

# Interview 10, "Iona"

Date: 24.05.2019, Duration: 58min, Setting: participant's garden

I = Interviewer, P = Participant

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I: So, can you just to begin with, can you just tell me a bit about the caring situation that you are in currently, so how did that come about?

P: Ok, so I, for as long as I've known, I've been a carer for my mum erm in one form or another but I've never classified myself as a carer, she got erm un, she's got erm neuromuscular syndrome that hasn't been diagnosed [mm] but we know it's a neuromuscular syndrome so throughout all my life I've always been helping with my mum, erm and about, pff I don't know 12 years ago or something she fell and broke her hip, [mm] and ever since then, it's kind of just gone downhill, then she also suffered with erm with ulcers as well, stomach ulcers and one day she had a duodenal stomach ulcer, so she, it split her stomach and her bowel and she was in intensive therapy and in intensive care, for months and months and anyway they say that that took, that with like traumas like that, it makes dementia come on much quicker [mm] so they say that it was probably underlining beforehand and looking back, I knew it and I was covering for her, but I didn't realise it, [mm]. Because I would sign her name for her and I would answer, I would, if people asked her questions she couldn't answer, I would answer for her, and things like that, but I wasn't, I was doing it subconsciously [mm] I didn't really think, because me and my mum were so entwined cos I was so involved with every aspect of her life. So, this happened about, the duodenal ulcer happened about nine years ago, [mm] so since that point, her dementia has just gotten worse, so erm you know the memory started going a wee bit, a wee bit, but now it's at the point where erm she can't really talk, [mm] she can't, she couldn't walk very well anyway, because of the neuromuscular thing. But err she's, she's not, not mobile anymore at all, erm and she's just probably at the very latter stages of dementia now. [mm] So the setup is, I have three older brothers and two older sisters, my three older brothers are on the Island and err one of my sisters, is on the Island so we have a rota for breakfast, lunch and dinner [mm] erm and we obviously know all her pills and things like that, and we don't want it on my dad err we don't want anything, any stress on my dad cos he's retired now he's done enough so, we do a rota for breakfast, lunch and try and come in every single day for an hour or so and sit with her at different times. Erm obviously with me in [place] and having been her carer before, I've got this unbelievable rack of guilt that I'm not here and all that's on my brothers and sisters, so I erm try and come home at least once, one week every month, if not one week every six months, err six weeks sorry, so erm and when I do I'll try and do all the meal slots and the pills and sit with my mum and things like that, just to give my brother and sisters a bit of respite.

I: Mm, so have you, do you have erm an official diagnosis of dementia for your mother?

38 P: Err yes, I think we do, I think when she was, when she was in hospital, we've now got a really,  
 39 really good GP, a really good GP, he comes regularly and I think on the notes there, he's  
 40 written down dementia [mm] I mean it was diagnosed, I just, my reason for hesitation is I've  
 41 never actually seen it written down, but they have referred to it so.

42 I: Yes, so you told me that there are all of your siblings and you helping together, to care for  
 43 your mother, erm can you maybe, is there anyone who you would say is the main carer for  
 44 your mum or is that,

45 P: No I would say it's all even, on err my three brothers and my sister and then whenever I come  
 46 home, I try and do my bit, so [mm] but I mean, I would say my brother [name] does, if  
 47 someone, if I were to identify someone that does that little bit more, I would say [name] does  
 48 because erm he'll come more often, but saying that, my other brothers have started doing  
 49 that too now cos they've realised it's a lot and not only with my mum we try and rotate so my  
 50 dad's not cooking, he's not very good at cooking so we try and do the meals for her, we clean  
 51 the house and things like that and just maintain everything so it's not, he's stresses out very  
 52 easily [mm] so just so he's not stressed out.

53 I: So how does things usually work with your siblings, how do you coordinate yourself, how do  
 54 you?

55 P: We are very organised, we have a, a programme in my mum's bedroom on the wall so we've  
 56 got an A4 piece of paper with all her pills on it, [ok] and err we've got it divided by day and  
 57 meal slot, [mm]. Then we've got another A4 piece of paper with a programme for the week  
 58 of who's on what meals. We have her pills in erm a pill container by day which also is erm  
 59 separated for morning, lunch and dinner [mm]. Erm and we have a logbook to track her liquid  
 60 intake and her erm she gets erm nutritional supplements [mm] erm [drug] is called, she gets  
 61 two of those, so we track that as well. We also have a logbook, which, so we have carers  
 62 coming in [mm] but they do erm like toileting and washing. So, they don't do anything else  
 63 other than that, so they fill the logbook in to say erm you know what the toileting situation  
 64 was for their session, erm and if she was well or if she seemed err flushed or anything like  
 65 that, so we'll check that everyday just to make sure that everything regular and there is  
 66 nothing to look out for.

67 I: Mm and so you each have erm a specified day when you come in or do you maybe coordinate  
 68 yourselves like every week say, you come this day, you come this day, how does that work?

69 P: No it's specified every, so erm for instance my brother [name] is on Friday teatime, he's on  
 70 every Friday teatime, [mm] if one of us are away, we've got a family WhatsApp and we'll put  
 71 the slots in that we need covered, and then we will just arrange it that way and somebody  
 72 else will do that slot. [mm] But if I come home, I'll just put in the family WhatsApp, 'I'm home'  
 73 and I'll do all the meal slots.

74 I: Mm ok, ok, we will definitely come back to the WhatsApp group, if that's ok with you [ok].  
 75 Erm can you maybe try to put number on it, how many hours a week you provide care for your  
 76 mum, [me personally?] you personally?

77 P: It's difficult to say [yes] because I'm not here, [mm] would like me to say for the week that I  
78 am here perhaps? [yes] Err an hour on breakfast, an hour lunch, an hour dinner, and then an  
79 hour in the evening, an hour hanging around during the day and things like that, so that's 35  
80 hours a week maybe, [mm] if not more, [mm] minimum 35 hours I would say.

81 I: Mm and so when you are not one the Island, when you are back in [place] is there any,  
82 anything that you would consider caring for your mum as well, that you do form a distance?

83 P: Not directly, indirectly I've joined a board that's a dementia charity and things like that, erm  
84 because I want to do what I can for the charities and to find out you know any cures and things  
85 like that, but in terms of directly all I'll do is research, research if she's got erm an ailment I'll  
86 do research to see the best cure or what available help and advice is out there erm I'll also  
87 erm looking at in subscribed like the dementia emails and things like that, [mm] and if there's  
88 anything that is relevant to my mum then I'll just send it on to the rest and see what they thing  
89 and discuss it that way.

90 I: Mm, mm are your siblings in contact with you when you are not on the Island to [yes] keep  
91 you updated or things like that?

92 P: Yes, so we have a separate WhatsApp group, that's not, so we have a family one WhatsApp  
93 group that has my dad in it and my sister in [country]. But we have a separate WhatsApp group  
94 that's just me and my siblings on the Island, [mm] so if there's anything that's concerning us  
95 about my mum, we will put it in that group, so it doesn't stress my dad out, [mm]. We'll let  
96 him know but we will talk about it in the background so it doesn't stress him out erm and we  
97 don't involve my sister in [country] because erm there's nothing that she can really do, [mm]  
98 so, it's just between the five of us.

99 I: Ok, so erm can you maybe tell me a bit about your work situation and how this erm works  
100 with caring erm so just to start off with can you describe a bit about your job?

101 P: Ok, so I work for [company] but based in [place] err [company] has an office [place] [mm] so I  
102 can quite often come home and work at the [place] office I haven't told anyone at my work,  
103 about any of this, [mm] so nobody knows and that's for err potentially three reasons. One,  
104 growing up being my mother's carer, she was very, like private and being on an Island  
105 everybody knows everyone's business, so she didn't want anyone to really, you know  
106 everyone was deemed as nosy and things like that [mm] so that was kind of, that's a need to  
107 me now, not to share these kind of things [mm]. Err and, number two, because erm I've dealt  
108 with it and I can carry on dealing with it, I don't need any help, [mm] and you know we've got  
109 a really good set up here and I don't see any benefit in sharing it with my work. And three,  
110 because if I were to share it with anyone at my work I wouldn't want any special dispensation  
111 or to be erm, err you know looked at, not looked upon as a charity case but kind of in that  
112 sense, if you know what I mean, [mm, yes] to be maybe not be considered for certain things  
113 like err trips away or things like that and erm yes those are probably the three reasons so it  
114 kind of works. I'm a project manager and err I'll just do my day to day job whilst I'm in [place]  
115 when I'm at home it's a bit more difficult, obviously working, a full time job and doing all the  
116 meal sorts and the pill and just checking on her in general erm but I will make it work erm I  
117 will work erm in the morning when I get up at like six, I'll do a couple of hours, clear the emails

118 and I'll go and give my mum her breakfast [mm]. Err that sometimes, depending on, she  
119 doesn't swallow very well so I have to do it through a syringe so erm I've got to make sure she  
120 doesn't aspirate so it goes down the wrong way. So it takes a long time, so it will take about  
121 an hour, an hour and a half and then I'll go back to, well I'll go to the gym, for a wee while, go  
122 back to work then make sure that I'm there for lunch and again I'll, I've got to erm my dad  
123 doesn't like rubbish meals so I have to spend a bit of time making the dinner and things [mm].  
124 And he has to have his dinner by six o'clock otherwise he gets very angry, so erm after, after I  
125 prepare dinner, cook it and lay it out, I'll go back to work for a couple of hours after that as  
126 well, just to keep track but like I say that's only a week out of every month, [mm] every six  
127 weeks so, I don't mind.

128 I: Since you have quite a bit of freedom regarding when you work [yes] yes [yes] it that due to  
129 the kind of job that you have, is it something that's a generous thing at the company that you  
130 work at?

131 P: I think yes, I think as long as, I think the company, the company is brilliant to work for, really  
132 like you know you're not micro managed at all, erm you are just left to get on with the work,  
133 if you get it done, you get it done, if don't then obviously people are going to ask, start asking  
134 questions and I get the work done so nobody asks any questions.

135 I: Mm so being a project manager does that mean that you have to erm also work with other  
136 people or can you just work for yourself?

137 P: Obviously I have to work with other people and if I have meetings or calls and I'm working  
138 from home, I'll make sure that they are at a time where err it's not mealtimes, [yes] so I'll just,  
139 I just have to slot the two into together and erm make sure to manage it well.

140 I: Has there, would you say is there any way that caring impacts on your ability to work?

141 P: No, I wouldn't say so, I don't think it, I don't think it impedes it at all, as long as I can manage  
142 it round the, the caring aspect of it, it doesn't have any impact at all.

143 I: Mm and the other way round, is there any way that work is impacting your....?

144 P: Oh hundred percent, because erm I would prefer to be up here more often [mm] but I don't  
145 want to take the micky you know this isn't where I'm based, so and I have meetings in [place]  
146 and things like that and I really should be in the city, that my job is located in [mm]. So erm,  
147 but that's more on me because I haven't told anyone at work so there may be more leeway  
148 [mm] if I were to be more open about it, but the way I's going right now it's seems to be  
149 working quit well.

150 I: Mm, so does that mean you would prefer if there was a position open on the Island working  
151 for your company that, that would be preferable for you?

152 P: It's to be honest the option is open to me, I could come to this office any time I wanted, it's  
153 more the, the fact that I'm married [yes] and err my husband is from the Island as well, but he  
154 is a mechanical engineer and there's no jobs up here for him. [ok] So, we can't move up here  
155 until he starts his own company or goes offshore or something like that.

156 I: Mm, mm I see, so you talked about working from home when you are on the Island erm is  
 157 there anyway would you say erm that caring affects your ability to work from home for  
 158 example erm? [yes], can't really say for example?

159 P: Err I mean I suppose sometimes, like if the carers are in or if the doctor comes in and things  
 160 like that and there's an issue, I have to attend to, err to you know err leave my laptop and go  
 161 and speak with the doctor or speak with the nurses and things like that but, that happens very  
 162 rarely and even if the doctors comes err once every two weeks to do her bloods anyway, so it  
 163 only takes fifteen minutes so it's not a big impact at all.

164 I: Ok, yes so generally speaking how do you feel about your situation, of being a working carer,  
 165 is there anything that you would want improved or?

166 P: Pff, it's really difficult to say because you know it's been my life, so I don't really know anything  
 167 different, obviously I haven't been working since I was wee but I've been at school. [mm] I've  
 168 been at University and now I'm working so I can't really say, it's not like I've come from a  
 169 situation where I haven't had to care for anyone and now obviously I'm having to care for  
 170 someone it's quite natural to me, [mm] so I can't think of anything that would change, that I  
 171 thought would be really beneficial you know, the might, I mean something might pop up but  
 172 I can't think of anything just now, [yes] cos that's genuinely just been my life what I've been  
 173 used to. [yes] I mean it would be more useful I suppose if, if you almost feel like you have to  
 174 fight for everything, erm you have to fight, if you, you know with erm professionals in the  
 175 health care and things like that, we really had to fight for the carers that she's getting just  
 176 know, erm [ok] and to have a certain slot and they were saying that you know some of the  
 177 carers were just being a bit dramatic and saying that she was like hurting them and things like  
 178 that but, the woman's thinner than I am, she's as frail as a you know a twig, you know you  
 179 could snap her if you wanted to and that, I think they were just being you know, on one side I  
 180 think there were being a bit dramatic, she's got dementia and maybe she was swearing at  
 181 them but they should be trained in that, so they should know to expect that kind of stuff, she  
 182 had no idea what was going on and imagine if someone was rolling you over back and forth  
 183 and you were in pain, and things like that so that created a lot of stress for my dad, and the  
 184 health care professionals seemed to be quite erm silent and not talking to one another [mm]  
 185 but we seem to be on par at the moment and every things going smoothly but that was the  
 186 beginning of erm when she got really, really bad and that was a really difficult period and  
 187 we've had to fight for all the care that she's getting, we've had to fight tooth and nail to get it  
 188 instead of just lying down and excepting, you know she gone into hospital three or four times  
 189 and they've said to us, oh you know she's basically dead just leave her, erm [what] and she's  
 190 not, you know and that's happened for years and year now. So, we know like she's a strong  
 191 as an ox erm and she's as stubborn as anything, we know ourselves last time when we were  
 192 in the hospital, like she's fine, you know she's not going to, granted you know her blood  
 193 pressure may have been quite low or something, but we knew ourselves that, you know we've  
 194 seen her much worse. [mm] But the doctor was saying to us, that's her gone, there's nothing  
 195 we can do, you may as well just take her home and we're like 'no you're going to carry on  
 196 caring for her and once she's better we will take her home. But he basically said 'take her  
 197 home and let her die'

198 I: That's awful

199 P: Yes, so things like that would obviously be more useful to, to have a bit more of a joined up  
200 approach between the different agencies and things like that and not have to fight so hard.  
201 To let people realise and give up on her you know.

202 I: So, the fighting was more with the personal in the hospital [yes] or was it with social care  
203 services or?

204 P: More the personal in the hospital and the carer services as well and again we've had to have  
205 the discussion of 'do not resuscitate' because that's on her record [yes] and we've been asked  
206 it three or four times that we've basically been told that she's going to die and in the end we  
207 actually asked the question 'well if we say we want you to resuscitate and the doctors  
208 disagree, who gets the final say' and the doctors get the final say, which gives us concern given  
209 that the doctors have said to us, you may as well take her home and let her die, we know that  
210 she's not dying and she just needs to get better, if that came to a point where she had to be  
211 resuscitated and that man said 'no we are not going to resuscitating her' even though we  
212 knew, you know his word would be final and that's where our concern is [mm]. So that's still  
213 a bit of a, we had a meeting, all of us, a family meeting at Christmas here, cos my sister from  
214 [country] came over and we've got a few action points that each of us have gone away and  
215 that's one of them to see you how that can be changed on her notes. Cos right now that's on  
216 her notes 'do not resuscitate' [mm] you know we want to know if that a blanket or I  
217 understand resuscitating will cause bone breakages and things like, but is it black and white  
218 or can resuscitate be you know erm through the mouth you know, mouth to mouth, [mm] you  
219 know things like that erm it's never really been explained to us and that's another example of  
220 where we've had to really you know do the investigating ourselves and when we ask the  
221 questions, we just kind of get fobbed off so it's where it is on us.

222 I: Erm so when she does go to hospital your mother, what is that usually for is that always the  
223 same issue or?

224 P: The last couple of times it's been because erm her sodium levels [mm] so that's really erm  
225 really bad if her sodium levels go below 120, [mm] and 115, she gets seizures [mm] and bites  
226 her tongue and you know goes into this horrible state where she, all her muscles, like a seizure  
227 basically [mm] erm and her sodium levels just keep on dropping and dropping but we've  
228 managed to get them to a level where there consistent but that's where the doctor comes in  
229 every two weeks to check her bloods [ok] and her sodium levels, [ok] just to stay on top of it.

230 I: So, in case, so when that happens, the doctor comes in, checks the sodium and if the sodium  
231 is low then she goes to hospital?

232 P: If it contain, continues to be low so we'll up her, she gets two sodium tablets breakfast, lunch  
233 and dinner [ok] and he'll probably increase them to three for a couple of days and if it  
234 continues to stay low, then he will admit her to hospital or she'll have a seizure and she'll go  
235 into hospital.

236 I: Does that happen? [yes] does she have seizures at all [yes] ok,

237 P: So, we just go in the ambulance erm and record, we know how to deal with them now, so we  
 238 record how long her seizure is [mm] and then err yes that's, that's just the way of it, this is my  
 239 brother [name]

240 [brother enters here "hello, sorry to interrupt, I'm [name]"]

241 I: No worries, so I was going to ask you has that ever happened erm, how would you erm know  
 242 that she has a seizure when...

243 P: Oh it's very obvious erm [yes] she starts dribbling at the mouth and she'll bite her tongue and  
 244 obviously blood will come out of her mouth, her eyes will go back and her entire muscle  
 245 seizure and she starts [yes] spazzing, so we all know that you know get all the pills out the  
 246 way, put her flat, role her on to her side and err time how long her seizures erm [mm] after  
 247 you know, if it keeps on going on for too long we will phone the ambulance erm and the  
 248 ambulance will come and access her and usually take her to hospital.

249 I: Mm, but so if you were not in the room when that happened how would you know?

250 P: Well we think she's, she's had a couple seizures at night because we've come down and she's  
 251 had blood down the side of her mouth, [mm] so that's where she's bit her tongue and err she  
 252 dribbles quite a lot so she'll have the blood pouring down the side of her mouth. And other  
 253 times it takes weeks, weeks, for her to recover from these seizures, [mm] because as you can  
 254 understand imagine your brain, you know spazzing out err so she's just away with it or she's  
 255 groaning and groaning and groaning so you know there's signs that we pick up on that maybe  
 256 she's had a seizure, [mm] but thankfully erm the major seizures err oddly seem to happen  
 257 about half six, seven in the morning when we are giving her breakfast every time it's been that  
 258 time [mm] we don't know why err we thought there have been with the sun, you know that  
 259 they light and there have been some kind of epileptic [mm] erm thing that but erm, but no  
 260 that's not been the case so we are not really sure but thankfully touch wood she hasn't had  
 261 one for a while.

262 I: Ok, ok that's good, erm how regularly would you say does that happen that she does have to  
 263 go to hospital?

264 P: It varies to be honest with you, every time she has a seizure, she'll go to hospital but the last  
 265 time she had a seizure was about, March was it, March and then the time before that, she was  
 266 actually in hospital for my wedding as well so it was July erm. So I mean they are quite spaced  
 267 out [mm] whereas you know so that was about six, seven, eight months maybe and other  
 268 times she's had them three months apart, [mm] but I think now that we've got the sodium  
 269 levels cos we couldn't, at first we didn't know what was causing the seizures, but now we think  
 270 it's the sodium levels and now we've got that managed, she hasn't had one for a while.

271 I: Ok, that's great, erm so to talk a bit more about the care service, is that organised by the  
 272 council, is it something that you've privately organised?

273 P: That's the council, [the council] so we get two women in or a guy erm at breakfast time and  
 274 then again at lunchtime, then again about erm half six, six o'clock and then again at nine  
 275 o'clock, [mm]. so that's erm the maximum amount of support that we can get, they don't give

276 her, her meals or anything like that, like I say they just change her and do her toileting and  
 277 things.

278 I: Mm, ok, ok and you talked about there being conflict, so erm is that mainly with like  
 279 misunderstandings of they are supposed to do or?

280 P: I think to be honest with you I think it's just the individuals creating a fuss, like I was saying  
 281 when my mum was in that stage of dementia where she was swearing blind at them and err  
 282 like my mum would never do that, it's totally out of character, but they don't understand that,  
 283 I think it is more lack of training from their part, [mm] and they were making a big fuss about  
 284 it, and then they were going to pull the service and we would be lost without that, you know  
 285 [ok] I mean that is so much help that they give us. So erm so yes there hasn't been any conflict  
 286 recently but that was just at the stage when my mum was able to talk and she was in that  
 287 horrible stage where she was anxious and swearing and telling people to 'f' off, and things like  
 288 that and that's not her at all, but they didn't know here when she, so they thought that was  
 289 her, [mm] they obviously weren't trained in dementia, [mm] so they didn't know.

290 I: So, the carers they you get are they always the same people, do they know her now or is it  
 291 always someone else coming in?

292 P: It's fairly consistent, they do rotations so erm they'll do week by week erm and it's say for one  
 293 week it's usually the same two people at breakfast and at lunch and the same two people at  
 294 erm late afternoon, and the same two people at night, but erm at periods like Christmas when  
 295 there's a lot of people off ill, there's new people coming in you know, right now, it's not an  
 296 issue because my mum's at that late stage of dementia where she's not really aware or can't  
 297 verbalise that she is aware, but when she was in that stage where she was very anxious and  
 298 swearing and things like that, there was some that she really, really did not take to, erm and  
 299 new people coming quite often and they just couldn't get the shifts right. And I don't think  
 300 that's, I don't think that that's perhaps something that the care service management were  
 301 doing deliberately, I think they were aware of it and trying to minimise it, but I think they could  
 302 have done more, [mm] to minimise the turnover in new faces, [mm]. Erm coming in, but they  
 303 do know my mum some of them have been there for years now so they know her really well  
 304 and know what she's like and they're really, really good like, they'll know that err if she's  
 305 looking a bit pink and flushed, they will come to us and say you know do you want us to get  
 306 her up today and things like that, and notice that she's not quite herself, [mm]. So, we've got  
 307 a bit more established with the carers.

308 I: That's good erm is there anyone else that helps you? That provides support caring for  
 309 example any erm charity organisations or anything like that?

310 P: There's a woman from the dementia resource centre, [mm] erm the link that I sent you [mm]  
 311 erm [name] she's just a volunteer and she'll come in once every two weeks on a Friday  
 312 afternoon for an hour or so, and she's brilliant you know she's, my mum's [from place] and  
 313 she hates, she hated the Island and anything to do with the Island, so anyone who's [from  
 314 place] or basically not from the Island, my mum would love, so back in the day when my mum  
 315 could chat and things like that she loved chatting to [name] and getting the crack with her,  
 316 from like a like a [place] respective [mm] a [place], erm so [name] is brilliant, she'll just come



317 in and make herself at home, go and get herself juice and tea and coffee and just go through  
318 and sit with my mum and talk at her [mm] you know erm and she'll, my mum's basically almost  
319 got this locked-in syndrome, cos you can see her eyes moving and you know that she's  
320 listening and very rarely she will respond but sometime she does, which gives you the  
321 confirmation that she knows. [mm] So when [name] it's nice because you can see, like her  
322 eyes moving and things like that. [mm] Erm and recently, over the last couple of days erm  
323 [Name] is a charity here, [mm] erm, and they've come in to see that they can err lend someone  
324 every second Friday for a couple of hours in the afternoon, I think it's two hours in the  
325 afternoon, erm to sit with my mum and that kind of takes the strain away from my dad and  
326 my siblings [mm] err cos we obviously feel like we want to and how to come in and interact  
327 with her because you'd be bored out of your nut if that was you, sitting there all day, listening  
328 to the radio or watching TV, [mm] you need interaction and different stories so, and it's good  
329 that a fresh face is coming in and someone who is experienced with dementia, but other than  
330 that, that's really all the support.

331 I: Yes, ok, so talking about technology, so you already mentioned that you are using WhatsApp,  
332 [yes] to erm coordinate, talk to each other erm how erm would you say how satisfied are you  
333 about the, about that, is there anything that you would like to improve about, how it operates,  
334 what it lets you do?

335 P: So in my mind I'm thinking that, I'm just thinking about when someone goes away, and each  
336 of us say, 'I'll do that slot for you, I'll do that slot for you', but I was thinking you know would  
337 it be useful if there was a separate platform within WhatsApp that you could go and check  
338 that, but you can do the search thing, the chat search and that always works well so I would  
339 say I'm satisfied with it, [mm] with how it functions and how we want it to function for us.

340 I: Mmm erm is there any other technology that you currently use, yourself or maybe you as a  
341 family group to help?

342 P: We have cameras in her bedroom and in the lounge just obviously we check and so we've got  
343 it linked up to her phone [ok] on the App. So when I'm in [place] I can check in the lounge and  
344 the bedroom and check in on my mum and if she's not looking, if she's say, if she's looking  
345 flushed in bed and her covers are up, I'll put on the WhatsApp that you know can someone  
346 just pop round and check on mum she is looking a bit warm can you pull the cover down or if  
347 her head is slumped, you know I will say to one of them can you go home and err prop her  
348 head up and things like that [mm]. Erm and they'll again check on my mum when they are at  
349 work and when they are not able to come and see her, herself err and when my dad goes out  
350 for say to do the shopping or erm err go out in the boat or whatever. Err we also have a charity  
351 shop that we all manage err in err in town, my dad does, there's lots in there so he will say to  
352 us, can you check in on mum on the cameras and things like that, so that works out really well  
353 for us.

354 I: Ok, do you have like a rota or something like that on who checks on the cameras or is it just  
355 whenever you have time [yes] to think about it.

356 P: Yes. So sometimes even when I'm sitting on a call or whatever I will just pop in and you are  
357 live you know so you can see live action [mm] if some ones in or things like, [mm] err and we

358 will just take screen shots and send it into the family WhatsApp, with the mum and dad group  
 359 and just say so that's the one without my dad, err we'll just say 'all well at home' or 'can  
 360 someone go and check on mum'.

361 I: Ok, that's great, who came up with that idea?

362 P: My brother [name] he's really good with that stuff, [name] is the techie one in the family, [ok].  
 363 So, he's, I think, yes it was his idea to do that and again he formed the mum and dad groups.

364 I: So how long have you had those in place the WhatsApp group and the cameras  
 365 approximately?

366 P: Err we've probably had the WhatsApp group now for about, I mean I can be way off on this,  
 367 I'm going to say three or four years [yes] and the cameras again maybe three or four years,  
 368 three years maybe, [mm]. Erm but they are really good cos you can listen in as well, you can  
 369 click on the volume of it [ok] so yes.

370 I: So, if you met someone else err who was combining working care would you suggest that [yes]  
 371 technologies with them?

372 P: Yes, although I can't say that I have [yes] but I would definitely recommend it to anyone,

373 I: Is there anything with the camera that you would say, I would like this improvement to?

374 P: Erm the camera is really good to be honest, it's good quality, the only this is sometimes there  
 375 is a bit of lag, cos you can move the, you can move the camera round the room and zoom in  
 376 and zoom out, [mm] and things like that, it's called Foscam, [Foscam](P spelling it out here)  
 377 [mm] so erm the camera is really good the quality is brilliant, obviously we bought it ourselves  
 378 and got the, the, I think [name] just researched himself, we didn't get you know we didn't get  
 379 it recommended to us by anyone, [mm] erm I'm trying to think, I don't think, I can't think of  
 380 anything that I would want to improve about it, [mm] to be honest, there is a bit of lag and  
 381 delay when you are moving the camera around but, I think that's tiny, [yes] I think that's more  
 382 to do with connection from my phone to be honest.

383 I: Yes, erm so you said you have been caring for quite a long time has throughout this err all of  
 384 these years has there been any other technology that has been suggested to you or that you  
 385 have heard about, erm that you were considering or maybe using?

386 P: No, I can't think of anything, [ok] erm I mean by technology do you, I suppose for technology  
 387 what would actually would be quite useful and this might be a bit out there, but on the bed  
 388 she's, obviously in like a hospital type bed [mm] which is pressure controlled [mm] and it  
 389 would be really useful, so before all this happened err she used to have erm pressure spots  
 390 and really, really bad ones like, gauged and I would dress them, so erm you could see like  
 391 inside her back and

392 I: You mean like ulcers, pressure ulcers?

393 P: So like scabs, [yes] and they would go deep, so I used to dress them and things like that, and  
 394 so that is always in the back of my mind like what can a pressure, so it would be really useful

395 if there was like an app or something to know her pressure points [mm] to know you know is,  
396 cos you know yourself if you are sitting too long in the same position, [yes] its' sore, so it would  
397 be really useful to have an app, where you could see the pressure points and adjust the bed  
398 to alter that, in some way or another [mm] but other than that, that is all I can think off just  
399 now.

400 I: It's a really good idea, I was actually going to ask you if you had like a magic wand, if there  
401 were no restrictions would other technology do you think might be useful, is there anything  
402 else that you can think about?

403 P: (pausing) If I had a magic wand it would be really useful to know what she's thinking, [mm]  
404 you know you get these, these things where you can, people with the locked-in syndrome you  
405 can track their eye movements [mm] and that is like, it tells, it speaks and it says yes or no. I  
406 feel like if we had that and some kind of erm think to track the, the perhaps like electro lights  
407 going through her brain or something you would know how aware she is and how acts, so  
408 obviously sometimes she totally dazed and other time she's really aware, so it would be really  
409 useful if we had some kind of technology where we could stick these things [mm] to know the,  
410 the electro lights that are going through you and to track her eye movements and then you  
411 would know how, how aware she is. [mm] Erm

412 (Someone enters here, 'Hello', sorry that's my niece, 'how are you?' Good come and give me a big  
413 cuddle)

414 P: Erm yes so erm it would be really useful to have something to, to say she's this alert [mm]  
415 she's not alert. The other thing it would be useful to know is you know if we put, I know there's  
416 apps for this but if we put all the food that we're putting into her and we could track her erm  
417 sensitivity, it would be good to know what foods were perhaps making her more alert [mm].  
418 You know so erm what's that app you get, it's like a fitness app, [mm] you put in your food,  
419 and it tells you your macros [mm]. If there was an app like that, that wasn't so arduous you  
420 know you didn't have to weigh everything [yes] and cos it's time consuming enough and then  
421 if you could combine that with errr tracking her levels of awareness. For instance, there's  
422 studies showing that blueberries and walnuts and all these can obviously I think she's a wee  
423 bit beyond you know redemption, in a horrible sense but you know even if she's just more  
424 aware, if there was something that would say you know there is a spick when she had  
425 strawberries in her alertness [mm] or her erm interaction. Then we would know that errr the  
426 nutrients in blueberries errr were improving her and we would be able to carry on giving her  
427 and then that would help us refine [mm] her food because we haven't had, in terms of  
428 nutritional guidance we've had very, very little [mm]. Even when she was at hospital they  
429 gave us a, a leaflet for the sort of things everybody knows, you know they were do detailed  
430 things, there was nothing specific to her, it was just people in general, [mm]. Not even specific  
431 to people with dementia [mm]. Erm if I had a magic wand what else would I do, errr that's  
432 probably all I can think off just now.

433 I: So, regarding the technology that you are using and when you are at work, has there ever  
434 been any issues with your ability to use, for example WhatsApp group or checking in on the  
435 camera, when you are at work?

436 P: If, I mean other than if I were in a meeting [mm] I wouldn't obviously get my phone out and  
 437 check the camera, or I wouldn't get my phone out and go on the WhatsApp group, but other  
 438 than that, there's been no issues.

439 I: Yes, and regarding technology that you use for work, when you work from home erm for  
 440 example to be connected to your company, your team members, is there anything that you  
 441 are using?

442 P: I use Skype for business [mm] erm that's really useful and thankfully, so I work for a  
 443 government agency and [brother] works for the Government, so me and him can chat on, on  
 444 the Skype, Skype for business which is quite useful erm we also use something else called Go  
 445 To, but that's for meetings, so like a Go To webinar thing [mm].

446 I: How about satisfaction with that kind of technology, does that, it that, does that work for you?  
 447 [yes, yes, it works really well] ok, great. Well, we are almost erm, almost at the end of the  
 448 interview so just to wrap up, what would you say are the most positive and the most negative  
 449 aspects of being a working carer?

450 I: the most positive things, is erm I would say, it's a privilege to be able to do it, [mm] to be able  
 451 to, look after someone erm and see their erm their good moments you know, to be able to  
 452 spend all that time with someone, [mm] erm you know I spend more time and I think it's  
 453 brought the family together as well, [mm] not that we've, we've always been a really, really  
 454 close family, but in terms of erm just in a different way [mm], erm I think we are all the same  
 455 par. We've had to have difficult discussions you know do not resuscitate, what to do with her  
 456 will, what to do when my dad dies, [mm] you know things like that so it's kind of brought  
 457 about potential difficult discussions and in a sense, you know erm you are kind of numbed  
 458 too, you are kind of numb to that kind of stuff now. Not numbed but you are not emotional  
 459 about it I think, if, when she had that ulcer, if she'd gone, we wouldn't have dealt with it very  
 460 well to be honest [mm]. So, I think that it's been more gradual, we've all been able to transition  
 461 and err adapt to it as well [mm]. Any negatives other than the fact that she's in that she's in  
 462 that position in the first place erm and having, I would say the negatives were having to deal  
 463 with the care services [mm] erm and making it coordinated [mm] err and the stress that, that  
 464 has put my dad through [mm]. But, I mean all an all, everybody's, I mean the carers she's got  
 465 now they are brilliant, we've got a really good set up with the doctor, doctor and carer is  
 466 brilliant an absolute angle of a man. Erm is just, he goes above and beyond, you know he will  
 467 come in on his days off, he'll, if she's in hospital when he comes in to do her samples, well if  
 468 he comes in to her samples and she's not there [mm] he will go into the hospital and look for  
 469 her and things like that, just in case she there and he's genuinely worried you can tell, he is a  
 470 brilliant, brilliant man. Erm yes, I would, I mean, I'm a positive person anyway, I don't like to  
 471 think about negative, I always see like the silver lining with things, [mm] so I would say I've  
 472 got more positives than negatives.

473 I: Mmm ok, that's very good,

474 P: You have to stay positive, [absolutely] there's so many negative people in the world.

475 I: Absolutely, don't get me started. So, if you met anyone else, who is also in similar situation,  
 476 combining work and caring for a loved one with dementia is there any advice that you would  
 477 give them?

478 P: I would say to fight, fight for, for what they feel is right and fight for the proper answers, you  
 479 know erm don't take the first clinical answer that they get and accept it as gospel, [mm]. You  
 480 know, research it, I would say speak to all the different charities they can, erm that are  
 481 relevant to that persons' ailment, try and gather as much information as they can, I would  
 482 obviously have a system with all of this, I would say if you can get family members involved.  
 483 Reach out to see what services are free of charge and again erm you can get tax relieve and all  
 484 that kind of stuff erm and again I would mention the technology [mm] cos that's a big, big help  
 485 for us, and I would just talk them through our won situation with the rota we've got, the pills  
 486 that we've got, [mm] you know how we work it and erm to review that, you know you've  
 487 really got to be on top, on the ball with all this kind of stuff. I would basically try and refer  
 488 them to all the information that we've gathered over the years.

489 I: Yes, yes that's really good advice, so regarding technology, you obviously said you had you  
 490 have your brother, who is very tech savvy and who knows about these things erm but where  
 491 would you expect that kind of erm information to come from, about technology that could  
 492 help?

493 P: Research yourself, [research yourself?] yes or reaching out to the various charities, but in my  
 494 experience, reaching out to the various charities hasn't really given much aid in terms of  
 495 technology. Yes in other aspects but not necessarily there erm yes.

496 I: So have, have you or any of your family members had a carer's assessment of your own needs  
 497 as a carer?

498 P: I haven't no, I highly, highly, highly doubt anyone else in my family has, [mm]

499 I: Erm yes so the final question that I have would be what are, what do you wish for yourself in  
 500 the future, the near future, in the next maybe one or five years, is there anything that you  
 501 want for yourself?

502 P: Err I would love to move home, I would love to move home and err be able to build a house  
 503 and things like that, and be at home, be with my mum and the rest of my family [mm] erm  
 504 just to be happy, just for my family to be happy, for my mum to be comfortable and happy  
 505 erm and for everyone to be well, [mm] it's a bit gay but, a wee bit fluffy but I think, I don't  
 506 know I think living up here you just, quite content with your lot and as long as you're happy  
 507 and I mean I don't want riches, I don't want promotion and so on and fancy cars [mm] just  
 508 quite happy.

509 I: Yes, ok, erm thank you very much, so that basically concludes the interview, I just have a  
 510 couple of very quick questions for the contexts, so the first one would be, how old are you?  
 511 [I'm 27] mm how old is you mum? [P is (pausing here) 68] 68, yes, [yes 51 she was born, so  
 512 that's 68] thank you, erm your husband does he ever help with caring?

513 P: No, no he is a, whenever he comes up here he's very busy erm with work and err, he has  
514 absolutely no experience with us whatsoever [yes] so it is completely alien and he has no idea  
515 how to deal with it, [mm] so he stays away, you know he will come in and err he'll say hello  
516 but he doesn't even know how to interact with my mum [mm] so I completely sympathise  
517 with that, I, I can't put myself in his shoes because I've always been in my own position, so I  
518 obviously know how to interact with other people who are in that situation but you know I  
519 mean at times it does get me frustrated, if he's at home and I'm not at home, he won't come  
520 in and see my mum, [mm]. Erm but you know that's fleeting moment and I'll step and I will  
521 think he doesn't know how to react you know he perhaps does want to but he doesn't know  
522 how to and things like that so he doesn't get involved with anything, you know he'll give, give  
523 some advice and you know err try and help if we've got questions in terms of, if she's unwell,  
524 he'll say 'well can't you research this and that' but that's probably as far as it goes.

525 I: Mmm ok, erm yes and how many hours do you work a week?

526 P: I work full time so what's that?

527 I: 38 or 40

528 P: Yes I would say about that, I'll probably do a bit more but I would say 40 hours a week.

529 I: 40 hours a week, ok and oh yes, the highest level of education that you have achieved?

530 P: I have an honours degree, [ok] and I'm looking to do my PhD,

531 I: Oh great, ok well thank you much again.

532 END