went into hospital
 638 I says, how about, I says "how about we go for a cup of coffee?" I says, "it'll be really nice", I
 639 says "we'll have a coffee and a slice of cake" I says, "rather than sitting here, having it, why

640 don't we go out for a wee while?" "Anyway", I says "maybe we'll go to Asda" I says, "or we
 641 can go somewhere" I says, "that you want to go", "no I don't want to do it". I says, "why don't
 642 you want to do it?" "Cos, I don't want to do it, I don't want to go anywhere, I want to stay in
 643 my own house". I says "oh fine, fair enough" and I says "do you know what, how about
 644 maybe" I says, "maybe we can do it another day", "yeah, yeah, ok I'll do it another day", "right,
 645 fair enough", he just, he just won't do it, he just will not do it and I mean we ask him know I'll
 646 phone and say "right let's go, let's go for a wee jolly today, how about we go for a wee run in
 647 the car or sort of thing?" "No, I don't want to do it". I said, "do you want to come up here, do
 648 you want to come up here and have, have tea with us, you know sort of like I'll take you down
 649 later", "no, no I don't want to do that either". He won't, I mean Christmas time we had him
 650 up here on Christmas day and he was really really good on Christmas day really good erm like
 651 I had, we had all the family here and had sort of like grandchildren, I've got three
 652 grandchildren and they kept on going they were sort of chatting away and my dad was there,
 653 so he was chatting to my dad and you know it was really really nice to sort of like see him like
 654 really chatty and things like that you know and I said to him "you can come up on a Sunday"
 655 and I says "cos my dad comes up on a Sunday" and I says "you know the kids are always about
 656 on a Sunday" and I says "so you can come up you know on a Sunday" I says "you know so" "no
 657 I'm not bothered", but he doesn't he'll not, he'll not he just, he just, recently he just not do
 658 anything and he'll not even make me coffee so I'll say too him, lets him down, "let's go and
 659 make me a cup of coffee", "no you can make me one", I says "but I like your coffee I says you
 660 make really really good coffee", "you go and make coffee"..."no" and he doesn't. He just, he
 661 just wants to do anything anymore, he just wants to sit. You know, and he sits, and he sits,
 662 and he sits, and you know he'll get pictures out and I says, "let's sort of have a look at it" and
 663 he says, "he doesn't want to do that", "so what do you want to do then?" I says, "how about
 664 if we", I says "we'll try a crossword puzzle" I says, "I'll help you we'll do a crossword puzzle",
 665 "no I don't want to do that either", but he just. It's like as if he's sort of it sounds really, it
 666 sounds really awful but it's like as if he's given up he just doesn't want to do anything anymore,
 667 he just wants to, you know just sit, I mean it's before he would have that sort of like get up
 668 and go and maybe sort of like if you were doing something he'd come and sort of say "what
 669 you doing?" "I could do that", I says "oh well that's good then right come and help me", I says
 670 to him "I need to do the washing, are you going to do the washing for me?" I says "you can do
 671 the washing" and beforehand he would say "I can do the washing better than you", "well
 672 that's fine then, there you go, off you go" and you know do things like that, but now, not you'll
 673 say to him, "I'm going to the washing" "I ok", "so you going to come and help me"? "Nah, nah,
 674 I'll just leave it thanks". It is it's just...

675 I: It's tough.

676 P: It is it's just, it's really, it is really hard, you just sort of want to wave a magic wand and you know
 677 sort of but he just doesn't, even I mean I didn't get annoyed I got I was really quite firm with
 678 him because erm he he said it would only have shower every three days, so I thought well it's
 679 better than nothing you know it, we can work on that you know, so like if like if someone got
 680 a shower every three days and that's fine, I'm not going to argue with them, if he's not going
 681 to have a shower that's fine, that's fair enough so anyway, we put in the calendar like these
 682 are the days that you're having your having your shower and I says "it's to be reviewed", I says
 683 "that's not going to be set in stone, it's to be reviewed" so he would just sort of like laugh, so

684 anyway it was one day I was down and I said "did you have a shower last night?" and he says
 685 to me "yeah", "but did you change your clothes?" Yes so I like sort of smells a wee bit sort of
 686 like not quite doesn't smell, you know doesn't smell clean basically, so anyway I asked, well I
 687 stayed and I spoke to the carer and I says "were you, you know here when he had a shower
 688 last night?", she says "yeah" she says "yes but funny you say that when he came out of the
 689 shower", she says "it was as if he was dry", I says "what do you mean?", "well he didn't, the
 690 towel didn't seem wet", I says "alright", I says "can you do me a favour"?, I says "are you" I
 691 says "are you allowed to sort of go like in the bathroom?" she says "I that's fine that's fine,
 692 that's fine, fair enough that's fine, ok fine fair enough", so erm she phoned me the next time
 693 he had a shower she says "do you know", she says "he actually went in the shower", she says
 694 "and he took his clothes off", she says and she says "and" she says "and he stood at the other
 695 end of the shower" and she said "he never washed himself", she says "he just stood there",
 696 she says "with the water running". I says "ahh that explains things", so anyway erm I went
 697 down, and I said to him "err I need to have a wee word with you", "why what have a I done"?
 698 I says "well" I says, "it's what you've not done", and he went "why", I says "did you have a
 699 shower last night"? "Yes", I said "did you wash yourself?" And he just sort of hesitated and
 700 goes "erm yes", I says "alright", I says, "I've been told differently" and he goes, "how do you
 701 mean?" I says "well", I says "I was told that you weren't in the shower", I says "and you stood
 702 at the opposite end of where the water is", I says "so you couldn't have showered yourself", I
 703 says "and I says the face cloth that's there is dry", I says "so", he says "I used that one that's
 704 over there", I says "but that one over there is dry as well", I says "you've obviously not been
 705 showering yourself", I says "and do you want to know something", I says "if you don't shower
 706 yourself" I says "you'll smell", I says "and furthermore your skin'll get really really sore", I says
 707 "and it'll all break out" I says "and that's not a good idea either is it", I says "so what you need
 708 to do is", I says "you need to have a shower", I says "in fact if you didn't have a shower" I says
 709 "I'll come and shower you", I mean I would never do that but I says, he say to me "you can't
 710 do that", I says, "no you're right", I says "but the carers can", I says "so", I says "so if you're
 711 not going to do it yourself", I says "I'm going to", I says, "get them to come in and shower
 712 you". "Oh no I don't want to do that", I says "well" I says, "the choice is yours", I says "you can
 713 either get them to shower you" I says, "or you can shower yourself". He says to me "there
 714 was a man in my shower", I says "there was a man in your shower"? "Yes, there was a man in
 715 my shower". I says, "I don't think so", I says, "how, how", I says "could there be a man in your
 716 shower?" "There was a man in my shower", I says "oh well fine but you need to wash yourself"
 717 I says "well if there was a man in my shower or not you need to wash yourself" so the last,
 718 that was just before he went into hospital, the last twice before he went into hospital erm the
 719 carers had been actually sort of going in and making sure he had been like washing his self,
 720 but I mean he was just...

721 I: It's tricky, very tricky.

722 P: Sometimes it's like "ahh, ahh"! Sometimes it's like caring for a child (yeah) like you know,
 723 "have you washed yourself" or...

724 I: So just to get back to the technology again, erm so you talked about it a couple of technology
 725 that you're using (yes) would you, so if you knew of someone else who was in a similar
 726 situation was combining work and caring for someone with dementia, would you suggest it to
 727 them?

728 P: Yeah I would definitely, yeah I think, I think in a way there should be like maybe even a support
 729 group (yeah), that you know sort of and a lot of the times to do with dementia and during
 730 your day which isn't very helpful, you know sort of, I would like to see you know like maybe
 731 sort of like support groups at night you know so these people, those people who do work you
 732 know could actually, you know sort of like still, still attend, could be attend could be attend,
 733 attend things like that.

734 I: So, when you say support group you would mean a group that would talk about (yeah)
 735 technology and (yeah) that's good?

736 P: Or even sort of like their experience, just to, you know sort you could sort of like get some
 737 pointers or you know sort of like, things like that, you know.

738 I: And the technology that you are using or that your uncle is using (yeah) would you like to see
 739 any specific improvements?

740 P: Erm, its I mean, they're quite, they're quite good I mean I think obviously I mean like the fob
 741 thing I think that was just unfortunate that erm you know, that, that didn't work but I mean,
 742 it's, it's really really good I mean there was a, there was a thing with they spoke about, they
 743 spoke about getting erm a thing on the front door to you know sort of like say like don't go
 744 out and things like that but I mean he would just ignore it and just go and do it anyway whether
 745 you know so they said at the time, "ok fine fair enough, it sounds a really really good idea" but
 746 I mean, I, I mean, I says "he would just ignore it and do it anyway".

747 I: They were thinking about something that would help something have written that...?

748 P: No just sort of like a thing that said sort of like don't go out you know sort of like, you know
 749 go back, sort of, you know don't go out (oh ok) you know, sort of like don't go out, go back in
 750 but I says he would just ignore it, I says "he would just do it anyway", I says "if he was like in
 751 that frame of mind and he wanted to do it, he would do it regardless whether you know there
 752 was a thing at the door as well".

753 I: So, if you had like a magic wand and you could wish for anything, what would you like
 754 technology to do for you personally?

755 P: Basically, I mean I would like the, do you know I would be like a sort of camera thing just to, it
 756 sounds really bad but just sort of like a camera thing just to make sure that you know you
 757 were actually, whilst you weren't with them you could actually sort of like, you know like just
 758 I suppose like a baby alarm type thing, just to sort of look to make sure that they are, that they
 759 are ok, you know then at least that way you know it would put your mind at rest because if
 760 you I mean I've phoned a couple of times and got no answer and thinking oh my goodness
 761 me, you know what, he's not, he not answering you know obviously, if there is something
 762 wrong, you know but not being to able to sort of you know go down right away you know, and
 763 you know and of there, if there was sort of like and like an alarm like I suppose like a baby
 764 alarm like I find that you could actually sort of like, oh he is ok you know he is sort of doing
 765 something or I mean all be it sometimes you know he was on the toilet or something that you
 766 know you just phoned at that particular time and you know he never, he never answered the
 767 phone and you're like, my goodness me I hope he's alright (yeah) or whatever.

768 I: Would you like, so if there was such a thing like a camera for example, would you like that to
769 be just accessible for you and your husband?

770 P: Yes, ah ha, just sort of like family just as we know, just as we know you know that erm you
771 know like, he is, he is alright yeah.

772 I: So not for example linking it also to the telecare alarm?

773 P: I suppose you could yeah, I suppose when we, when we you know when we went there (yeah)
774 that would be yeah, that would be quite good. Just to sort of, yeah, just to keep an eye on
775 him just to make sure that he is ok and I mean it, It sounds I suppose it's just like a sort of spy
776 thing, oh my goodness me you know, but it would, I think it would sort of like put your mind
777 at rest (yeah) if you weren't you there all the time. I mean as I say when he's at home, I, I
778 worry, I worry all the time cos I think you know what happens if this, and I'm not there but
779 you know I think, what happens if this happens, what happens if that happens you know it
780 just is and I mean as I say just now whilst he's in the hospital your sort of you're not worrying
781 as much because you know fine well there's somebody there and you know he's, he's been
782 looked after (yes). I think I think that's the main thing, the the carers are a wee bit I mean it's,
783 its fine, they're doing a really really good job but I feel that you know sometimes, if you'd been
784 that wee bit more like sort of time spent, you know go in, get them ready for breakfast, etc,
785 etc, but maybe even have sort of 10 or 15 minutes so they can just sort of sit there and chat
786 to them cos sometimes that's all they want, just a wee, a wee bit of conversation. But you
787 know it's sort of like you know, go in, do sort of what they have to do and then out because
788 they have to get onto sort of get onto the next, the next patient (mmm) which I think , I think
789 it's wrong sometimes and the, I was a bit annoyed about the...not not him in general, but
790 when he was in, when he was in hospital and I mean, I do, I do understand but you know we've
791 now got to, if he does go home, we've now got to go through the whole process again sort of
792 like try to find a care package because erm they said they'd only keep the care package open
793 for I think it was five days, seven days at the most because erm the carers only get paid by
794 sort of like contact time, so they only kept it open for sort of like a week, so I mean now we've
795 got to go through a process again, so if he does get home erm we've now got to go through
796 that process again of you know waiting on a (ok) waiting on a care package.

797 I: Did you used to have the same carers coming into the house?

798 P: Yes, I have, there was two, there was two erm carers who used to come in sort of like on a
799 regular basis, the pattern they worked was, I think it was three days on and I like two days off,
800 yes so it was like three days on, two days, three days on, two days off. The only, the only thing
801 about that was it was a bit, I mean it was fine, that was ok, but the times were a bit sporadic
802 at times erm because he first started off, they weren't coming in until half nine in the morning
803 which we thought was quite late especially for you know sort of like for him, but eventually
804 we got it down that they were coming in a 7.45 which was really good, we thought that was
805 really really good and then they were back in again at 12.15 but from 12.15 they didn't come
806 in again until 6.30 so that was quite a, that was quite a long you know like spell and this is
807 when he used to get really sort of quite he would get quite lonely you know he'd say "it was
808 fine but the carers you know, they left me about erm 12.30" and then they're not back in again
809 until 6.30, you know and I'll say "yes that's fine yeah" but you know just and then they would
810 be there at 6.30 and then they would be there again at 8.30 which was sort of quite, quite and

811 I mean I know they've got of like sort of different like runs and things like that you know but
812 it was it was quite a long, it was quite a long gap between 12.30 and 6.30.

813 I: Were you given any say regarding...?

814 P: No not at all no we just have to go with whatever they had sort of like, like space.

815 I: And how about when erm when the telecare was set up (ah ha) and the alarm and all of that
816 were you consulted or...?

817 P: Yes, yes, we erm spoke to them you know sort of like erm about when erm obviously he had
818 the fall erm I spoke to him and said, was there anything else that you know sort of they could
819 put in place and they were really really good you know they said that they could press your
820 alarm, that's what it was called, a pressure alarm on the bed and then he could put like a
821 pressure erm mat on the floor so as you know sort of like when he got out of bed then you
822 know they would time it for 30 minutes and then if he wasn't back in bed by 30 minutes then
823 they would sort of contact him to you know sort of find out but no they were really really,
824 they are really really good yeah, they're very good.

825 I: And so, did your uncle have a say in that as well, did they show him the technology saying this
826 is what's it's going to do?

827 P: We, showed him what to do (ok) we showed him what to do because it was installed before
828 erm he came back from hospital (oh ok) yes it came because we wanted it sort of like there
829 just to for sort of like peace of mind to make sure that you know there was something in place
830 before he actually got home, so it's one of the things...

831 I: And so, this alarm that he has to wear is that a problem, does he sometimes forget it maybe
832 or...?

833 P: He forgets, he forgets about it (yeah) you know he forgets about it and I said to him when he
834 had that fall when he fell you know, or whatever happened, I said to him "why didn't you
835 press?", I says "because if you had pressed your alarm", because he said to me he says, "where
836 were you, I shouted on you and you didn't hear me"? I said to him "but I was in my house and
837 you were here and I couldn't hear you", you know and similarly he had he had been lying for
838 over four hours and you know I said to him, "why didn't you press your alarm?", I says
839 "because if you had pressed your alarm we would have known that you had fallen" I says "and
840 that way they would have been able to get in contact with us and then we would have been
841 able to you know come down and make sure you were ok". "But I couldn't" so I says, "why
842 couldn't you?", "because it wouldn't let me", "but I still couldn't get a", I don't know why but
843 erm.

844 I: So, he was wearing it?

845 P: He was wearing it yeah, because we thought at first, he wasn't wearing it but no, but he said
846 something about everything, because when I pressed it erm it wouldn't, it wouldn't work, it
847 wouldn't work.

848 I: Was there an instance where when he had to press, and it did work or was that??

849 P: No that's, (ok) no he just pressed the erm like if he wanted them, he used to press you know
850 there was a thing at the side of his bed and he just used to press, press that if he needed,

851 rather than doing that, but I mean, he did, he did wear that because we always used to make
852 sure that he did have it on his erm, on his arm, I mean now he's got one on as well, he
853 doesn't go for a wander.

854 I: Erm is there anything that you do for yourself personally being a carer, something that helps
855 you go on basically?

856 P: Walk.

857 I: I don't know...

858 P: Walks, I just go for walks and just sort of erm like sort of think about it. [Name4 1:11:29.5]
859 also put me in touch with sort of like a counselling (yes) erm service which is down in
860 [Place1:11:34.4] I've had my initial erm you know sort of admittance thing, but they said it
861 could take up to three months you know sort of like for an appointment so. Sometimes I
862 actually like family I sort of talk a lot to sort of talk a lot to family and you know sort of really
863 good friends that you know sort of have a wee chat, sort of have a wee chat with them

864 I: Have you had a carers assessment from the council?

865 P: No, I never.

866 I: Did you ask for one or?

867 P: I didn't know there was anything existed, it's what I'm saying that's why I think, I think that's
868 why they should have like a booklet to say you know this is, this what should happen. I just
869 feel that you know if they said oh well this is what would happen in the community, that is
870 what will happen in the community, nothing's happened, nothing, nothing at all I just, I said
871 to you before, I just feel as if you know that's it, he was in [Hospital 1:12:26.1] once they, you
872 know got him home that was it, nothing else you know it's like as if, I mean it like you had sort
873 of like a social worker whilst he was in [Hospital 1:12:35.3] but after they and I mean I suppose
874 they're attached to [Hospital 1:12:39.4] but you would have thought that there would have
875 been sort like some communication between himself and you know like community team
876 whatever, I mean but as I say I have to keep on, sort of like phoning and phoning and phoning
877 and sort of like social care direct saying "look you know what is, what is happening you know
878 he's come home, we were told after four weeks there would be sort of like a case conference
879 and you know we would be told what you know what to expect etc" but nothing, I mean like
880 a bathroom assessment, I phoned you know like a bathroom assessment you know sort of,
881 but I feel like as if it was me that, I had to keep on doing everything and only now they sort of
882 like found out by sort of by [Name4 1:13:20.6] you know sort of like pointing me in the right
883 direction or I phoned the dementia erm careline erm one day to just sort of like ask I can't
884 even remember why I phoned them to ask something and you know they said to us this is sort
885 of and I mean she was good, she was really really good but as she says "you know" she says
886 "I've you basically all that I can tell you " she says "you know, how, what you're telling me it
887 really needs to be sort of like, it really needs to be like in care home rather than he is in his
888 own home". I says "that's great" I says "you know but" I says "but thanks, but he's quite
889 determined he want's to be in his own, in his own home and you know we're sort of trying to
890 facilitate that as much as, as much as possible" (yes) you know and it is, it's really, it's quite,
891 it's quite, it's quite hard more than anything else to sort of...

892 I: Is there any advice you would give a person who is in a similar situation like yourself?

893 P: Get in touch with VOCAL, get in touch with them definitely cos I mean I would never ever have
894 known the, half the stuff that I know now (yes) if it wasn't you know sort of like for, for [Name4
895 1:14:31.3] and I mean I've sort of like got booklets and one of the girls across the road her
896 mums erm you know got dementia so, you know I said to her, sort of like "do this, this and
897 this..." you know it's been, it's been really quite good for her as well because she like, she was
898 like "oh I wouldn't have known that" you I says "you know well I wouldn't have known that
899 either until you know" but I think if, I, if it's just just, it's so if somebody just to go like bllurrr
900 to you know sometimes when like you're doing, you're talking family or are the family are like
901 sort of like they're involved as well you know. Sometimes it's just really, it's a bit easier to
902 sort of like say to sort of like to a stranger "you this is how, this is how I'm feeling, you know
903 I'm feeling really like rubbish, I'm just feeling, I'm really really, I'm not, I mean I'm am emot,
904 I'm an emotional person but not, not as bad as what I have been feeling as it is". Some days
905 I'll just sort of sit here you know sort of or like at night I'll just look at my husband and burst
906 into tears and he'll say to me "what's wrong with you, what's the matter?" "It's just that I'm
907 exhausted, I am I'm just exhausted, I just feel as if I never seem to get out a bit, there's not a
908 day where I wake up and think oh, today I'm going to like do this, this, this and this, you know
909 and I just feel as if sort of like our life's been put on hold" I mean not, not in a bad, not in a
910 bad way, I just, I think maybe if I had had more of a break I think I probably would have been
911 I wouldn't have said prepared for it but I don't think I had enough time to sort of like just get
912 you know sort of like, gather, you know sort of just try and sort of get myself back together
913 again sort of like after my mum you know and erm before we had to sort of go right back into
914 the depth of things again, and you know I just like yesterday morning when the phone you
915 when the phone rung saying it was the hospital I just though "oh no, what's going on"? you
916 know. And it is I mean you just sort of think well is he ok, I really did I was terr..I mean they
917 left a message on the answering machine because I couldn't get to it quick enough and I was
918 frightened to like to phone them back, cos I mean my heart was going like d,d,d,d,d....my
919 goodness me, what are they going to me you know, sort of what are they going to me and you
920 know there's that as well, I mean you go up and you look at him and you think you're just sort
921 of fading away like in front my eyes, you know you're just, you know but I mean there was, he
922 just never ever got a like you don't get a proper conversation out of him anymore, he's just...I
923 mean it is, it's, funny sometimes and sometimes we've got to laugh because if we didn't laugh
924 you would cry but yesterday I says to him "how are you?" he says "four foot two" so "oh are
925 you ok" I says "that's really good I'm glad to hear you're four foot two today" He says to me
926 "do you want to come to the toilet with me?" I says "nah, no thanks" I says "its fine, you can
927 go yourself." He says to me "but you can come", I says " no I don't want to go to the toilet
928 with you, go yourself," and he says to [Name2 1:17:31.5] "do you want to go to the shower
929 with me/" [Name2 1:17:32.9] and he says "no, its fine" you know it is I mean it's, it's not funny
930 ha ha but I mean some of the things that he comes out with and you're like "what?" you know
931 it's like my mum used to...I mean one day my granddaughter she's erm, she's 12 and erm we
932 were up seeing her one and she says to her "go and move your chair quick" so of course me I
933 sort of got the chair and she like this "gran why are you moving my chair" "she better move it
934 in a wee bit further, a wee bit further because I" she says "ok, fine" so anyway so moved it,
935 she says "thank goodness for that" then she goes "why did I move my chair" she says "look

936 there's a train coming" she says "you might have got knocked over by that train if you didn't
937 move your seat" "oh ok, fine". Some of the things, but some of the things, what else was he
938 saying yesterday, something to do with the army, ok fine, it's fair enough. But if you, you
939 know try to have a conversation with him and he.."well I was really good at that" I says "were
940 you that's really good" you know, I says to him, I says "I've come to the conclusion that you're
941 a jack of all trades, master of none" you and you just sort of try and sort of try and have this
942 conversation but I mean yesterday sometimes you can get like a thread and you think oh well
943 maybe this is what he's talking about but yesterday there was, there was nothing, there was
944 not a not a thing, nothing at all.

945 I: I take it you had any indication from the hospital when he might be discharged?

946 P: He's still on antibiotics erm he started off on a broad spectrum antibiotic and then they did
947 erm a MRI scan to find out what was going on, and this is when they found out, at first they
948 didn't know where the infection was they were just grabbing at straws thinking there's an
949 infection there because he inflammation indicators were quite high but they hadn't a clue
950 where it was, he started off, he did had a chest infection and we still don't know where he got
951 a chest, we wasn't coughing and he wasn't like he didn't sound wheezy, he didn't have a cold
952 or what so there was nothing and then his gallbladder was a bit inflamed and they thought
953 maybe that, that seemed to like settle down and then they just didn't know where the, the
954 infection was coming from but you know the inflammation indicators weren't going down at
955 all there were still staying sort of quite high so they gave him this broad spectrum antibiotics,
956 but it wasn't doing any good whatsoever, so he was on that for 10 days and then they gave
957 him an MRI scan and this is when they found out that he had an inflammation in the soft tissue
958 of his hips, which that's what he was complaining about when he went into hospital. Erm but
959 he's also got this bulging disc and his, and his back as well so erm they gave him sort of like
960 specific antibiotics they, he was on two IV antibiotics and an oral antibiotic and that stopped
961 on Friday, Thursday. That's stopped on Thursday, so they then did more blood tests and they
962 have taken him off the IV antibiotics and they've given him one gram of erm amoxicillin three
963 times a day and he's on that for the next two weeks. Erm they then said that they will review
964 it in... then. They're not 100% sure whether he, they might want keep him in for maybe like
965 about another week to two weeks to make sure that they have got on top of the infection
966 before like they decide to do anything or it might be that they might just keep him in for a
967 week after that and then decide what we're doing, but I spoke to the doctor on Friday, I say
968 to her "can you please you know, he doesn't have a care package, he can't go home, like you
969 know without anything because we can't be there obviously like 24/7" I says "so we really
970 need to have a care package or something in place before he goes home" so what she says
971 was "it might be, that he might get transferred over to [Hospital 1:21:28.8] erm you know sort
972 of once he's you know sort of like a wee bit better until such times as they get like a care
973 package in place or whatever, whatever's happening" so I said to her "well if you know, when
974 you have an indication as to what's going on, can you please let us know, cos I need to get in
975 touch with the social worker" and then he wants to come in and have a meeting with a like
976 multidisciplinary meeting with everybody so we can sort of talk about you know the options
977 of what's happened.

978 I: That's sounds good.

979 P: So we get erm a Friday she gives us, she's going to phone every Friday afternoon and give us
 980 an update on a Friday afternoon because obviously sort of like during the day like I can't get
 981 in, like tomorrow morning I've got to go in because I've got erm, his pyjamas got, his six pairs
 982 of pyjamas and five pairs of pyjamas are dirty erm from over one day so I don't know what
 983 he's been doing so I've had to sort of...he's got two pairs of pyjamas in there so I've had to
 984 bring them back and wash them, so I need to take them back again tomorrow so he's got
 985 pyjamas.

986 I: So, we need to wrap up, I only have one big question left (ah ha) which is one basically; what
 987 are your wishes for yourself for the future or maybe the next year or?

988 P: That things that sort of settle down and I sort of get my life back again (yes) you know because
 989 my daughters getting married in two weeks and I just feel as if I've not, like I've not helped
 990 her enough you know sort of, I've been there obviously and did you know but like my, my
 991 focus, you know sort of like part of my focus has been sort of like put on the wedding but
 992 obviously you know there's that in the background. I just want him to be, I want him to be
 993 safe, that is basically it, I want him to be safe, I want to be relaxed knowing fine well that you
 994 know he is safe (yes) you know that is it, that's all, that's all we want to know that he is he's
 995 safe and he's not going to come to any harm whatsoever, you know. And I mean if we could
 996 wave a magic wand then you know, and everything would be ok, you know then I would I'd
 997 like him just to be happy basically (yes). I mean at this moment in time it's just, he's not, he's
 998 not happy and it's a shame, it is horrible I think is the worst disease ever of seeing somebody
 999 just deteriorate in front of your eyes and you can't do anything about it, they can't tell you
 1000 sort of like how they're feeling or you know they just don't, they don't know, and I think that,
 1001 I think that must be really really scary thinking you know sort of thinking they're losing it and
 1002 they don't know what's happening. I remember my mum telling me and she used to say, she
 1003 used to say "I know there's something wrong with my head" she says "and I don't know what
 1004 it is" and it's horrible, I mean that must be horrible and I sort of like now panic thinking "oh
 1005 my goodness me you know, is it, is it hereditary, you know just you know have I got sort of
 1006 like a higher chance of getting it because you know sort of like my mum had it and it is it's
 1007 horrible, you know that just goes through, through your, through your mind and a friend of
 1008 mine her mother in laws got it and she really quite young she's only 63 you know and it's
 1009 horrible you know and I've said to her "look you know" I said "just you know just sort of keep
 1010 a chart" I says "do a memory book show, that you know, like just keep on, just keep on sort of
 1011 talk about memories and things like that" I says "you know" I says "we just sort of keep on
 1012 talking you know about different things" I mean now he's the only one left erm sort of like out
 1013 of five of them, you know he's the, he's the only one left now you know and it is it's just you
 1014 know we talk about you know sort of like what happened you know like a long time ago or
 1015 you know sort of you try and get him to talk about, I mean he doesn't, he doesn't remember
 1016 like what he had for his dinner, he told me, he told me, he told us one day he had bird seed,
 1017 so I was like "what" he says "I had birdseed for my breakfast" I says "that's really nice" I don't
 1018 know whether it was muesli or what, I don't know but he said birdseed "oh that's really good,
 1019 that's fine" I mean some of the things he tells us, I mean it is funny but you know your just
 1020 sort of thinking it is it's just sad but yeah just you just get, you just get on with it cos you don't
 1021 have any choice in the matter, I mean I would never ever walk away from him, I would never
 1022 ever do that. You know sometimes you feel like it, sometimes you know if things are getting

1023 on top of you, you just sort of think "I've had enough, that's it, I can't do this anymore" you
 1024 know but you never, I would never ever do that.

1025 I: Thank you very very much.

1026 P: Sorry I've just gone like "wooooo".

1027 I: Not at all, not at all. I really appreciate it. Erm I just have a couple more very quick questions.
 1028 (Yeah, that's fine) To provide a bit of context. So, the first would be how old are you?

1029 P: 61.

1030 I: Erm how old is your uncle at the moment?

1031 P: 83 in August.

1032 I: 83 ok. When did he get his diagnosis of dementia?

1033 P: Over five years ago. (ok), yeah over five years ago but its its not, I mean been that bad, I mean
 1034 sort of like a bit forgetful but nothing, nothing compared to what has been sort of...

1035 I: Erm so how many hours would you say on average do you care for your uncle a week?

1036 P: That's quite hard to sort of say, err, erm I don't know. I mean it's not, like we go down there
 1037 and then we can come back up and maybe go back down, I think probably, probably between
 1038 10 and 12 (10 and 12) yeah yeah remember sort of like you know we do, we do things for him
 1039 I mean contacting but I mean, we're doing, we're doing other stuff like in-between times like
 1040 you know phone sort of like making appointments you know sort of trying to get stuff
 1041 organised sort of like for him and things like that so I mean it is, it's probably more than that
 1042 you know by the time you sort of you do erm like you know sort of phoning for different places
 1043 and things like that. I mean he's in hospital just now and we will go up and see him I mean
 1044 we're down sort of like checking the house as well, just to make sure like there's, like the mail
 1045 and everything's all ok and things like that because there was erm, we thought somebody was
 1046 trying to break in, you know because there's a key safe and we always sort of like put it to sort
 1047 of like four zeros you know when we, I mean we've all got a key but you know sort of like if
 1048 anybody sort of like nurses or doctors and if you know they've all got a code for the key safe
 1049 so they can get themselves in but we always sort of put it to like four zeros and I went don't
 1050 one day last week and it was all sort of like jumbled about the bit at the front was down and
 1051 all the gates were open (oh oh) you know so I'm thinking "mm there's something not, sort of
 1052 like, something not quite right here" so I took the erm key out the key safe I just sort of took
 1053 it out completely and utterly I just left it open and I'm thinking fine fair enough, they can see
 1054 that you know, sort of there's no key there so you know that's that but you know sort of try
 1055 and keep, make sure that you know like the house is safe as well and things like that.

1056 I: Erm right so you said your husband is working full time? (Yes.) And so, the final question would
 1057 be erm regarding education, so what would you say is the highest level of education that you
 1058 have achieved?

1059 P: What me? (Yes) HNC. (HNC?) Yes.

1060 I: Great that's. Thank you very much that's it basically so I'm going to...

1061

END