

# Interview 5, “Hannah”

Date: 27.3.2019, Duration: 65min; Location: participant’s home

I = Interviewer, P = Participant

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I: Ok. Right so erm to start off with can you tell me a bit more about er the situation of you being a carer? So how did that come (ok) about?

P: Ok so my mother is 84 years old and she has a diagnosis of dementia. Erm she was formally diagnosed in January of 2018. Erm we first approached a GP to talk to them about did she have dementia in October of 2017. But that was after a while of maybe slight denial? (Uh-huh.) Since she’s been formally diagnosed – initially she was coping pretty much same as ever. Now she, it there, there has been a, kind of dramatic change (uh-huh). And the way we managed that is she is, she lives 5 minutes’ walk from here. Erm so that’s easy to do. Erm. So that. That’s the general background (uh-huh). I can explain a little bit more about what I do day by day or?

I: Yeah that would be good.

P: Or follow your questions. Whichever works for you. So generally speaking on a working day erm we would leave here at just prior to 7 o’clock. Erm sort of 6.45 to be there at 6.45 and a bit. Erm I take the kids and go in, check that she’s ok. That she’s. Currently she’s not getting up at that time, she used to get up. Erm currently basically she’s well. She’s got her medication. And then the children will sit and eat breakfast with her until it’s time for them to go to school. But I will cut away from there about 20 minutes or so after that. So that’s each morning. And then in the evenings there will be another call in. Make sure she’s ok. Make sure that she’s either. Is going to eat her dinner or has eaten her dinner. Just by checking what’s gone (uh-huh). Erm, and then the weekends tends to be a little bit more intense at the weekend. So at the weekends I go in on a Saturday and I change the bed, do the laundry. She doesn’t have a sense of smell so I have to enforce a change of clothes if she’s not had one. Erm, so change the bed, do the laundry. Erm, open the mail, sort out any admin out the mail. I have some electrostatic paper that I use on the kitchen wall so that is the diary for the week. So, update the diary, clean it down from last week; put next week’s diary up and erm. Go to pick up the medication. And do any banking which she needs doing that I can’t do week-by-week on the app. So going to the Post Office for her pension and that kind of stuff. And on a Sunday I’ll just pop round just to make sure things are ok in the middle of the day. So that’s kind of how it works.

I: Uh-huh. Erm on the average how much, er how many hours would you say you spend on all of these tasks a week?

P: So I’d say it’s an hour a day probably on a working day. That’s on a regular nothing’s happening (mm) kind of day. Then there’s probably about 3 hours at the weekend on Saturday and maybe half an hour on the Sunday but it just depends what’s happening. So for example, we’ve had the doctor in yesterday during the daytime. That wasn’t pre-planned (uh-huh). Excuse me

40 *[blows nose]*. So that was the district nurse calling me up to say that she was concerned. That  
41 she was going to send the doctor round. So that, that sometimes depending on whether they  
42 need me to be there. Yesterday it happens that we have a companion person comes round on  
43 a Tuesday. So I knew they were going to be there so I didn't have to drop everything and  
44 (mmm) get round there. Erm if it'd been on another day of the week, depending on what was  
45 going on I might try to get back. Erm the reality though is I have epilepsy; I don't have a driving  
46 license. And I work at [Inaudible, Place1 \*00:04:58\*]. So public transport between here and  
47 [Place1] is OK morning and evening but if you try and leave [Place1] at any other time in the  
48 day, it's not geared up. The buses are geared to go at the beginning and the end of the working  
49 day.

50 I: Mm. So they're not very regular?

51 P: In the middle of the day. Yeah. You can get to the airport or you can get to the [place] because  
52 that's where they think that people want to go (yeah) on their lunch hours (uh-huh). Erm but  
53 they don't necessarily link to the railway stations (uh-huh). So. But my. My previous. I changed  
54 roles about a fortnight ago. My previous role I was finding it a real challenge. They weren't  
55 that understanding. My current manager couldn't be more understanding. We're two weeks  
56 in but I, I just get the feeling that she, she is much more erm understanding in general. Much  
57 more compassionate, empathetic (uh-huh) and much less a micro-manager (uh-huh). So I  
58 think it will work better in every respect yeah.

59 I: Is it the same company that you work for? (Same company yeah.) Just a different department?  
60 (Yes. Yeah, yeah yeah.) Did you have to change because of your caring duties or were there  
61 other reasons?

62 P: Erm, 50% probably was as a result of that. So the relationship with my manager and partially  
63 her manager had broken down (oh dear) in extric, oh gosh I can't get my tongue round it. It  
64 was beyond repair. Erm it got to the stage that I raised a grievance against them. My grievance  
65 was upheld and as a result of that I thought pfft. Even though the grievance has been upheld  
66 it's not going – the problem is not going to go away (mm). So I have to move myself out of  
67 that. So that was that. There was some other issues alongside of that, but primarily it's difficult  
68 to say because obviously I don't know what's going on in their heads (uh-huh). But my feeling  
69 is that it, yeah. A, a proportion of it was due that that.

70 I: Mm ok. Can you tell me a bit more about your work situation? So what exactly is it that you're  
71 doing; how many hours a week do you work?

72 P: So, I work um, for a large banking organisation (uh-huh). Erm, I work 35 hours a week. That's  
73 my contract. I'm currently as of two weeks ago a Privacy Officer (uh-huh). Prior to that I  
74 worked in an innovation department where I did risks and controls which included privacy  
75 erm for that department. Now I'm facing out to the more frontline banking part of the  
76 organisation erm, looking specifically at privacy.

77 I: Mm, ok. So how does a usual, er a normal work day look for you?

78 P: So normally speaking at the moment we leave my mum's. I can be at my place of work by 7.30  
79 (uh-huh). So I start at 7.30, erm and I finish roundabout 4. Erm a normal working day will be a  
80 combination of desk and meetings. Erm meetings will sometimes be face to face in meeting

rooms, but predominantly because of the size of the organisation and the locations, (uh-huh) it will be meetings on a audio conference (uh-huh) or a videoconference through your mobile.

I: Mm, ok. Erm in your job do you have any control over your schedule? So when you work for example, when you start your work day, when you end your work day. Would you be able for example to take a day off on short notice? Something like that?

P: Erm. It's, it's a bit of a tricky one to say because in my old role (uh-huh) and this has got nothing to do with my employer's regulations and policies, but in my old role, taking time off at short notice was frowned upon (uh-huh). Erm, in my new role I suspect they're going to be much more accommodating. Erm and I, myself had an impacted wisdom tooth the other week, erm and had to go in on my first day to say 'I've got to have a tooth out on Thursday so I'll be, you know away?' With the nature of the role there is, there is flexibility in that some of it is work, that it doesn't. Out with the meetings the work doesn't necessarily need to be done at a specific time of day (uh-huh). Because of the nature of the role there will be some deadlines, for example, if we have to respond to the Information Commissioner or something. We will have an enforced deadline that we have to meet. But that can probably still be accommodated day by day (uh-huh). You don't, you don't have to be 9-5 to do that (yeah). Erm, my employer also is, uses a lot of technology so I have the ability to work from home (uh-huh). I was working at home this afternoon erm so that makes things easier. Generally speaking as regard to my mum, I have a pattern where I try and routinely work a Wednesday at home (uh-huh). For example this morning we had members of our team from other cities up yesterday/today so we did have a team meeting this morning. So I did go in this morning, back this afternoon – I tramped back at lunchtime. So I will try and use Wednesday afternoon late on for any appointments to do with my mum if I can (uh-huh). What I do find though is social work and some of the caring charities they, their working hours are much more 9-2 (uh-huh) or you know, they're they're not flexi hour type people. Erm even I've had social workers like going 'Oh yeah we'll do it before you go to work!' and you go 'Well I leave at 7 o'clock' and they go 'Ok wish I'd never said that now!' (*laughing*). So it tends to be that for those kinds of meetings, the flexibility has to come from my side (yeah). That I always find a bit of a challenge. Erm because there's part of me that thinks. It's the same with doctors surgeries. You know, they must know that a huge part of the population works (uh-huh). So why nobody has sat down and said, actually if we ran a surgery from 7-10 and then we all had a break in the middle of the day and then we had another surgery from I dunno, 3-6 we might be able to accommodate more people? But far be it for me to say. Erm and the same. There does seem to be a perception amongst social care, [charity], that carers don't work (mm). I think probably historically a lot of the carers have been the spouses of the individuals (mm) and therefore they're past retirement age. But yeah working carers I think are a bit of a rarity. And I think because of that; more off the radar (mm). Because we don't go to, for example, they run something called Dementia Café (uh-huh). It's 12-12 on a Tuesday afternoon (mm). Where they have time out for, er they'll have a bit of lunch and then split. The people that have Alzheimer's go off to one room and they sing or play games. And then the carers er are supposed to be kind of, sharing experiences; supporting each other and so on. But the reality is, if you're a working carer, you're not gonna be there between 12-2 on a Tuesday afternoon (mm). So that I find odd. I suspect in [place], I don't know whether they are maybe a little bit more aware and because of the quantity of people they're facing off to (mm) they might so

125 oh yeah we'll do one on a Saturday morning – I don't know. Erm but yeah I think working  
126 carers go under the radar because of that. Because we're not turning up to (mm) these carer's  
127 coffee mornings (mm, mmm).

128 I: Erm would there be something you would like to participate in?

129 P: *(Sighs)* Would I? It's *(sighs again)*. Yes and no. I'll tell you for each. Yes because you get that  
130 support and you find out a bit more about what's going on and what's available to you and  
131 those kinds of things. No because I guess there's part of me that wants to not badge myself –  
132 I am a carer (uh-huh). Erm and particularly when it's your weekend, and you think oh I've done  
133 a week's work, plus a whole load of stuff for um er, I refer to my mum as Grandma cos of the  
134 kids (yeah). Loads of stuff for Grandma round the edges, and you think - this is my weekend!  
135 So the thought of then going to the carers' coffee morning is probably not number 1 priority  
136 of what I want to do! On the other hand, maybe if it was there and you could dip in on the  
137 weeks where you're thinking I don't know the answer to this situation (uh-huh) let me go  
138 along on this particular week and I'll find it out rather than make it my normal Saturday  
139 morning activity then yeah?

140 I: Yeah. Um so you talked very briefly about being able to work from home. Er is that something  
141 that you have to, you know erm agree with your supervisor/with your line manager with? Or  
142 can you just say today no, I have to work from home.

143 P: That varies across the organisation (uh-huh). And I think given that I'm only 2 weeks into this  
144 role. I think that if I was to text my manager in the morning and say 'Something's happened. I  
145 need to do x,y and z. I'll be working at home today.' She would probably be very  
146 accommodating. In my last one, they would erm. It's happened before. Not so much about  
147 my mum, but my daughter broke her arm and long story short; we didn't find out till a couple  
148 of days later and then my husband was working in [place] at the time so [son] was already in  
149 bed; I had to take the children to A&E but by the time we'd done all that, we'd left. I ended  
150 up. We weren't going to get home so I had to call somebody to say 'Can you take.' I'd left [son]  
151 next door (uh-huh). Who he knows quite well but probably not well enough to sleep over  
152 (mm). So I'd had to call somebody that we knew really well to say he's next door to us, can  
153 you go pick him up and take him back to your house alone, sleep over there and I'll get him in  
154 the morning. So the following morning of course we had the sorting out Grandma's  
155 medication, breakfast and making sure she's up, well alive and dressed! And picking up [son]  
156 from where he was. And when I called my. My manager was off. I called my manager's  
157 manager and she was saying, 'Well do you want to take parental leave?' Now parental leave  
158 is pretty much like carer's leave (yep) you get a week off and it's unpaid. I'm thinking no,  
159 actually all I need is for you just to realise that I'm going to be logging on half an hour later  
160 (yep). I don't need to take a week off unpaid to go and pick my son up from around the corner!  
161 But that was their mentality. It was kind of like that you know?

162 I: Yeah, not very flexible?

163 P: Yeah, yeah. Whereas I suspect that my new manager from what I can tell, it would be a lot  
164 easier. My new manager has already told me that there are 2 people on the team who were  
165 carers. The people that they cared for are now deceased (uh-huh) so that gives me a lot of,

166 the feeling that you, the situation's understood. Because I've got people on the team who've  
 167 been there and my manager has managed carers before (mm).

168 I: Yeah. I would imagine that's a good feeling? (Yeah.) Yeah.

169 P: When she told me that I was just thinking. Not only was I in a meeting where we agreed that  
 170 they were going to take me on secondment, and then she told me all that and I was just  
 171 thinking yep! This is, this is the place I need to be!

172 I: That's really good to hear. Erm can you think of any instances where your caring and work  
 173 situations sort of collide? Is there anything where caring interferes with work or the other way  
 174 around?

175 P: Erm. So, I can think of a couple of things. It tends to be things like meetings for [charity] Link  
 176 Worker which tend to be 2 o'clock in the afternoon (mm). So those are ones where I will just  
 177 say I need to log off at this time, I will be back online at 3, and I will just make my hours up.  
 178 And I knew that I'd do that (yeah). Um, and I, I think that should be ok going forward in my  
 179 new role. It's. Where I think it's harder is when you've got meetings set up with your team  
 180 (uh-huh), and you're the person that's supposed to be going to, I don't know, some big  
 181 governance meeting of umpteen people (uh-huh). Where you're either gonna have to find  
 182 somebody else to represent the team (mm) or you know, you can't really say to somebody  
 183 who's organised something bank-wide say look can you move this cos I need to go and take  
 184 my mum to the doctor (mm). So it's those kind of things or that you're meeting, you've got a  
 185 long arranged meeting with somebody external to your immediate team and then you kind of  
 186 feel oh gosh. And it's probably not insurmountable. It's probably those people as individuals  
 187 would be really understanding for the most part (uh-huh) unless they're somebody like my  
 188 previous manager. But, it's, it's that guilt thing (uh-huh). I've. I have spent the last year feeling  
 189 guilty a lot of the time. Either feeling guilty that I'm not giving the time I should do to my mum  
 190 (uh-huh). Or, guilty that I'm not doing what I should be doing at work (uh-huh) 100% of the  
 191 time or I'm having to kind of send people messages going 'I'm going to be delayed, I'm going  
 192 to be here, I'm going to be doing it this evening instead.' (Mm). Those kind of things. Erm, one  
 193 example that springs to mind. Unfortunately it happened on a Wednesday. It's a bit graphic.  
 194 The medication my mum takes causes constipation (uh-huh) so she was taking over the  
 195 counter laxatives (uh-huh) to resolve that. We have had to take the laxatives out of my mum's  
 196 flat cos because what was happening was she was taking them, forgetting, taking them again  
 197 and then that ends up being a bit of a mess. So, there'd been a couple of times where I'd gone  
 198 in the morning fortunately, it'd always been either at the weekend or a Wednesday where  
 199 I've gone in, and the last time it happened it was Wednesday and [son]'s little face when he  
 200 got to the top of the stairs and realised that she'd obviously made her way across the landing  
 201 to get to the bathroom (oh dear). It obviously wasn't pretty. Um, so it's things like that, that  
 202 you don't really want to say. Ringing into your work and go 'I'm gonna be late cos I'm currently  
 203 scrubbing poo off my mum's carpet!' (*laughing*) It's the reality of what happens! Yeah.

204 I: Mm, mmm. Um, so talking about the kind of support that you receive, so obviously your  
 205 current line manager is quite supportive (uh-huh). Is there any other form of support that you  
 206 receive from your workplace? Are there official policies for example?

207 P: Yeah I. Er, it's a difficult one. It's. I can see it from both sides of the equation. So, ideally if you  
208 could get a policy that said look, you do your hours and you deliver what you need to deliver,  
209 and we'll be a bit flexible, it'd be great (mm). But obviously because we're an organisation  
210 where that policy fits across everybody from people in back office roles to people that are  
211 standing in a branch (uh-huh). They're never going to be able to introduce a policy that is that  
212 broad and that flexible (mm). And that's where it comes down to I think management  
213 interpretation (yeah) and unfortunately my previous manager didn't interpret it that broadly.  
214 My current one does (mm). But it's that kind of thing to be able to say look, I can work  
215 remotely, I can work at any time of day, I know when my deadlines are, just let me get on with  
216 it. And all that you know, where, broadly where I'll be (yeah). If I've got a meeting in the middle  
217 of the day at my mum's house I can say I'm going to be logged off between x and y. So  
218 everybody knows and doesn't think that I've gone AWOL. That, that I think is the, the number  
219 one thing that would make life a lot easier. I haven't actually had a 1:1 meeting with my  
220 manager since I've been on that team yet (uh-huh). So that's something that I need to talk to  
221 her about. Um, that, that to me is what really makes the difference. There's a few other things.  
222 When you talk about technology there are a couple of things that we looked at. My mum got  
223 scammed a couple of times in the lead up to Christmas (uh-huh) and I think it was a seasonal  
224 thing that people er. Didn't have the money and needed it for Christmas and picked some  
225 other ways to obtain it. But there was a couple of things happened in the run up to Christmas.  
226 And she'd let this guy into her house, given him £100 and then rung me up and said 'I don't  
227 think I should have done that should I?' Erm and I'm going 'No you haven't had anybody, well  
228 other than [Inaudible \*00:25:15\*] you know yeah he's just running you a line. And at that  
229 point I did go and look at technology in John Lewis's where you have some kind of CCTV that  
230 links to your phone (uh-huh) but the reality when I. I thought yeah it all looks great when  
231 you're reading the blurb. But the reality is probably every time the neighbour's cat runs along  
232 the wall, your phone's gonna go be-beep be-beep and you're gonna be in a meeting going oh,  
233 alright nothing to worry about (uh-huh). And then I was thinking do you almost get blasé about  
234 it and start to ignore it thinking oh it's gonna be next door's cat and then find that (something  
235 does happen) it's something you should have looked at (yeah) So, in the end I didn't do it.  
236 What we have done is put a dummy CCTV camera up (uh-huh). And since that's been up, as  
237 far as we know we haven't had any more trouble.

238 I: That sounds really good. (Yeah.) Erm so coming back to support that you receive. Um, are you,  
239 would you consider yourself the main carer of your mum? (Yeah.) Yeah.

240 I: We don't get any. At the moment we are on the list with social work to get 15 minutes in the  
241 morning and 15 minutes in the evening. We have been on that list now for about 9 months  
242 (uh-huh). I think the reality is that [place] social care budget is something like £130m for all  
243 social and community health and that can't go far (mm, mm). And I think there's some other  
244 issues that they used to use their own staff, they now use some private organisations to sub-  
245 contract that out. I think there were some issues in the past I've learned from [carer  
246 organisation] that previously the people that were employed in some of these positions didn't  
247 have maybe all the kind of rights that you might expect (uh-huh). That's been put right now  
248 but what's happening is now because people are able to go sick, when they're sick they go  
249 sick (uh-huh) whereas before they were just struggling on cos they knew they weren't going  
250 to get paid. Where that now I think is causing problems for them trying to manage the service

251 (uh-huh) um, where they need to know that every morning somebody's going into all of these  
 252 houses (mm). So I can imagine it is a nightmare to manage but? Yeah.

253 I: Mm, mmm. So er have they given you a date when? (No) No ok.

254 P: (*Laughing*) I just opened another letter saying we'll be back in touch!

255 I: Oh dear ok. Erm is there any help that you get from your family?

256 P: So my sister lives in [country] (ooh, OK) so there's 2 of us. So my sister lives in [country]. She  
 257 comes over from time to time. And (*sighs*) I feel really bad for her because I think. She's remote  
 258 so she doesn't know what's going on (mm). Um, so a lot of the stuff like I dunno, we had to  
 259 put my mum in respite a couple of weeks ago cos she got so ill (mm) and she was on antibiotics  
 260 and when I was ringing her up to say it's time to take your next penicillin, she didn't know  
 261 what I was talking about and she'd gone a bit delirious (mm). Um so in the end I just thought  
 262 this is not working. Um we'll have to get really shirty with social care and get her an emergency  
 263 respite bed. And that, that worked and she is a lot better now. She's out. But erm, it's things  
 264 like that, that I'll text my sister, and I'll sometimes feel guilty about that because I'm thinking  
 265 there's nothing she can do (mm) but then I'm thinking it's only fair that she knows (mm) that  
 266 some of these things are going on. Um and things like, you know the other bits and bobs that  
 267 you do round the edges that aren't in the routines. Like having to go and buy her clothes when  
 268 she, you know she's lost a lot of weight (mm) and so her clothes weren't fitting her so I had to  
 269 go and buy a whole new lot of new clothes. These kind of things, you think do you bother  
 270 telling, do I bother telling my sister about that? But then you know I think she feels guilty if I  
 271 tell her. I feel guilty if I tell her. But if I don't tell her I'm feeling like I'm (yeah). She's not part  
 272 of the equation any longer (mm, mmm). So yeah there's the 2 of us and because of. My kids  
 273 help out like I said with breakfast. There will be some things because of their age that they  
 274 can't do. So my daughter is 14, or just about to turn 14. So she's coming home from school by  
 275 herself in the afternoons and lets herself in now. Now, if she was 16, will I get a text randomly  
 276 from Boots which means the doctor's been in and they've now written a prescription and  
 277 Boots want me to go and pick a prescription and I'm 12 miles in the other direction. I'd be able  
 278 to go to [daughter], 'on your way home from school can you go to Boots?' but I can't cos she's  
 279 not 16 (mm) so she's not allowed to pick it up. Erm so yeah, they do do stuff, but there's a lot  
 280 they can't do. [son] used to do the shopping (uh-huh). Er but I used to meet my mum after  
 281 school and they'd go round Morrisons together on a Friday afternoon and he would be given  
 282 a rough idea of what they were supposed you know, what the objectives were (uh-huh) but  
 283 my mum now goes to day-care on a Friday so that's kind of landed back on my list of things to  
 284 do on a Saturday morning. So there are small things that they can do (mm) but the reality is  
 285 there's not a lot. I mean I. There's some things that you think, I could take children round there  
 286 and say look you can help me change the bed, but at the end of the day she's not going to be  
 287 able to cope by herself (mm) so it's not saving me any time. I'm still there (yeah) doing all of  
 288 these things. She's just maybe writing a shopping list while I'm making the bed or something  
 289 (yeah) yeah.

290 I: Ok I see. Er generally speaking, how do you feel about your situation of being a working carer?

291 P: Erm. Sometimes it really gets me down (mm). I was signed off, I've been signed off twice in  
 292 this period. I was signed off September through October for a month. I was signed off during

293 February. February it was predominately about work and the fact that my grievance was  
294 ongoing at the time (mm). It was just the biggest nightmare. Erm but that was interesting. Cos  
295 when I was signed off in September/October time I, I made the mistake of letting my mum  
296 know, so that she ate up more and more of my time as a result. Now as a result of that, I did  
297 go along to the Dementia Café and that was quite interesting because there's a retired GP  
298 from our local GP practice; it's the doctor that runs the Dementia Café (mm). So when I was  
299 introduced as a new person, he was talking to me and you could see his eyebrows go up when  
300 I said oh 'I'm currently signed off' and he was going 'Right you know, do social work know  
301 that?' And the answer to that was yes social work knew that. Social work still probably have  
302 so many people ahead of me on their queue of people they need to look after (uh-huh) that  
303 having some middle-aged, middle-class person signed off from their work because they're a  
304 working carer is probably the least of their problems (uh-huh). And they've probably got really  
305 elderly people that have got no relatives (mm) that they still can't find care for (mm). So and  
306 from those I get too guilty. I, I try and rationalise the situation by saying oh there's all these  
307 other people who are in worse situations, have no relatives looking after them and then other  
308 people go but that's not your job to worry about! But, that's. The reality is that yeah.

309 I: Er did you get a carers assessment from the council?

310 P: I did yeah. (Ok. Ok.) I thought that was (*laughs*). Err, erm the reality of that is that was probably  
311 a bit of a waste of time you know? It was an hour and a half out the middle of a working day  
312 where (mm) you go. It was done by [carer organisation] on behalf of social work. Cos social  
313 work. If I'd waited for social work to do it, it was never gonna happen (mm). And the lady at  
314 [carer organisation] is making all the right noises. But the reality is, what's happened as a  
315 result of it? Nothing really.

316 I: Uh-huh. Uh-huh. Do you think that's also due to not having enough resources or?

317 P: I don't know. I think it's. Yeah I don't. I don't actually know what anybody can really do to  
318 make it different. Short of us getting to the top of the queue and knowing that social work are  
319 popping in twice a day. The reality is. Yeah people. There's the opportunity for you to go and  
320 attend these things that happen in the middle of the day (mm) so people can make you feel  
321 better about yourself. Realistically? (Mm, mm.) Um. You hear about people saying you know.  
322 People have said to me 'oh you know once they know you're a working carer, they may look  
323 at erm GPS bracelets (uh-huh) so that you know that your relatives not gone wandering.'  
324 Nobody mentioned that. I think. I think the reality is [place]'s social work budget is so  
325 squeezed that if they think that they can get away with it they will! (Mm,mm). Yeah.

326 I: Yeah that already brings me to technology. So you mentioned that you have yourself been  
327 looking into technology (yeah) because you thought it might be helpful. And you've just  
328 mentioned the GPS (yeah) tracker. Are you using any kind of technology at the moment to  
329 assist with caring?

330 P: The only thing that we do is we have a really basic technology that is the, the CAS alarm. The  
331 community alarm (uh-huh) system has got now got a recording on it twice a day to say  
332 remember to take your medication. The reality is we still go in because it's not working (mm).  
333 Erm I think she hears it, she turns it off and forgets all about it because you can go in the next  
334 day and the medication's still in the snap box (uh-huh). So, my honest opinion about some of



335 these technologies is, and this is coming from somebody who works or has worked in an  
336 innovation department is, it's gotta be something that is so simple. If it's. If the person with  
337 dementia. Now obviously you'll be looking at people caring for a variety of situational  
338 conditions (uh-huh). In the dementia situation I think it's either got to be something that is  
339 happening in the background and the person with dementia doesn't even know about it (mm)  
340 and it's something that makes my life easier. I dunno maybe something on my phone that I  
341 can look into my mum's flat or something like that (uh-huh). But anything now that is new –  
342 introducing any new processes – forget it. I mean we had. Like I say I've got the electrostatic  
343 paper up in the kitchen (uh-huh). With. And I write out every week what's going on and you  
344 know, it's clumped into hours and it's got wee messages like oh 'you're running out of bread  
345 have you looked in the freezer?' and stuff like this (mm). But I don't think she looks at it (mm).  
346 Cos there's been a couple of things that's happened and she's said 'oh I thought so and so was  
347 coming' and I'm going 'but it's not on the calendar!' Erm hmm so. I don't know. (Mm, mm).  
348 Yeah.

349 I: Erm so let's just assume like you had a magic wand (yeah). Erm what would you like technology  
350 to be able to do for you personally?

351 P: The funny thing is I've now moved on in my thinking about this. And I've now got to the stage  
352 where I think, what I want. What I think is best for everybody is that my mum goes into care  
353 (uh-huh). Erm so right now if I had a magic wand, it'd be a magic wand that sorted through all  
354 the Care Commissioner reports (*laughing*). Went and visited everything, sorted out, got a  
355 place and got it. Whereas that's not really probably the answer you're looking for. (*laughing*)

356 I: Absolutely. If that's something that you think would be helpful that's absolutely the answer  
357 that I'm looking for!

358 P: Erm I think because we've now got to that situation. Because. So a little bit of background.  
359 My, my mum cut her leg in August of last year and it was, it should have been stitched (uh-  
360 huh) apart from her skin's too old to stitch (uh-huh). So they taped it and glued it and it has  
361 now healed. It's only about this big but it was about that big the cut originally (mmm). But it's  
362 ulcerated which is now where all these infections are coming from. Erm so my mum's not  
363 been in a shower for 7 months. Erm we're waiting on the boot which allows her to go in the  
364 shower but that's not coming as far as we can make out anytime soon. So that's now forced  
365 me to the situation where I just think we are going from one infection to another at a rate of  
366 about once a month (mm) so I'm out now. We are, we are looking for care homes (mm). If  
367 there'd been, if you'd spoken to me before I'd made that decision, yeah potentially something  
368 that you could see into her flat and communicate (yeah) would work. Erm, and that she could  
369 communicate back out to you (uh-huh) cos there will be. My phone network is [omitted] (uh-  
370 huh). Where I work which is out getting out towards the airport, no reception at all (uh-huh).  
371 We as an organisation have to have you know, the mobiles that we use, which happen to be  
372 on the [other network], we have [other network] boosters to, because that's the provider that  
373 we've chosen (uh-huh) just because we're out in the sticks (uh-huh). Erm, so sometimes even  
374 if my mum tries to call me, she's not necessarily going to get through (ok) because the  
375 network's not working. So yeah if there was some kind of, I dunno. Erm I'm just trying to think  
376 what you'd call it. You know, I dunno beeper or? What do you call them? People that are on  
377 call and things used to have them?

378 I: Yeah I'd call them a beeper or something?

379 P: Yeah and if I had a little-

380 I: A pager or I think that-

381 P: Yeah! A pager. If you had a pager with a video screen (uh-huh) and you know, the person's  
382 got one. Again, it relies on the person cos it's got to be so basic (yeah) for them to be able to  
383 use it (uh-huh). But that. I mean you could at least have a conversation and potentially. So  
384 things like when my mum's saying 'I don't know what you're talking about' when I'm saying  
385 it's time to take your medicine (uh-huh). That if she could even then and I'd I go 'walk in the  
386 kitchen, look on the kitchen by the hob.' And she can show me what she sees (uh-huh, uh-  
387 huh) and I can go 'it's the yellow packet.' Whereas sometimes she'll be going 'there's 4 packets  
388 here' and I'm going right ok. Um I, I cannot remember right now (of course) what they all look  
389 like and say. So I don't wanna say 'yeah it's the yellow one' when I'm going err, might not be,  
390 don't know what I'm saying (yeah, yeah). Yeah whereas if she could show it to me I'd be going  
391 'yeah that's the one.' (Ahh). I could see that that might work for a number of situations. Erm.  
392 She doesn't at the moment wander yet. And I know that that wandering becomes for some  
393 people and issue (mm) and that's where I think the GPS tracker type thing might work. That if  
394 you can have it set up that it's set that you're fine within this 1 mile radius and it bleeps (yeah)  
395 if that person goes out of whatever that radius is. And you go right ok it's time to worry a bit  
396 (mm). So that I. You know could see would be useful for you know, certain scenarios. Erm.

397 I: Do you think your mum would wear such a thing? Is, is she used to maybe wearing a watch?

398 P: Yeah you see this is it. So at the moment she's adapted to the CAT alarm. We got the CAT  
399 alarm put in quite early (uh-huh) and she's fine about wearing that. It's the. I, I can see because  
400 we've never got as far as the tracker, whether it needs to be something that almost sticks on  
401 the back of the watch face (uh-huh) or the reverse (uh-huh) so she doesn't even know she's  
402 got it. You stick it on – she wears her watch as normal. Rather than being a separate device  
403 (uh-huh) erm where you then have to go 'you know you need to remember to put this on  
404 every day.' (Yeah.) Erm. The. I've also been told about one that goes in your shoe but then it's  
405 kind of, how many do you have to have? My mum's got far more shoes than I've got and it  
406 would just become a nightmare if you go (mm) 'have you changed your pair of shoes you need  
407 to move your tracker' (mmm). Um, but yeah something that sticks on the reverse of your  
408 watch I think could work (uh-huh). Erm, I guess something about the, the door control. I saw  
409 something. I don't know whether you've seen this? There was something on Facebook not so  
410 long ago about an 11 year old boy (uh-huh) who had a Great Aunt with dementia and they  
411 had similar problems (uh-huh). She was letting people in. So he has set up some facial  
412 recognition door (uh-huh) alarm (uh-huh) where it's stored the, (uh-huh, uh-huh) the facial  
413 combination of, I dunno, a number of approved people (uh-huh). And if you're not on that list,  
414 you don't get in. So there is no more having to you know. So we put. My mum. My mum's in  
415 an upstairs flat but she's at a main door flat so it's (uh-huh) very similar across the road. That  
416 grey door actually goes straight up (uh-huh) and, and into the first floor. Hers is somewhat  
417 similar to that. When she first moved there, she just had a regular doorbell. And she'd go  
418 downstairs and answer the door. Then I got an intercom put in (uh-huh) like you'd have in a  
419 tenement flat. But that was a bit hopeless. That was initially done so that she didn't need to  
420 speak to charities that are doing doorstep (mm). When I first took over her account she was

421 signed up to give money to half the world. And. But what I was finding was through talking to  
 422 my kids, they'd buzz the buzzer, she wouldn't bother saying who is it (mm), she'd just release  
 423 it (mm). Erm so the facial recognition thing?

424 I: That's really clever.

425 P: Yeah! And that's an 11 year old kid and you think wow well done him! I'm assuming it's true  
 426 but it was on Facebook so it might be a load of guff. You never know but even the idea erm.

427 I: Well we're gonna definitely look into that.

428 P: Or voice recognition or something like that yeah.

429 I: Yeah that's really clever. Erm. Do you think you might be able to use technology at work? For  
 430 example, what you talked about a device that allowed you to be in video contact with your  
 431 mum if, if it were not for the connection, would you be allowed or able to use it at work?

432 P: Yeah. I think in principle yeah that would be allowable in obviously the kind of role that I'm in.  
 433 (Yeah.) Obviously I could imagine in some work places (mm) if you're working in a branch –  
 434 you're probably not (mm). Erm but you know for the, for a huge number of people that are  
 435 working in office based roles. I can see that that would work (yeah) but yeah no equally I can  
 436 see that there are kind of customer facing type roles (yeah) where people go no sorry you're  
 437 not doing that (mm). Yeah.

438 I: Yeah yeah. Ok great so we're already basically at the end of the interview (uh-huh). Just to  
 439 wrap up I've got a couple more questions. Erm what would you say is the, is the most positive  
 440 and the most negative aspect of being a working carer for you?

441 P: So the positive. The positive is that I think my relationship with my mum has got a lot better.  
 442 I was never. You know you hear about people who'll go 'I ring my mum up every day' you  
 443 know, they're 36 years old. I've never been that person (mm). Erm I went away to boarding  
 444 school when I was 11 (mm) and maybe it's because of that I've always been quite  
 445 independent. But, so my relationship with my mum is probably stronger now that I'm seeing  
 446 her every day. But obviously the relationship I've got is with somebody who's not quite who I  
 447 think my mum is (mm). But there's still that kind of like feeling of love even though sometimes  
 448 I feel like she's my third child (mm). Um, the negative is guilt (mm) that whichever way I look  
 449 at it I'm either feeling guilty about it and I'm not doing my work, guilty about something I'm  
 450 not doing it for my mum or guilty that my kids have had to move down the queue (mm) and  
 451 it's like right once we've finished doing all this stuff for grandma, I'll look at your homework,  
 452 or I'll do whatever it is that you want me to do (uh-huh, uh-huh). Or they get the, that I'm  
 453 stressed out about a combination of grandma and everything else so they get the nippy  
 454 mummy rather than the, yeah sure come and we'll have a look at that. They'll get (*shouting*)  
 455 '*WHAT! WHAT IS IT YOU WANT NOW!*' or you know (*laughing*)? (Yeah.) Yep.

456 I: Er what advice would you give a person that is in a similar situation as being a working carer  
 457 of someone with dementia?

458 P: I think you have got to realise that you do your best (mm) and it's good enough (mm) and not  
 459 kind of judge yourself. I think also particularly, I don't know how much this would apply to er  
 460 people caring for other conditions. But with dementia you've got to remember that this isn't  
 461 the person. What they're saying to you isn't necessarily what they mean or what the old

462 previous person would have meant (mm). So sometimes – not all the time, but sometimes my  
463 mum can be a bit nippy, a bit shouty a bit foot stampy and the initial reaction is, look I'm  
464 bending over backwards here to do all this stuff for you and you're just shouting at me (mm).  
465 And it's that. To be able to take a step back from it and just go just walkaway, you don't mean  
466 it. Erm yeah. And that you're doing your best and there might be better ways of doing it but  
467 if, if that's your best; that's your best. Yeah?

468 I: That's good advice. That's really good advice thank you. Erm and the final question would be  
469 what, what are your wishes for yourself for the, for the future?

470 P: This is gonna sound so selfish. But having a resolved all my work situation, my next one is to  
471 get my mum into a care home where she can be properly looked after. So that when I do go  
472 and visit her, we're actually. I can't imagine it's going to be an amazing conversation cos you  
473 know, that's just not where she is. But, spending as close as possible to what you might call  
474 quality time, rather than saying 'give me your diary, show me your purse' you know 'let's have  
475 a look what's in your fridge' (mm) erm and just be able to chat. Even if it's a one way  
476 conversation (mm) erm and have yeah. That bit of quality time rather than feeling. And then  
477 also by the same token, some spare time for myself (mm) that isn't taken up with work or  
478 grandma.

479 I: Yeah yeah (yeah). Thank you very much.

480 P: Oh thank you!

481 I: Erm just to, to wrap it up. I've got just a couple more questions (uh-huh) that are for context  
482 sake (yeah). So they're going to be really quick because most of the questions we've already  
483 answered (yeah) during our conversation. So er can I just ask you how old are you?

484 P: Me? I'm 50.

485 I: 50, ok. And erm what's, what's the highest level of education that you have?

486 P: Er not a lot actually to be honest. Erm I did my A Levels and er because of my epilepsy I never  
487 went to university (uh-huh). I went and did a kind of Business course (uh-huh) in a  
488 independent college in [place]. And that's the limit. Yeah.

489 I: Well that's great! Erm yeah and er the final question that I have is. So you mentioned that you  
490 are married? (Yeah.) Is your husband providing care as well for your mum? Helping out?

491 P: He will from time to time. So. And particularly the fact that I'm not a driver (mm). That comes.  
492 He will do stuff from time to time. My mum's got to have her cataracts done. Last cataract op  
493 he drove us there, drove us back. Last night I went out in the evening with my new team (ok)  
494 so he and the kids will fill the gap last night and on the kind of checks and so on (ok).  
495 Sometimes that doesn't necessarily work! Erm and you go 'did you find out if this happened?'  
496 'Oh I forgot about that.' Erm you know, there is that willing there yeah yeah.

497 I: Yeah, yeah ok. Great and that's it! Thank you again so much.

498 END