

Interview 12, "Liam"

Date: 25.5.2019, Duration: 67min, Setting: participant's home

I = Interviewer, P = Participant

I: Ok so, tell me a bit about the caring situation-

P: Er, so it all happened maybe around seven years ago where my mum had, she got rushed to hospital with a perforated bowel and er, to cut a long story short she ended up getting flown away to [place] and she was in hospital for two weeks on a life support machine but she managed to come out, but then in the process of getting better, well in the process of the trauma and two or three weeks later we realised there was something up with her, she wasn't thinking and speaking as quite as clear as she was before she went in and it turns out that was Alzheimer's (aha) and she, we knew we'd have to care for her initially anyway but then we didn't realise, we didn't know about, to an extent what dementia and Alzheimer's and everything else was; we've soon since learnt but we were caring for her three weeks, four weeks, five weeks before we knew that, before we could probably get a care package by the local Council and so that was quite tough and since then we've got a care package but we're still, thankfully we're still caring for her but thankfully because there's quite a few of us, we're able to take the load as opposed to just have my dad do it, because he obviously lives with her. So, and now we've got into a, we've got a rota for meals, visiting her, making sure she gets her medicine and water and spending time with her as well.

I: Mm, so when you say we, you mean your siblings and yourself?

P: That's right, yeah.

I: Yeah, yeah, is there anyone else that is included from maybe your wider family or neighbours?

P: No, in short, no, but there was a local group called [name], I think, and they could provide someone who could come in and spend time with her. They came once and it just, my dad didn't think it was suitable the time because the day that they came was a Friday, there was a lot of people there and we, she, well my dad felt that she was just not being utilised as best as she could be if she was at someone else's house. So he just said 'it's ok, you know it's fine' and recently we've got in touch with them again and she visited, or some woman visited and is happy to come round and hopefully we take that on, it's obviously my dad who makes the decision but he's so used to trying to do everything himself, which is so dangerous because it will have a detrimental effect on his health (mm), maybe not physically initially but eventually it would because of the strain and stress and everything. So hopefully he does take that on and it helps us as well and, but there is a woman who would come in from Alzheimer's, local [organisation] and just sit with my mum, my mum initially when she started arriving, it got, my mum was at the stage that she couldn't really, she couldn't converse so and now I don't even know if she's aware that anyone's here, so when she comes round, she just sits with her and she's really good because she doesn't expect

40 conversation back, she just talks to her and er, and she says she can definitely and we know
41 my mum can hear but now she physically cannot respond back (ok) but as far as, yeah
42 there's just that, [name] and the Alzheimer's and I'm still not sure if the Alzheimer's lady is
43 still coming back but it would be maybe once every three or four weeks for two/three hours
44 or something but besides that, that's it.

45 I: So, was that you and your family reaching out to those organisations or how did they, how
46 did you get in touch with them?

47 P: I think it, I think it was us getting in touch with these organisations, yeah. The help was
48 probably offered to us initially when my mum first came home out of hospital, but because
49 we'd never cared before, we had never had to care for someone before, we didn't know the
50 true extent of how it would impact our lives. We would, we said, it might have been offered
51 by Social Services, Social Care; 'there's agencies available to help, would you be interested'
52 and we said 'oh, I'm sure we'll be fine just now' (yeah) but obviously with dementia there's a
53 definite trajectory that her health is going and you know, maybe we in hindsight, wonderful,
54 we could've accepted that help knowing but we didn't have a good understanding and
55 knowledge of dementia at the time, so we just said 'it's ok' (mm) yeah.

56 I: Yeah, aha, can you talk a bit about the care that you personally provide for your mother? So
57 what, what does a like a typical day look like when you provide care for your mum?

58 P: So, a typical, so we have a rota, and it would be, the idea was set up so my dad wouldn't
59 have to do everything because he stays with her and he would feel obliged being her
60 husband to care the whole time, so we designed a rota and the rota was based on the time
61 available from, the time available that me and my brothers and sisters had. As it happened,
62 it ended up being me and my brother [1] that did a lot and the rota would be feeding my
63 mum breakfast, lunch and dinner (aha), spending time with her and making sure she had
64 water. So, within that, so a week could be- Monday I would feed her breakfast which now
65 can take up to 45 minutes (aha) and then lunch and dinner. So Monday would be breakfast
66 and then evening meal, Tuesday would be evening meal, Wednesday breakfast and lunch
67 and then Friday breakfast and lunch and then Sunday cooking the Sunday roast for everyone
68 and feeding my mum, but then on top of that, spending time with her, so maybe going
69 round to the house three/four times a day, just checking in on her because my dad's got a
70 concern that maybe she, she might you know fall over on the couch and she doesn't have
71 the ability to sit up because on top of her dementia she's got MS so her motor movements
72 are gone, she can't walk and eat; she doesn't have the strength. So, constantly checking in
73 on her and making sure she's getting enough water, also sitting with her so for example-
74 Monday, go round, give her breakfast, maybe come along again at 11am, give her some
75 water, speak to her, chat to her and then go along again at maybe half two/three, do the
76 same thing again; evening meal, give her meal, yeah. So, each day varies but you know that
77 would be like a busy day.

78 I: Mm, can you put a number on it- how many hours a week you on average do these tasks?

79 P: Hmmm, maybe four to five in total (aha), four to five hours, off the top of my head, yeah.

80 I: Ok, so you mentioned that you have a care package for your mother (yep), who is it in your
81 family that coordinates with the carers?

82 P: First point of contact would be my dad (aha) and then, because we would like to have, if
83 there's any correspondence usually the same person is making the correspondence because
84 you have a better understanding of who it is you're speaking to and they, likewise, who
85 they're speaking to (mm) because we've got such a big family it wouldn't make such sense to
86 have five different people from the same family speaking (yeah, yeah). So, it would either be
87 my dad or my brother and they would take that on because they were both lawyers so they
88 are, they might carry a bit more clout and they might be taken a bit more serious.

89 I: Mm, ok (yeah) yeah, ok. So, talking about your work situation, can you tell me a bit about
90 your job?

91 P: Ok, so up until recently I had three jobs, I was working as a, with the Fire Service, a full time
92 job, 35 hours a week but then I've got two part time self-employed jobs as well and that
93 would be running a [business], [business description omitted as it would be identifiable]., and then the other job was I've got a camper that I hire out (ok), so getting that prepared
94 and getting that ready for the guests to hire out. But I left the Fire Service four weeks ago
95 and so now, it's really, last year, it was full on trying to do three jobs and I do a lot of kind of
96 sports, I train for different sports and I try and have a social life and look after my mum. It
97 got full on, so I said 'nah, that's it' so I left the Fire Service and now I've just got two jobs.

99 I: So, on average you can, how many hours a week do you work on those two jobs?

100 P: Thankfully it is a lot less, I would say [long pause] maybe 17 at a push (aha) yeah (ok) fifteen
101 to seventeen.

102 I: Ok, can you tell me a bit about those jobs regarding um, so what does a typical work day
103 look like for you?

104 P: So, it would be, once I'd fed my mum on a Monday for example, I would go into the garage
105 where I keep my stock for the [business], fill the boxes up, then drive around to the various
106 sites, should normally be done by about 11 am at a push and the idea was to have the rest of
107 the day to do what I wanted. If the camper is going out that day, I would also get that
108 prepared, so get, complete wash inside and out and get the linen and then, that might take
109 an hour and a half, so could be done by half twelve or one o'clock.

110 I: So, with regards to when you work, that's completely up to you? (Yeah) and also the ability
111 to take breaks, is that as well? (Yeah) so whenever you get a phone call for example, you
112 could just, there's no, there's nothing-

113 P: Nope, I'm the boss (ok) yeah (great) yeah.

114 I: So maybe talking a bit about the job that you used to have with the Fire Service (yeah), can
115 you maybe tell me a bit about a typical day that you used to have back then?

116 P: Yeah, typical day would be- start at, so feed my mum and then start at 8am and then there'd
117 be a lot of office work for the first couple of hours and then I would be out in my van,
118 speaking to, going round the houses doing fire investigations in homes and maybe until
119 lunchtime and then in the afternoon a bit of paperwork, maybe emails and then finish at 4
120 o'clock.

121 I: Ok, so with, with that job was it just a weekday, did you have to do Saturdays- (Just
122 weekdays yep.) Just weekdays ok (yeah) and the times when you had to go into work and
123 you were able to leave, they were always the same?

124 P: Yeah, essentially yes, I was, it was a good job in the sense that I managed the hours (aha) so
125 it was 35 hours perspective week, but you decided when you would start and finish. So
126 that's why I decided to go in at 8 and finish at 4, just to free up some time (ok) yeah but
127 there wasn't a great deal of pressure in terms of having to kind of do certain hours.

128 I: Yeah, so regarding that job, did, were you able to take breaks at that job when you needed
129 to, for example to take a phone call or something like that?

130 P: Yeah, it was good that because I managed the hours myself, I could leave, say if something
131 happened with my mum I could head up to the house and it was only a mile away so, which
132 was partly the reason that me and my brother [1] he was in the same position, he could
133 leave his job a lot of the time to go, so if there was any issue then we could answer the
134 phone call, if it was a doctor phoning, we could answer that or if the doctor was visiting my
135 mum we could you know drop everything and head up (mm), so it was really flexible.

136 I: Ok yeah. Did anyone from your former know that you were a carer for your mother?

137 P: Um, in a local capacity, yes, and my line manager who was based in Inverness, he did, but
138 they probably, they knew my mum wasn't well and I would say, I said to my line manager
139 'sometimes there's, I have to kind of go up and just check she's ok' so they probably didn't
140 realise the full extent of what being a carer was (ok) you know the kind of, how often I
141 would go and, I definitely wouldn't say if I just thought it was a bit easier to not tell them the
142 extent of how often I would go and see my mum (aha) you know they didn't need to, they
143 were in Inverness, they didn't to know, you know, if they knew they might have, I don't
144 know, there could have been a fear or, there maybe was a fear they could question 'what
145 are you doing' you know, 'you can't be going up there..' I don't know, I just thought what
146 they don't know won't harm.

147 I: Yeah, did you feel that they were supportive towards your role as a carer or-

148 P: I guess so, yes, I definitely wouldn't say they ever objected to anything I did you know, any
149 time I mentioned 'my mum's not well so I have to look after her' they would be very kind of
150 sympathetic towards us.

151 I: Ok and regarding your colleagues here on the island, did they know about it?

152 P: Yeah, yeah they knew, they knew and very much the same, just 'that's fine, whatever you
153 want to do, go and do it'.

154 I: Yeah ok, aha, aha. Have you, did you have the opportunity with the paperwork that you
155 mentioned to work from home as well?

156 P: I never did, I would of [sic] I would of yeah, erm, but I never took that opportunity to do that
157 and I don't really know why. It might have been a guilt thing, it would be better just to do it
158 at work as opposed to spending too much time away, yeah.

159 I: So, thinking about combining work and care, so were there ever any situations where caring
160 impacted on your work back then, back at the Fire Department?

161 P: Erm [pause] to be honest, I always put my mum first as a priority, I didn't care about work
162 (aha). Given the choice of the two, work was second and if anyone said anything I would've
163 left work (mm, mm) I would've been, you know, it's, and that's why I was more than willing
164 to be the first, to have my phone available for anyone to call (mm) you know, can say, we've
165 got a WhatsApp family group and if someone said 'the doctor's coming up, I've got a
166 meeting, I can't make it, can anyone go?' or 'can someone go to the pharmacy and get my
167 mum's medicine' or- 'yeah that's fine, I'll do it' because she is unable to and my dad's 77 or
168 78, can't remember and he would do it, always, but I'm a lot younger and you know, I'd
169 rather do it myself than him. She couldn't do it so yeah, I always put her first and work came
170 second and there was no, there was no question of that.

171 I: Did work ever impact on your ability to care for your mum? So, was there ever a situation for
172 example when you got a message, 'something happened, can you please come' and because
173 of work that just wasn't a possibility?

174 P: No, no, no. I was quite fortunate with the job I had that that was never the case (aha) yeah.

175 I: Ok, how do you personally feel about being a working carer? Now at the moment and back
176 then when you still worked for the Fire Department?

177 P: It was just something, you know, life isn't always straight forward and sometimes things
178 happen and you've just got to take it on the chin and you know, my thought process was my
179 mum looked after me when I was younger, and now it's you know, life, things go on, things
180 change, things happen and she's in a position that she's in now, so it's my turn; I'll look after
181 her, along with my brothers and my dad and you know, my sister when she can. So, yeah
182 that's, that's just the attitude I had, I mean I think brother [1] was the same, it was just a
183 case of 'yeah, that's fine, whatever it is, we'll do it. We have to, you know'.

184 I: So how does that work with you as siblings, how do you coordinate yourself?

185 P: It's, a lot of the time it's just through the family group on the WhatsApp. Someone would,
186 you know we would communicate there and it's all very amicable, we would always say 'can
187 someone do this time. I can't manage my Monday slot for lunch, can anyone do that' and
188 then someone would either swap or just cover it. So, yeah we worked well to', we work well,
189 in that sense.

190 I: Has it ever happened that for example you would have to find someone else for a slot and
191 there was no one available? Has that ever (yeah) yeah?

192 P: Yeah, erm, me and brother [1] always, well we do more than anyone and sometimes my
193 sister [1] obviously lives in [place] (aha) so when she's not here, she can't do anything, but
194 my other sister, she's got a daughter so, my brother works, he's got a family, so a lot of the
195 time it was me and Brother1 who, we'd both if us aren't married and we don't have family,
196 kids, so we, I don't know if the others felt that we had more time available and there was no
197 dependents so we ended up having to do quite a bit more. So if, if for example someone
198 couldn't do a slot, I would just, whatever my plans were, I would drop it. If it was work or
199 training or social stuff, whatever, it would be dropped because well, my mum's not going to

200 feed herself and it would be quite selfish for me to go 'no, I'm off swimming' or 'I'm off to
201 the cinema' (aha) you know that's yeah.

202 I: Did that happen often?

203 P: Hmm, I don't know, I mean I, I wouldn't say too often but I wouldn't dwell on it too much
204 because well it's life you know it's, these things happen. Over the course of six years or
205 seven years, it had definitely happened because me and Brother1 were used to taking care
206 of my mum more than the others (mm) and I don't think they realised how much what we
207 did, um, but getting upset and moaning about it, well that's not going to do anything you
208 know, so you just go 'that's fine, whatever, tomorrow's a new day, we'll start tomorrow
209 again' yeah.

210 I: Ok, do you ever though try to talk to your siblings about that when that comes up, 'how can
211 we make sure this is more fair on everyone?'

212 P: -laughs- sometimes [pause]. Yeah, I guess, there was definitely, there's definitely room and
213 there has been room for me to kind of confront them a bit more (aha) I mean [partner] is
214 always saying 'you need to speak to them more' but it's like when something's so obvious
215 and staring you in the face, it doesn't have to be said you know? (mm) It's like erm, it's just
216 too obvious, so we have said it and you know, I, I've not been as forward in just saying 'look-'
217 there has been times we've said it in those early days, but how many times do you keep
218 saying something? They know it, we've told them and then so many times, me and Brother1
219 have just gone- give up, what's the point you know, it's no surprise; they know what needs
220 to be done but -sighs- less needs to be done now, in the sense that we don't have to visit my
221 mum quite as much as when she had early stages dementia. So, there's less required and
222 less asked of us.

223 I: So, in terms of, when you say what's asked, in terms of how much care is needed, how do
224 you decide as a family group how often you need to go visit your mum-

225 P: Yeah, so for example, she was taking two litres of water a day, so we measure the intake of
226 water that she takes and she was taking two litres of water a day and that definitely
227 required going to my mum's in the say middle, 11, say between 10 and 11 o'clock to make
228 sure she gets her water and then again in the afternoon to make sure she gets more water,
229 in addition to breakfast, lunch and evening. Plus, spending time with her where she could
230 hear, she could maybe chat to you early days and just making sure she wasn't on her own.
231 Plus keeping my dad company as well because you know, he has said at times that he gets a
232 bit lonely because he's there on his own really.

233 I: Mm, mm, so, it's, it develops basically out of-

234 P: Yeah, so dynamic and then over time you realise you know, how much involvement you
235 need to have and things change yeah.

236 I: Yeah, so, talking about technology now, so you already mentioned the WhatsApp group
237 (yeah), can you tell me a bit more about how that works for you and your siblings?

238 P: So we've got a WhatsApp group and it's actually a group that doesn't have my dad in it (aha)
239 because there's all groups we're all excluded from -laughs- so and it's just easier if he's not in
240 it because we want more stuff ourselves because he would always say 'oh no, I'll do it, I'll do

241 it, I'll do it' and so any time there's a phone call from the doctor or there's any update
 242 concerning my mum, we would always put it onto this group and/or the family group, where
 243 my dad is in it (aha) and it's really good because it's obviously got a record, you know and
 244 it's, there's photos as well so you can put photos onto it so you can quickly see, say if you
 245 took a photo of my mum's list of medicine, you can go onto WhatsApp group, go to the
 246 media and see the photos and any, plus you've got the voice messages as well so it's a lot
 247 easier to (mm) you've got, you can put a message across to everyone at one time and you
 248 can do it instantly so any information you hear you can instantly put it on before you forget
 249 it and it's on record, it's there.

250 I: Aha, so for the group that your dad is not part of, does he know that you have that group?

251 P: -laughs- I don't know (laughs) he might do -laughs- I don't know if he's that switched on,
 252 maybe not. He's not amazing at technology so he probably doesn't realise.

253 I: Ok. Who was it that came up with that idea to use WhatsApp?

254 P: Ooh, I don't know. We all use it, we've all got our own WhatsApp phones and but I don't
 255 know, I mean yeah, what, me or my brothers; one of us-

256 I: It just developed (yeah) yeah. How happy are you with WhatsApp, is there anything that you
 257 would like improved for example, any additional features that it could have?

258 P: Ooh um, off the top of my head, I'm gonna say no. There's nothing that jumps out, there's
 259 nothing that I think if there was, oh you know, over the time that we've used WhatsApp,
 260 there's nothing that I think this would be a really good function to have (aha) erm [pause].
 261 No, I can't think of anything that would help.

262 I: Would you recommend it to someone else who was combining work and care?

263 P: Oh yeah, definitely (mm). It's a really good tool for communicating, really, really good. It's so
 264 handy (yeah) and just that, for sending photos it's instant, as long as you've got broadband,
 265 WIFI or 3G or whatever, yeah and it's fantastic for recording information and it's always
 266 there.

267 I: So, talking about the camera that you already mentioned, tell me a bit more about that.

268 P: So, the camera came about by chance, I think it was Brother1 who came across it, he was
 269 looking to find a way because my mum was having seizures and hopefully that's past tense
 270 and gonna be past tense. I don't think she's going to have, well I don't know, I don't know;
 271 hopefully she won't have any more but there was a period where she was having seizures a
 272 lot and my dad wouldn't leave the house in fear of her having a seizure and him not being at
 273 home. So he was- 'I've got to stay at home' I says 'dad, that's not healthy, you have to leave'
 274 so Brother1 obviously thought there's got to be a way, so he went onto Amazon and found
 275 this camera and the good thing was in addition to this camera there was a speaker, so you
 276 could speak to my mum and you could reassure her and just tell her that everything, you
 277 know because she, you could see on the camera and you could hear her and she might be
 278 distressed because there wasn't anyone around. So you could speak to her and she was able
 279 to understand, you know when you said 'mum, remember we've got the camera over there
 280 and there's the speaker so if there's someone speaking to you then it's probably through the
 281 speaker, so don't be panicked, it's ok' and that was good and allowed my dad to leave the

282 house and definitely helped him yeah, get a wee bit of independence and the camera's great
 283 because it works and there's a night vision mode. I think it cost 35 pounds perspective
 284 camera, it works off WIFI. There's also a motion sensor so if there was someone with
 285 dementia who had mobility then I guess you would get an alert if they got up and started
 286 walking around which is, a definite risk and concern for some people but yeah, it's really
 287 good.

288 I: So, the function that you can also talk to your mum, is that all in one device or is it an extra
 289 speaker somewhere, positioned somewhere?

290 P: Yeah, so you buy the speaker in addition to the camera, so you just plug the speaker into the
 291 camera but it works off the app, there's an appointment for the camera and then it's just
 292 touch of a button and just record and it goes through (hmm). There is a slight delay with
 293 what you say and what the person being cared for hears through the speaker, might be
 294 two/three seconds (aha) but that's, that's the only kind of um, thing that could be made
 295 different with that camera. If there wasn't a delay it would make it, because they don't
 296 understand and a conversation might be all over the place (aha) you know, they might start
 297 asking something before what I say comes through on the speaker (ah, ok) so it would be
 298 quite confusing and you definitely don't want to confuse someone who's got dementia.

299 I: Definitely yes (yeah). I'm wondering, how did your mum react to that disembodied voice?
 300 Was that ever-

301 P: Initially, when she had early stages' dementia she was, she was ok with it, she was fine and
 302 then as time went on she didn't, she was questioning where it was coming from and then
 303 eventually she didn't, she didn't know.

304 I: Aha, but it was never so that she'd maybe got afraid of it or something like that?

305 P: No, no (ok) thankfully not.

306 I: Ok, do you have any suggestions other than the time lag, how to improve that technology?

307 P: Erm, I don't know, because I can only comment on the state that my mum's in (aha) and she
 308 didn't have, she doesn't have her mobility, so the camera that we use is suitable for the
 309 needs that we have in relation to my mum so, there was never anything, I mean -sighs- it, it
 310 is a really good app. For example, you can record what you can hear, so if I go onto the
 311 camera via my app, I can hear the clock ticking or conversation in the room that she's in.
 312 There's was one time where, I can't remember the exact thing, there was dispute with the
 313 carers and us and they, I, I can't remember the specifics, it was something about what the
 314 carers were doing or maybe weren't doing (aha) and we were speaking to the carers'
 315 supervisor, who said I don't know- 'we can't trust what you're saying'-

316 I: They said that to you?

317 P: Something like that (ok), we needed evidence (ok) so what we did was, we said 'that's fine,
 318 you know, we're not lying here, our main, primary concern is my mum and if we don't feel
 319 that she's getting the best care, then we're not gonna sit back, we're gonna do something
 320 about this' (yeah). So there's a record function, so when my mum was, and the carers were
 321 coming in to see my mum, we could record the footage and we could record the audio, so
 322 we could use that as evidence to put to, I don't think we ever needed to, in the end they

323 believed us, they took our word for it. Like I says because my dad has been working as a
 324 lawyer for 40 years, he doesn't, he doesn't suffer fools (mm) and he's got, maybe this is a
 325 thing for people in their 70s who've been working their whole lives or just for people who,
 326 the type of work that my dad was in, but they've got -laughs- they've got something I don't,
 327 they've got a tone, they can speak and people listen and they know there's a good bit of
 328 gravitas behind what they're saying-

329 I: So, sort of an authority (yeah) yeah.

330 P: Yeah, authoritative tone (yeah) which I wish I had -laughs- but from him speaking, they were
 331 able to go, take on board what he said and there's probably a fear as well because he's a
 332 lawyer, maybe (mm) but it's, the camera is, it's brilliant. It's allowed us to do so much and
 333 say if my dad, say we know that no one's gonna be able to see my mum for two/three hours,
 334 we'll put onto the appointment 'can people just keep an eye on mum on the camera
 335 because you know, I'll not be able to go and see mum this afternoon' and two or three will
 336 respond- 'yep, no bother' so they're periodically checking on the camera.

337 I: That's really good (yeah, it's really good). So, do the carers that come in know that there is a
 338 camera?

339 P: Yeah, so we've told them and-

340 I: Has there been, has there been any conflict regarding that?

341 P: No, so we'd said it is, we told them the truth which is we've got cameras in the lounge, a
 342 camera in the lounge and a camera in her bedroom to allow my dad to leave the house
 343 because there was a fear that she might have a seizure and he couldn't leave the house' and
 344 there's never been any conflict made known to us, they might think oh, what are they doing
 345 (mm). Who cares? I couldn't care less, my concern is my mum so you know and er-

346 I: So, when you did get the camera? That was at a time where your mother was at an earlier
 347 stage of dementia?

348 P: Yeah, that's right.

349 I: So, did you, did you discuss it with your mother at the time that you got the camera, to say
 350 this is what we're thinking?

351 P: Yeah, yeah, we described, we said 'look mum, we've got this camera and it's just to check in,
 352 just to make sure you're happy, to make sure you're ok' and she goes 'yeah, that's fine, no
 353 problem, that's ok'.

354 I: So, from the rest of your family, were there any concerns regarding the camera that was
 355 going to be put in place?

356 P: No, no, we were all of the opinion that whatever equipment we can get that helps all of us
 357 as well as my mum, then that's fine, that's good (yeah). If it's something that's gonna help,
 358 we'll take it on board and we'll welcome it, yeah.

359 I: Yeah, that sounds really good. Have you ever considered any other kind of technology to
 360 help with caring, either you yourself or you as a family group? Has there ever been

361 something that you maybe have used or maybe thought about using but then have decided
362 against?

363 P: Yeah, just going back to the flat I was telling you about in the Nursing Home (aha) that's got
364 pieces of equipment set up, I went along just to see what they had and there was quite a
365 few- [to someone else- are you away? (yeah) cheers] - there's quite a few things that were
366 good that could have been suitable for my mum and for us, had we known about it in the
367 initial stages of my mum having dementia (aha) for example there was a clock, size of an A4
368 page and it had in bold the time, the date and the day because she would quite often say
369 'what day is it? What time is it?' you know. So things like that which we got that from the
370 [dementia organisation], which it would've been fantastic if they had told us that about it
371 earlier on, but also there was a thing I seen which is a bit like a robot and it's got a screen on
372 it and you can kind of speak to it via your app. and it can speak, it'll have your face and the
373 person, so for example my mum would see my face on this robot and you could reassure her
374 and you could go around the house and it like, it had wheels and it's a bit like these, have
375 you ever seen these in hospitals? (Aha) Yeah it's a bit like, it's just a small robot with a screen
376 and-

377 I: So, it would be your actual face (yeah), not just a simulation of your face?

378 P: Yeah, you're actual face.

379 I: So, you be basically like on Skype, you would be on this (that's right) robot, moving around
380 the house (yeah) ok.

381 P: But it's so expensive, it's like two/three thousand pounds (mm, aha) yeah and at the time
382 when I seen it, well my mum, it wasn't suitable for us to get that for my mum.

383 I: Yeah? Um, why is that, was it too late?

384 P: Yeah, she just wouldn't have understood, she, her, she, yeah she, it would make her, she
385 was so confused it would, she wouldn't understand what it is (mm, yeah) at all (yeah) yeah.

386 I: Was there anything else in that show flat that you thought that would've been good, had I
387 only known?

388 P: Erm, there was one other thing, there was three things, erm, off the top of my head, I can't
389 remember, no.

390 I: How did you learn about this show flat I'm wondering?

391 P: It was just through my work at the Fire Service, working with the different agencies and just
392 through conversation with the [dementia organisation], they said 'oh, if you're interested-'
393 because I think I might have said 'if only there was something, a bit more technology or
394 whatever' and they brought this- 'you should go up to this flat and it's designed in a way for
395 you to see in different parts of the rooms what is suitable for different areas of the flat' but
396 it was just a chance conversation.

397 I: Mm, yeah. Was it just you that went there or did your siblings go as well?

398 P: Me and my, asked my, the only person who could make it at the time was my brother [2].

399 I: Where would you want or expect that kind of information to come from about what support
400 is out there for people, carers, so not just technology (oh-) in general?

401 P: I would expect that kind of information to come from the, maybe the Social Care or,
402 probably Social Care and at the initial diagnosis, because we didn't know what dementia
403 was. In general terms we knew that you get confused and it eats away at your brain and
404 everything else, but we didn't know the stages and the processes but people do and then
405 when someone says to you 'your mum's got dementia' you go 'hmm, ok, ok she's got
406 dementia' and then you learn over the matter of six/seven years, whereas she should be,
407 when she gets told she's got dementia, someone should say 'this is what it is, now, this is
408 technology that would really help you. You won't need it now-' my mum was at an advanced
409 stage so by advanced meaning was the trauma from the time that, the traumatic even that
410 she had, it acted as a catalyst for her dementia. So when she came out of hospital she might
411 have been two/three/four years ahead (aha) so, but what someone should say is, it would
412 be really beneficial if as soon as the diagnosis has been made, for someone to, even as
413 simple layman terms- 'this is the certain stages that someone with dementia will go through;
414 this is technology that will help throughout those stages' even from day one (right) because
415 we felt that we've been left to fend for ourselves in the sense that we have to do our own
416 investigation and chance conversations, Google searches for things, thinking outside the box
417 you know, if there was something like 'dementia camera', now that would be simple, that's a
418 really good business idea for someone to you know, come up with, whereas what you've got
419 to do is instead of typing in 'dementia camera', which doesn't exist, you've got to go camera,
420 you know, 'to be linked in with WIFI that you can speak through' -laughs- you know, you've
421 got to really think outside the box and find something that's designed for something else but
422 is actually we can use it for my mum, whose got dementia.

423 I: That's actually something I wanted to ask you is, the camera that you have in place, so it was
424 not marketed as a care tool (no, no). Do you, can you remember what it was marketed as?

425 P: Just as media security camera, yeah.

426 I: Yeah, ok, so did your mum get the dementia back when she was in hospital because of the
427 health issues that she had or was it at a later stage?

428 P: Yeah it was probably 2/3 months after leaving hospital because she was confused and we
429 said to the doctor when she was in hospital 'she's quite confused' and he said 'it's probably
430 because of all the drugs' she was on, she was on a lot of drugs and there was two pages of
431 drugs to help her become better and we said that's fine because you listen to a doctor in
432 good faith and that might very well have been normally the case, you know, the drugs do
433 make someone confused. But then two months later we said 'hmm, she's still confused, the
434 drugs must have worn off, it's been two months' so, maybe over the course of the next two
435 months or maybe it might have been longer- four or five months, we got someone, she was
436 invited in to the hospital and I don't know if it was a psychiatrist or a psychologist, someone
437 did a test on her and said yes she's actually, basic questions and understanding and memory
438 and she completely failed at and she said 'yeah, she's got dementia and she's at the stage
439 now where the initial drugs we could give, won't have any effect on her' (mm, mm) yeah.

440 I: Yeah, that really would've been a good time to get in touch with someone to explain what
441 that means (yeah) yeah.

442 P: And it's, what it is, the biggest issue is, which is quite common, you've got no, you have
443 different agencies, so [dementia organisation], NHS, Council services being Social Care,
444 Respite Care, Technology designer maybe or whatever, but no one speaks to each other,
445 which is so common, so common. People are, are so, they will do their job and that's it,
446 where there needs to be something that marries it together. So, in terms of technology, that
447 could be easily fixed. Now the way to fix that is an app; simple. You've constantly got your
448 phone on you, you can see it over there, but everyone carries their phone, they don't leave
449 the flat without carrying their phone; everyone's constantly looking at their phone. If you
450 have an app and it says 'your, someone you know has Alzheimer's, here's a breakdown', in a
451 real simple bullet point and suggested pieces of technology to help. So you might have like a
452 timescale, it says if your, 'if someone you know has just been diagnosed with dementia, then
453 don't worry, we're here to help; this is the stages' because it's all about understanding (mm)
454 as opposed to learning the hard way (mm, mm) 'this will help you, this will help you, this will
455 help you, maybe go along to speak to your doctor to get this drug' you know and apps can
456 be updated but if you can get it designed by and get the information installed, so get the
457 app' designed and information comes from reputable, say like the [dementia organisation]
458 for the UK or something, where they can insert information into this app so it becomes
459 credible you know where they could, new findings, new research has been found, it can go
460 onto the app.

461 I: Have you ever used the internet to look for information regarding dementia, regarding
462 caring for someone with dementia?

463 P: Yeah, not for a long time but yeah and you just get streams of and you don't, where do you
464 start, where do you choose you know and the, the difficulty was we were in a situation
465 where a lot of the information we got would be to do with mobility (aha), someone with
466 dementia who has their mobility, that is a big concern because someone with, whose got the
467 mobility will go and turn the cooker on, put their kettle on the hob, will leave in the middle
468 of the night, will just leave their house, they'll jump into a car or they'll forget where they
469 are; all this. So that is where a lot of the kind of information is, but someone who doesn't
470 have, that's where we found, a lot of the information wasn't useful for us because (mm) and
471 that's, and technology, that's not applicable to us. My mum doesn't have mobility so she
472 can't move around, so we were limited, so that takes away two thirds of the technology or
473 the information, so what, you know, that's why we had to kind of learn things ourselves.

474 I: Mm, so would be good to have a way of personalising the information that you find online
475 (yeah), make it more suitable for your-

476 P: Yeah, just filter it (yeah) yeah, you know it's simple, does mobility- yes/no, in normal life that
477 works.

478 I: Mm, yeah, absolutely. A bit more abstract question, so if you had like a magic wand, if there
479 were no limitations, what would you like technology to do for you?

480 P: Hmm, at what stage? Any stage?

481 I: Say now, in the situation that you now, what would you like technology to do for you? Or
482 maybe also a couple of weeks back when you were still working with the Fire Department?

483 P: Ok. Let me think about this. So, it would, it would be a piece of technology, for example,
484 you've heard of Garmin, Garmin watches (aha), so runners and cyclers use them (aha), so

485 technology with Garmin watches is moving on and is getting quite advanced, but if there
486 was something similar, a watch that she could wear that, that technology is linked to an app,
487 so on the day I could see how her sleep was that night, was she awake, just a simple, you
488 know the same information you get from a sleep appointment where it tells you deep sleeps
489 and light sleeps throughout the night, her heart rate and maybe things like you can get
490 information that tells you, you know, how much water she's drank, is she hydrated and stuff
491 to talk about her health because it's, for example the sleep, that is she, is it dementia or did
492 she not sleep last night you know, is that actual dementia confusing, is the confusion coming
493 from dementia or is it because she didn't sleep. What's her heart rate like? Is it going to lead
494 to other problems and like for seizures and (aha) so it's a real monitor health check (aha).
495 Yeah, that, that something to reassure us, knowing that she has had you know enough sleep,
496 she's had her meals, she's had her medicine, she's physically fine. If you had that
497 information, it could use it to tell you what could be the likely outcome and you could
498 prevent it (mm), prevent seizures or whatever because the thing is with her seizures, when
499 she comes out of them, the dementia is much worse and you can't reverse dementia. So
500 yeah, something that tells you her health state, yeah.

501 I: Yep, that's really interesting, ok. Is there is there anything else apart from technology that
502 you think could make it easier for you?

503 P: -sighs- Ooh er [pause] I don't know. Someone that could remove the dementia -laughs- (mm,
504 mm) because it is what it is, you have to be there, you have to, I'm always going to be there
505 to make sure she gets her meals and her water, talk to her; so I don't know what could
506 replace that, what could make it easier you know?

507 I: Yeah (yeah) ok, so basically to wrap up what we've been talking about, can you say what are
508 the most positive and also the most challenging aspects of being a working carer?

509 P: I guess, a good aspect of being a carer is that you're always there; you get to see your mum
510 constantly, where if, I know that if she was well and fit, then you wouldn't see the need to
511 necessarily go round and see her. She'd go 'oh, yeah, it's fine', she could text you, it's ok, you
512 know, you might not see her for two or three days. Whereas being a carer you're there all
513 the time and you don't see the deterioration as much, until you look back at maybe a video
514 or a photo a year ago (mm) and you go woah, you know, she's in a bad state now. So that is
515 probably a positive and the negative is the stress. You don't realise the stress, I'm stressed, I
516 am so stressed and it's not like superficial stress that someone that say, you speak to your
517 friend and go 'how are you?' and 'oh, I'm stressed' you know (mm, mm) that's, I don't know,
518 I'm not, I don't know anything about it but I know there's two types of stress- there's initial
519 stress like 'ooh, that was stressful' or stress that's deep in there, that affects your head and
520 depression and all that stuff and it's just real like, because I've left the Fire Service, who
521 knows where I'd be if I was still in the Fire Service and working three jobs and looking after
522 my mum? Looking after my mum when she's in a, when she has seizures or when, it has such
523 a, you can see why carers, why their health goes too, deteriorates and why they end up
524 needing cared for eventually, because it's just, you've got, it's, it's, you're backed into a
525 corner. Whether you care for your mum or you don't, she's always going to have dementia,
526 so you have to, you've got no choice, but you have to look after her. So that is definitely the
527 negative and, and it's gonna take a long time for me to lose that stress (mm) because what
528 I've noticed- I used, I used to say I was a very laid-back guy but there's certain things, not
529 certain- now, lately, it doesn't take much for me to get stressed. I'm like 'oh man -sighs' I've
530 had a headache for seven weeks at times, you know (mm) you know I don't want to use this
531 as a kind of therapy session but it is what it is you know and it is def', I, you've gone to the

532 doctor and things and it's the same with my brother, he says 'oh, stress' I'm like I know
 533 exactly what's that like, I'm so stressed. Normally I use sports, I go out running, swimming,
 534 cycling, surfing; whatever and that helps, you have to do that but it's gonna take a long time
 535 to lose that stress.

536 I: Have you had a carer's assessment or an assessment of your needs as a carer?

537 P: Me, no, no.

538 I: Ok. If you met someone else who was in a similar situation so, a worker carer of someone
 539 living with dementia, what sort of advice would you give that person?

540 P: -sighs- Oh, I probably sound like a little bit of a hypocrite here but I'd say take as much help
 541 as you can (aha); don't do it all yourself (aha) which I definitely do try to, and I would pass on
 542 as much knowledge as I have, when I was working with the Fire Service during fire
 543 inspections in homes, any time that there was a family member there I would tell them
 544 about the camera that we use, other pieces of technology like the digital clock, the dates
 545 and the time and the day and safety aspects you know, kind of pressure mats if they were to
 546 leave the house and the community alarms and all of that stuff (aha). So, I would try, I would
 547 definitely pass all that information on instead of them learning the hard way because I know
 548 that no one's gonna tell you unless you do your own investigations.

549 I: So, you just said it'd been difficult to except help for yourself, why do you think that is?

550 P: I dunno maybe every carer would say the same, but I'd say it's also in my nature. I would
 551 rather do it rather than my dad (aha) and I would rather my mum was looked after and as
 552 opposed to thinking about me, I'm fit and healthy, physically super fit and healthy you know
 553 I'll do it and it's my debt. I think it's my nature although I'll always try to do as much as I can
 554 and I'm really competitive so I'll show you I can do it (mm) yeah.

555 I: Ok, yeah so basically the final question that I have is- what do you wish for yourself for the
 556 future, for the next year, for the next five years?

557 P: In relation to my mum?

558 I: In relation to you; what do you want for yourself? (oh) That could have to do with caring but
 559 it could be something completely different.

560 P: Well, I think I've got it, where the idea is for me to work two/three hours a day and then just
 561 try to have time for my family the rest, or friends and choice. If I work 7/8/9 hours a day, I've
 562 got to do work, if I'm on a job, say the Fire Service, you had to work seven hours a day, you
 563 had to work seven hours a day, whereas now, I only have to, by 11 o'clock I might finish
 564 work and I've got choice, I can choose to work more or I can choose to go for a surf or hang
 565 out with my dad, hang out with my niece, nephews, whatever. So, I think over the matter of
 566 the next year, that will take effect and help with kind of the stress and whatever.

567 I: Hmm, do you have plans to maybe return to the job that you had?

568 P: No, no, no, no way; I'm done. I only want to work 2/3 hours a day, that's it.

569 I: Ok, great. Thank you very much. That was the last question that I had. I only have a couple of
570 very short ones to, for the context of the interview; so, the first one of that would be how
571 are old are you?

572 P: 34.

573 I: 34. How old is your mum currently?

574 P: 67.

575 I: Aha. What's the highest level of education that you have?

576 P: An honours degree.

577 I: And we have addressed this, yeah, so are you in a steady partnership at the moment?

578 P: Partnership?

579 I: Like a girlfriend or-

580 P: Fiancée.

581 I: Fiancée? Oh (yeah) congratulations (thanks). Does your fiancée ever help with caring?

582 P: Um, she, in terms of time spent with my mum, not really because I've never asked her to do
583 that (aha) I don't know if she, she er, we've all got our ways of looking after my mum and
584 making and feeding her, so it's just easier if we do it (yeah) but she will, she will help with
585 getting information and try to help with you know, 'oh I've heard this-' she works at the
586 hospital, she's a [job] but in meetings that she might have or conversation with someone at
587 work she's found out this information, she says 'oh, do you know about this, are you aware
588 of it?' and she'll help out like that (ok). I mean she is supportive (great) yeah.

589 I: That's really good. Ok, yes that was it, thank you (good o')-

590 END