

Interview 11, "Max"

Date: 24.5.2019, Duration: 52min, Setting: participant's home

I = Interviewer, P = participant

I: Got it now. Here we go. Okay so the first question I have for you is just to talk more generally about the caring situations so how did caring come about for you?

P: In terms of ourselves or in terms of (for you) for me personally? OK. Well this is a situation developed with my mother about five or six maybe six years ago when she was taken into hospital with a perforated bowel, nearly killed her, I mean, she made a recovery and when she came home, and it became apparent that she had dementia or and can actually get worse. And I suppose looking back you can see the signs beforehand, but it didn't kind of crystallized in our minds until after this operation and so on. And so, it kinda gradually became worse and worse and then her health otherwise isn't, isn't great. She takes flips and things like that. So but it got to the point that in terms of our care once you once you get home from, from hospital after she was really poorly she, she had lost the ability to look after herself altogether. So that was one thing she couldn't kind of mobility wise. She had mobility problems prior to that. That's another issue. But. But well that was not, when it came to the point that she could move from hospital she had no ability to look after herself in any way shape or form and then as I say, the dementia was kicking in as well. So. Basically we as a family, I'm one of six children, and so what we decided to do was to try and take the burden off my father. Because my father is of a generation and from a particular area on the island where it's kind of a stiff upper lip, and I don't have a problem with that. But, but his mindset is, it was his part and himself. So he would fight to take everything on himself to the point that, and this is very early afterwards she came back from her operation. And for instance she wasn't sleeping through the night she was having these waking, waking nightmares type of thing. So he was still, he's recently retired a few years ago, but at the time anyway. He wasn't sleeping and he wasn't telling us because he couldn't sleep. He was there, he was with my mom all the time and then he would go to work and after a couple of days you could tell that he was exhausted and wouldn't tell us. So eventually we realized and we asked him and so from that point on we tried to take the part and also we just forced his hand basically. And so the likes of going up throughout the day to check on her, giving her enough water because, because of her condition she wasn't she couldn't, it came to the point where she couldn't feed herself she couldn't drink water. Initially she could but she wasn't (uhm). So even the likes of taking in a sufficient amount of water, giving her her meals we took that off him and we were doing that so we set up a rota. Obviously three meals a day over seven days. And so we took that off and then we are back and forth all the time giving her her water throughout the day, checking on her and so on. So that particularly me and my, my other brother (uhm) because we're not married. The other ones have kids and so pretty much and so the burden was mostly

41 on the two of us. Because the others had responsibilities that we didn't have. So anyway.
42 That's it kind of started because of this illness and then because of the onset of dementia
43 which seemed to coincide with her coming out of this operation gradually got worse.
44 And also in the back of our minds our desire to take the burden off my father because as
45 I said if left to himself he would do it all himself and he would just, he'd end up in it
46 himself. So that was kind of how things started.

47 I: So between you and your siblings was there anyone who took the lead on that or was it
48 you deciding unanimously. How was that?

49 P: Uhm, well initially probably me and my brother [brother2]. So it kind of as I say we
50 developed a rota eventually but first of all we were doing just kind of main meals and
51 then my brother [2] said that dad was doing breakfast every morning it's a rubbish way
52 to wake up and have this every day. And so we eventually developed the whole rota for
53 three meals a day and as I say it was really mostly my, me and my brother[2]. [sister3] is
54 over in [place] as well so when she's home she does a lot as well. But my older sisters in
55 America I mean [older sister1] and my younger sister [sister2] and my older brother
56 [brother1] are here but they're married with kids. So time is more of an issue there. So
57 it's kind of fell mostly to me and [brother2] to do that. There's also other issues like you
58 know medication and things like that as well, going round when the doctor is going to be
59 there or going round from various people are going to be there. So again we try to do as
60 much as possible to take it off my father. So that's kind of just how things developed as
61 we went (uhm). Yeah.

62 I: So what kind of care do you personally provide? What tasks?

63 P: I just say that the main thing is going up pop up throughout the day. Well originally it
64 started popping up throughout the day from work just to check on her. To give her her
65 meals to give her water. But also the idea was also, well we couldn't do that during the
66 day but after work we would spend time with her, sit with her, give her interaction
67 because it must be just horrible because not being able to do things for yourself and
68 having, if everyone is out and having no interaction so the idea would be to spend time
69 with her and try to encourage her to as I say I said dementia get worse and particularly
70 laterally, our communication has pretty much ceased to the point that you really get
71 either a nod or you get sometimes one word answers. So. But in the back our mind was
72 to just to give her company to give her interaction because we know that spending time
73 when we spend so much time with her, we know that even though she's not
74 communicating as much she's showing us enough so that we know that she is
75 understanding what we're saying. You know because she's nodding at certain times or
76 she's you know, so because her communication's mostly gone. If you were to pop in and
77 speak to her you'd think well she's not focusing she's not listening she's not hearing. But
78 we know that she is. So that's the type of care really, we want to spend time with her.
79 We want to give her nourishment and so on but it's not just a case of, of coming in and
80 giving her her meals (yeah). We want to, want to do more than that (yeah, of course). I
81 mean she looked after us all these years. So it's only right that we do the same (uhm)
82 you know. So. That's, that's basically what we're trying to do.

83 I: Is it possible for you to put a number on it how many hours a week you spend on caring?

84 P: [pause] Uhm, throughout the day, like if that's what really, let me think, so I do, in terms
85 of meal slots, I have, I think six meal slots so sometimes you can be there, so the
86 difficulty is sometimes she takes her food reasonably well, other times you can be there
87 an hour at a time. So, a week, maybe eight to 10 hours, I don't know it's hard to say. It
88 varies (uhm, uhm)quite a lot. Really just a lot of it as I say are mealtimes and so on. But
89 as I say we'll try to split it amongst ourselves as well.

90 I: So how does that work? Do you have, you said you have developed a rota. Is that fixed?
91 Do you negotiate for every week? How does that-?

92 P: The rota is for meals only. So that's fixed. So we have like slots for morning after, for
93 breakfast lunch and tea. So sometimes you have to, if one of us is away we'll cover the
94 other person and so on. But other than that it's generally fixed to that's for the meals.
95 But aside from that it's a case of popping up throughout the course of the week. Some
96 way to spend time with her whenever we can depending on what we're up to and what
97 our schedules like and so on. So. So this is the meals rota is fixed but other times it's just
98 as you see fit and as you can.

99 I: And do you coordinate that as well, so do you say for example 'Oh for you today I want
100 to go up and spend some time with Mom'. Do you let the others know?

101 P: No we don't coordinate it because there's not much point coordinating in a sense
102 because everyone's schedules are so different so it's fine to coordinate the meals rota.
103 But yeah I mean we just, we just go up as we can through the course of the week
104 anyway. So that's not to coordinate other than that.

105 I: OK. OK. So can you tell me a bit more about your work situation? Can you describe what
106 work is about for you?

107 P: What my work is about (yeah)? OK, so I'm a civil servant, I work for the Scottish
108 Government and in economic development. So we give out grants basically and in short
109 we give out grants across Scotland for a variety of areas.

110 I: How many hours a week do you work? (35) OK. And can you tell me what a typical day at
111 work looks like for you?

112 P: OK. Well I'm trying to say it without boring you to tears (both laugh) but it's basically
113 office based most of the time and so we deal with projects. People apply to us for
114 funding in certain areas and so we have to assess applications and then we approve
115 some of them. Kind of large scale grants and then once they're approved the projects
116 will come to us for funds throughout the course of the year. And we're assessing how
117 the projects are going. We're assessing the finances, we're almost of an audit element as
118 well to what we're doing. So a lot of it is kind of office based but we also travel to see
119 some of the projects as well to see how the funds are being used and to see who's
120 benefiting from the funds. So it's kind of a rough overview of the type of thing. We meet
121 with them we speak to them on the phone. We do a video conference and all that kind
122 of stuff.

123 I: So do you have a fixed start and end time for your day? Or is that up to you when you
124 start?

125 P: Well that's one of the benefits of the job, it's flexible. So I tend to go in early in the
126 morning before 8:00 and then I'll take a half hour lunch and I can leave early. So it's just
127 it's flexible so if I need to go up to the house and I don't have a meeting or something or
128 some sort of deadline or whatever I can go up whenever I want. My boss is aware of the
129 situation with my mother. My boss is, my boss is based in [place] actually there's only
130 four of us and we have a division of about 70 people but four of us are based here, the
131 rest of us are based in [place] and [place] but my boss is very aware of the situation.
132 That's just fine with me popping up as and when, like for instance the other thing is that
133 we have a family WhatsApp group. And we also have a WhatsApp group for us six
134 children. The idea is to discuss things apart from my dad to avoid stress stressing him out
135 and so on (uhm). So we're always back and forth on that throughout the course of the
136 day. When my mum was taking fits and seizures you know if someone was, and she
137 would always strangely take her seizure at the same time in the morning every single
138 time it would be around 8, half 8. So I'm not because of that one of us would generally
139 be there, giving her breakfast maybe around that time or spending time with her after
140 breakfast. And so I've been at work and I've got a message 'Mum's taken a fit' and I went
141 straight up there. You know so it's very flexible like that (uhm).

142 I: So the message would come from your father? (more likely one of my siblings) OK. Do
143 you have to tell anyone at work that you're going up or is it really up to you?

144 P: No I just, I just, I mean as I say the way my work is the burden is on me to do my work.
145 Nobody else is going to do my work. So as long as the work get's done. And as I say it is
146 it's it is flexible and you can clock in and clock out when you want. So that's one of the
147 benefits of, I mean, I would, I can get, I live ten minutes walk to work. So I've got the car I
148 can be from my work in a couple of minutes to my parents' house. So it's really close by.
149 So again it's one of the benefits of living here. Yeah yeah.

150 I: Yeah. So do you have the ability to work from home as well in your job?

151 P: I've never worked from home actually. I could if I wanted to work from home I know
152 some people that. And, some people in our [place] office for instance they work from
153 home. And again I've never had the need to work from home because I live so close by. If
154 I was maybe living elsewhere I'm in this situation I would work from home if need be but
155 it makes no sense to me whether to work from home I work from here because I'm so
156 close anyway.

157 I: Yeah. Yeah. So would you say, is there any instance when caring interferes with your
158 work?

159 P: Definitely, definitely. Because as I say I mean for me. My, my mother, caring for my
160 mother comes first. Because for obvious reasons as I said she, she cared for us all these
161 years and it's only right that we do the same. So if I'm in the middle of something I could
162 be in the middle of something at work. Something that requires a lot of thought and
163 attention and some, I may be halfway through and you're right in the middle of

164 something if something comes up from home I'll have to leave. And I don't know that's,
165 that's just the situation and I'll do that. The only way I wouldn't, I wouldn't do that is if I
166 was sort of in a video conference and I didn't have my phone with me for instance and I
167 was in the middle of a discussion with someone. That's the only time I wouldn't do that.
168 But if I'm in the middle of something on my desk I would definitely just leave and go. So
169 it does. It does happen. I mean, as I say in particular when she's had her seizures and so
170 on and she probably had, over the course of the last, since she started taking her
171 seizures perhaps three or four years. She's had about, maybe, eight seizures or
172 something so and I've been there myself a couple of times giving her her breakfast and
173 she's taken the seizures. It's a horrible sight. You know, but thankfully they've changed
174 her medication a bit and she hasn't had one since probably the beginning of, maybe
175 since last year actually, a while anyway. So but as I say I'll drop everything and go.

176 I: So before she got the medication, before it got stabilized, the seizures, did that impact
177 you at work? So were you maybe worried when you were at work that that might
178 happen and you might have to be called away?

179 P: Yes you are. But the thing is she, she had been so unwell because before she took this I
180 just had five or six years ago she had a perforated bowel, gradually her health had been
181 deteriorating she had a muscular problem and like so getting round the house her knees
182 would give way under her and things like that so I've been used to her you know, her
183 being unwell but it also gradually got worse and worse as I said to the point that she
184 nearly died five six years back. But then post that you've got the dementia coming in. So
185 it's not as if, it's in your head if it's in your mind that she's poorly anyway so it's not as if
186 so many of these things happen that it's just come out of the blue. So it's, it's, you're
187 kind of almost used to the situation that she's poorly. You know. So of course when
188 something happens or when she takes a fit you know that gives you a jolt and you just
189 want to get up to the house. If you're not there make sure she's okay and you're worried
190 that I mean on one occasion I was worried that, would she make it through because to
191 me she wasn't breathing and I had to put her into the recovery position. Anyway that
192 just came on you like that. She was absolutely fine. I was giving her her porridge in the
193 morning and it just came on so. But in terms of the work situation yes you, you're always
194 worried about her. But it's maybe different to someone who has had somebody whose
195 health is in reasonably good order when something all of a sudden comes upon it. So I
196 think there's a bit of a difference there. But I mean you do of course you are, yeah, but
197 it's almost like a constant worry more so than anything. (Mm hmm). So yeah if that make
198 sense.

199 I: Absolutely. Yeah. So you talked about putting her in the recovery position. Did you get
200 any special kind of training on how to be better able to care for your mother?

201 P: Not, not in terms of our situation with our mother. Like I have I've had first aid training
202 before through some volunteering work I've done so, it, only through that what I find
203 that my mind went almost blank straight away like there was a bit of a what on earth is
204 going on here. I mean you kinda catch yourself. And then you try to start thinking what
205 am I supposed to do in this situation because I think it's maybe different if you were to
206 see somebody in the street taking a turn. It might be a bit easier to think logically and to

207 have reasoned thoughts in your mind but when it's your mom. It's just it's a bit of a
208 shock. So my dad was there as well at the time I called him through and he was even
209 worse than me. You just stood there and I started to scream at him to phone the, phone
210 the ambulance you know on a number of times eventually he did but as I say that's not
211 an easy situation to deal with. But anyway you've got to get on with it.

212 I: Yeah. So how do you generally feel about your situation of being a working carer?

213 P: It's just the reality of the situation. You can't do anything about it. So I mean I know
214 there's people who have said this to people before. If people in my situation and my, you
215 know, my friends and so on. As far as I can see they don't have real burdens in their life
216 and they probably don't realize how easy they've got it you know because like my life
217 basically revolves around my parents' home. And I've got other things that I've got, other
218 interests in life that sometimes have to take a backseat but I don't, you know, I don't
219 begrudge in any way shape or form. It's just the reality of it. You have to do it. And I
220 know there's other people which I have never understood. There's people who are, at
221 the first opportunity that their parents, either of their parents take unwell they want to
222 put them in a home, you know. I'll avoid that if it's within my power to do anything
223 about it. I'll do it every single time. Just because it's my duty you know. So that's how I
224 look at it. You know as I say I have, you do have to kind of sacrifice some of your time but
225 it's not a sacrifice in a sense or because it's as I say it's your duty. So I know that my mom
226 and my dad as well have sacrificed so much for me. So what, why would I not do the
227 same. You know it would be selfish of me. Absolutely. So selfish of me. I wouldn't want
228 to countenance that.

229 I: So your siblings all of you working together to care for your mother, is there anyone else
230 that helps you with caring?

231 P: So they have a care package through the council, so the way that works is, so she has
232 carers coming in first thing in the morning and then four times a day basically. So first
233 thing in the morning, mid-morning, about lunch. Hold on. First thing in the morning,
234 about lunchtime, mid-afternoon. I mean at night. So what the Carers do, and this is a real
235 help for us, a massive help, so they kinda get her washed and changed in the morning. I
236 mean throughout the day, they attend to her throughout the day, and then put her to
237 bed at night so she stays in her bed in the morning till about lunchtime and she gets up
238 she goes to the sitting room for a bit of normality rather than just staying put in the one
239 position and then eventually come up at eight o'clock at half eight at night, sometimes
240 nine to go back to bed and that's her there for the night. So that's a massive help for us.
241 Initially we didn't have any of that help. Initially. So. For a small, small period of time
242 after she got home from hospital after her perforated bowel, and we were having to do
243 a lot ourselves and I was just exhausted. And so as I said my dad tried to do it himself, to
244 take care of the situation himself. Initially for the first few days and then eventually me
245 and my brother started sleeping over with her. Well we'll be upstairs and we'd hear her
246 throughout the night. And so I'd go down and it was so exhausting. But thankfully the
247 kind of waking nightmares that she was having, they didn't last and one of the best
248 things about it is just she sleeps really well throughout the night but unfortunately also
249 sleeps through the day quite often as well.

250 I: Yeah so does your workplace offer any support with caring other than you having that
 251 flexibility which appears to come out of just the job that you have, is there any support
 252 you get?

253 P: No, no I'm not aware that there's, I mean maybe that, maybe there is that I'm not aware
 254 of really.

255 I: OK. How about maybe charity organizations, is there someone that provides any support
 256 either for your mother caring or for you as carers?

257 P: Not for us as carers. Although recently and there's uhm, Crossroads in [place] like I think
 258 there's Crossroads nationwide. So it's, I think it is but I might be wrong but certainly I
 259 don't know if you're familiar with them. They're, so, caring for the carers. So it's the idea
 260 it's obviously that someone comes round, spends some time with mum or does some
 261 maybe housework or whatever I think it might be. We've tried that previously and for
 262 various reasons that didn't work. My older brother since organised for someone to come
 263 around again. So that's probably going back five years or four years since we tried it. Um
 264 at the time I think because mum was more with it at the time but she and she maybe
 265 didn't quite understand why these people were coming around. 'What's wrong with me.
 266 There's nothing wrong with me, I don't need someone to come around', and it's the
 267 same applied to the carers. Quite a year. You know again it would be hard understanding
 268 was she was sharp but in a sense but also not what it once was. She didn't she didn't
 269 realize that she was unwell and she needed help and that they were also helping us so,
 270 but as far as ourselves we're not massively aware of any help that there is but as I say
 271 Crossroads is something that hopefully that might be a help.

272 I: Have you yourself received a carer's assessment for your own needs (For my needs? No.
 273 No). So other than technology which we will come to in just a moment how do you and
 274 your siblings coordinate yourselves when looking after your mum?

275 P: Yes so as I say we have a WhatsApp group particularly just for us siblings. So a lot of that
 276 everything goes through that. It's just it's just the best medium for us to communicate
 277 about it. Every little detail about it, when someone needs to go and pick up some
 278 medication or someone's put in a prescription and they can't pick it up someone else will
 279 pick it up. Someone has to do this, that and the other whatever it might be just it's just
 280 easier like that and as I say set up particularly with my dad in mind. So he's not on that
 281 group. So there's all the things like for instance all of this as I said to take the burden off
 282 my dad and it allows him to go on holidays and things like that. So when he's not there
 283 me, I, my other brother [2] who will stay over with my mom. So we want to make it very
 284 clear to my dad so that he's retired a couple of years retired now. And he should be free
 285 to be able to do a few things that he wasn't able to do previously when he was working
 286 all these years so. So it's not just with my mom in mind, it's with my dad in mind as well.
 287 So that's all part of this WhatsApp group that we have and we're try and take the burden
 288 off him when he's been abroad three times in the last year. So this just allows him to do
 289 that. And we want to try to we had to force his hand you know. But he gets a benefit out
 290 of it. So that's the whole point.

291 I: When you say forced his hand, there hasn't been any conflict about you taking over?

292 P: No, no, no. No conflict. Just starts that. I suppose he can be a bit stubborn. Like we all
 293 can. So we just have to say 'no look I'm doing it' and he knows that we're trying to help
 294 and he doesn't, he just, in his mind, he feels that he's the father. Even though he's
 295 retired and we're all you know grown up or whatever he's still used to being the head of
 296 the house and that's the way our family was. Mum looked after us at home and my dad
 297 worked and he was still the head of the home type thing. So you still got that mindset so
 298 he doesn't realize you know, he's retired, he's older, so but forcing his hand. It's never
 299 really there's never been conflict. Yeah it's just we just do it because he'd do everything
 300 himself.

301 I: Yeah yeah. So. So talking about the technology. So WhatsApp. You said basically
 302 everything runs on WhatsApp (yeah, yeah). Is there anything you would like there to be
 303 improved? Any, any maybe extra features (on WhatsApp?) that you would wish
 304 WhatsApp to have?

305 P: Well, really it is pretty flexible. You know you can put in videos we can, we can put in lots
 306 of photos as well as text. I'm not sure in my mind I haven't really thought through it but
 307 there's nothing that comes to mind, uhm, that would make it any, any better really. I
 308 guess it's pretty good for what we need.

309 I: Yeah. Can you remember, you said you had to, you have it in place for a couple of years
 310 now (Yes), whose idea was that originally or was it all of you coming up with that
 311 together?

312 P: OK. Well that was, our group was originally supposed to keep that, we set it up on
 313 Christmas to, to discuss presents for my parents, I mean it morphed into this basically
 314 you know caring for my mother and also getting things done so my dad doesn't have to
 315 do it. So that's how it started. (OK) So as I say we've got this family WhatsApp group for
 316 all of us including you know husbands and wives of the various, various siblings and so
 317 on and it's just my dad's on that so we didn't want him to be on this group to be honest.
 318 (Yeah. Yeah.) Because that would stress him out so we want to try and minimize the
 319 stress so he doesn't know a lot of what's going on in the background. We tell him things
 320 so he's up to speed on everything. But as to the intricacies of things and things that we
 321 think that need sorted he doesn't need to worry about these things so he's got he's got
 322 the full picture of her health and so on that's fine. But just again just to take the worry
 323 off and take the burden off him.

324 I: Yeah. Is there any other technology that you, you personally or you as siblings caring for
 325 your mother, that you use for caring?

326 P: Yeah I mean I'm sure my sister mentioned this, the best, the best thing technologically
 327 speaking aside from WhatsApp is the cameras we've set up, the cameras. So what I've
 328 said because as I said the likes of me and my brother [2] in particular because I had a
 329 flexible job, he was working at the fire service and he had a flexible job. So me and him
 330 were constantly back and forth all the time throughout the day checking on her,
 331 especially if dad was out, checking on her because maybe she's taken a turn not knowing
 332 if she's in the house on her own and then you know giving her water and things like that
 333 particularly but particularly checking on her. So anyway someone suggested we get

334 these cameras. So a friend of mine who's you know into IT and that he came round and
335 he set them up. We had one set up first and then we had the second one set up so we
336 got one set up in her bedroom which points at her bed and the other one set up in the
337 sitting in the living room pointing at the couch. So at any point in the day through an app
338 on our phone we can check in on her and make sure she's OK. It's got audio, we can
339 hear. You can zoom in. If she's asleep we can zoom in and just you can see that she's
340 breathing OK. Gives you peace of mind. So it takes the stress levels down a wee bit
341 because as I say you get peace of mind you don't need to leave your work and go up as
342 much. So when we got these cameras it was massively helpful. And you can even check
343 in on her abroad you know like when I'm on holiday I tried to, we tried to switch off
344 when we go away because other people at home should be taking the burden because
345 we need our time as well to kind of rest and so on. But you might want to check in on
346 her just to see if she's ok. So it's amazing App. And it's been massively, massively helpful.
347 Like for instance checking in on her throughout the day, if dad's out and maybe she's on
348 the couch and she's kind of slumped over a wee bit, to the point that she's
349 uncomfortable, you go up and sort it. But, that you know without the camera you
350 wouldn't know that she was like that. But as I say it just makes it a lot easier without
351 having to pop up to the house every two seconds just know if she's okay. You could see
352 that's the type of thing, that people in our situation should be advised on because, like
353 we, no one advised us on that you know from a health perspective or whatever and it
354 was someone who was just we've been to IT and so on 'you should get some of these
355 cameras.'

356 I: So was it your friend that (yeah, yeah, yeah) suggested that?

357 P: I think it was, I'm not a hundred percent but certainly with my friend came up and
358 installed them for us. We were having some problem installing them and eventually it
359 was really complicated. I, I'm, I'm fairly good with IT but anyway I got my friend to do it
360 eventually but it was really complicated. So whatever other people are going to be
361 advised on these things you know, maybe something a little bit less complicated or,
362 anyway.

363 I: Are there any downsides to this camera that you mentioned other than installation
364 being rather complicated?

365 P: The only problem is I found, some of us found as well, and we'll maybe see a message
366 going up onto the WhatsApp group 'Can you, is your log in working' because you can log
367 in sometimes and other times it doesn't let you in. I think it may be my mind, I haven't
368 said this to the others, but in my mind I think only one person can be logged in at a time.
369 So I assume when we're not being able to log in maybe someone else is on. It's all done
370 through one log in, my log in. (OK). But other people have access to it. So I assume
371 maybe that's part of the problem maybe if you could have, you know multiple log ins. I
372 don't know.

373 I: So you all have the app on your phone (yeah) and when you want to check in you access
374 the app and you have to put in your log in details (yeah).

375 P: Well, you don't have to put in the log-, you know, the way it's set up is if you have a log
376 you can save and it will remember the password and username so you just go straight on
377 and it will show you. You got one camera here for the, for the bedroom, and the other
378 camera for below for the lounge and you just choose which camera up and then it will go
379 and log in. So generally it's excellent. So yeah.

380 I: So I'm interested before you actually got that in place. Were there any discussions in
381 your family with your siblings on whether to get it at all or were there any reservations
382 from anyone?

383 P: I'm trying to remember if there were any reservations perhaps reservations about the
384 security aspect of it. Now you hear these stories about people who have cameras or web
385 cameras and people accessing it so that I think that probably if I remember correctly
386 came up. Yeah. Aside from that I don't think there were any reservations because as I
387 say it's very helpful for us and it's very helpful for mom as well. And it also means that I
388 have so many knock on effects because it means that dad can go out again. Trying to,
389 trying to do everything himself. He was sitting at home and just hardly could be going
390 out and just wanting to be there all the time. Now he can drop us a message on
391 WhatsApp and say 'Right I'm going out for the day. I've got something over on the west
392 side or whatever it is. Keep an eye on mom and the camera'. So it has so many benefits
393 to Mom. You know she's OK so that Dad can go out, and for us, so we're going to go back
394 and forth. We can check in on her and make sure she's OK. So it's like that's a really
395 massive benefit for us. You know (that sounds really great) it's excellent.

396 I: Yeah. Is there any other technology that you're currently using or that you might have
397 considered in the past and are no longer using or decided against?

398 P: In terms of our care particularly or just in the whole situation?

399 I: Yeah basically the whole situation so either caring but also you combining work and care.
400 Is there anything that you have been using or have considered and decided against?

401 P: I don't think anything maybe that's specific to what we're talking about here. The only
402 other technology we have used was Skype which was for my mother's benefit when,
403 when she was a bit more with it because my sister is in America. So. We were using
404 Skype to allow her to communicate with my sister. Skype did a smart TV and then what
405 they did was they removed the Skype facility from all smart devices. So what we did then
406 was we got an X-Box and connect it because you get it on an X-Box. And so we connected
407 that up. So that was the only other technology we used because we thought it would be
408 good for her.

409 I: That was for your mom to be able to communicate with your sister in America?

410 P: Yeah, and my dad as well, so. That maybe slightly off what we're talking about here.

411 I: OK. That's really great. So is there any do you feel any restrictions using that kind of
412 technology at work other than the one you already mentioned when you are in a
413 teleconference and you can't take your phone into that? Have there been any maybe
414 issues with work colleagues or-?

415 P: No. I mean I share an office with one other person that I've worked with there who I
 416 know really well and she's very relaxed and stuff and she knows the situation with mum.
 417 So it's not like I'm in an open plan office. I can close, I can just close the door if need be
 418 for privacy that's fine. So my work situation lends itself very well to the situation with my
 419 mom. So I haven't had any problems really. If I need to go out I just go out.

420 I: Can you say maybe how often a day you would check on the camera or on the phone
 421 whether there was a WhatsApp message?

422 P: Oh, all the time for WhatsApp. I can just glance at my phone. You know what it's like
 423 nowadays everyone's on their phone constantly anyway and I'm I'm like that as well. So
 424 if there's a message coming through I'll see it pretty quick. Throughout the course of the
 425 day maybe, the idea is that all of us are checking in on. You know all of us siblings so I'll
 426 check in at work maybe three or four times just gradually throughout the day if I can.
 427 You know in the knowledge that other people will be doing the same. And like for
 428 instance [sister3] in [place], she's not here obviously but if she was to see some problem
 429 on the camera she would put a message on WhatsApp and someone would check in and
 430 go in and see if dad's outside go in and see and sort her out or whatever it is. So, so
 431 that's the idea. It gives you peace of mind that not only can you check in but other
 432 people if you've got a busy day sometimes I can't make things, the days are flat out and I
 433 struggle to check in once or twice. But if I, if I got more time and the thing is it's, it's a
 434 very quick process. So if you, if you're, if you've not got a really busy day where you need
 435 to just, need to leave your phone or whatever, you can just have a quick glance and it's a
 436 couple of seconds you know. And that's really helpful. So. Sometimes I'll be at work and I
 437 think you know my thought will come to me I wonder if mum's ok and I'll quickly check
 438 in. So that's kind of why it tends to work. I don't it's just as and when throughout the
 439 day.

440 I: Mm hmm yeah. So a bit of an abstract question, so if you had a magic wand and there
 441 were no restrictions whatsoever what would you like technology to do for you?

442 P: Pff, that's a good question. [long pause] If there were no restrictions [long pause]. Well
 443 one thing that's just come to mind is if you had communication between the carers who
 444 come in to get my mum up in the morning and change her and so on and who come in at
 445 lunchtime on ourselves if there was some means I'd be able to have a line of
 446 communication because I could come, see I'm gonna give her her lunch or something. I
 447 could leave work, log out and go up and put on her, put on our food. And then ready to
 448 give her her food and the carers will come in and there's no communication. We've no
 449 idea when they're gonna be there roughly. No, we know roughly they're coming
 450 between this and this hour. But if you've taken your lunch off and then you have to wait
 451 for it for ages. And that's fine but you just have to take more time off sometimes,
 452 sometimes maybe 15 20 minutes just because you're waiting for them to do their job
 453 sometimes half an hour depending on how she is and what's going on. So that's just the
 454 reality of it. But it might be helpful if we knew that. When they might come up or, so you
 455 could plan accordingly. That's gonna be really difficult to do because their days are all
 456 depends on who they see and they've probably no real way of knowing unless I suppose
 457 you could say if they had a list of houses that they were going to visit and when they've

458 left the house previous to that if there was some way of communicating that through an
459 app or something. I don't know that that's very far fetched but that's the kind of
460 someone some of that kind of stress that we have if we take our time off and then you
461 want to give her her lunch and then you end up waiting for ages and then you have stuff
462 to go back at work and stuff that's placing whatever no one even on the weekend maybe
463 you're doing the same and you've got stuff you've got to do or even, even if you're going
464 to meet up with someone who you're going to do something because you need your
465 downtime. Yeah. And then you know so that that will be helpful in some way but it
466 would never happen though because it's probably there are maybe restrictions on these
467 type of things. But just knowing when they were likely to be there and we could plan
468 accordingly.

469 I: Do you know in advance which person is going to come to tend to your mum? Is that
470 something that you know or is it always a surprise every time, who's going to come?

471 P: You have roughly a similar pool of carers who come. But it varies within that pool. So I
472 think they deal with various you know geographical areas that are in their groups and so
473 you might see the same group they work in pairs usually so they might come along
474 maybe three or four times the same day the same people or they did come a number of
475 mornings or whatever. But we got to know most of them fairly well and so on but there
476 was someone excellent but yeah so it just depends really and sometimes we'll get relief
477 ones coming in as well that we probably don't know that well but it was it was great for
478 Mom anyway. Initially when she was when she was more aware that she she became
479 friends with some of them. You know they got on really well with her and things like
480 that. So but we don't tend to know who is going to come, exactly who is going to come.
481 You have a rough idea who may be there are but we don't know exactly who's going to
482 come or exactly when they're going to come. So yes it's a. Somewhere developing
483 something of an app, or something that could be helpful (to coordinate) yeah, the
484 coordination between the family and the carer.

485 I: Yes that's definitely something we can look into. OK. Can you think of anything else to
486 make it easier for you to reconcile caring with work?

487 P: In my situation, in terms of my working situation (yes, in your personal situation)? I don't
488 think so as I say my work is very flexible so I don't have to like I think in my situation it's a
489 lot better than other people's. Because it's so flexible because I live so nearby I can react
490 in the most part pretty quick and I haven't really seen any major problems in dealing
491 with it. In terms of my work situation other people, their work's not so flexible, we have
492 really, really flexible work so not everybody has that. So I can imagine if someone like for
493 instance my brother my older brother [1] is a lawyer so he can't just up and run. He's got
494 clients coming in all the time type of thing whereas my most of my dealings are I'm
495 working in systems and so on unless I have, fair enough people are phoning and services
496 and things like that which allows me to be flexible but his work doesn't allow that. So
497 again my my younger brother's the same. Anyway, he'll probably tell you that himself so
498 yeah.

499 I: Great. Okay. Yeah. So so basically wrapping up what would you say are the most positive
500 and the most difficult aspects of being a working carer?

501 P: Well the positive aspects I've touched upon is doing your duty knowing that my mom is
502 safe and you've done your utmost to care for her. I mean obviously the thing that we
503 could forget about is my father and all this which is something we'll try not to do. We try
504 to take it as I said the burden off and we're trying to get him to learn to enjoy retirement
505 and so on so that's the positives the negatives really for myself. Well the negative.
506 Obviously the reality of the situation is negative and she's really, really poorly. You have
507 to see your mother in a really poor state when she's someone who was always doing
508 everything for everyone in the family and you know she was a housewife and she was
509 kind of cooking and cleaning and doing everything for us and loved all that stuff really.
510 For myself personally like I get very kind of. Not not in my thinking but I got to the point
511 where I was very worn down a couple of times last year that happened to me and
512 happened to me again. You know recently I do go to the doctor about it because like I'm
513 very active I played football and I run long distances and so on. But I was getting to the
514 point where I had just fatigue and exhaustion. And so I went to the doctor and they did
515 blood tests on me and things like that. And I was having palpitations in my heart. So they
516 gave me a heart monitor for a week and everything came back fine. And so the doctor in
517 both situations, so the doctor thinks that was some sort of stress related physical
518 manifestation of stress. Generally in my thinking. I don't I don't feel stressed in my
519 thinking on the most part I. When I'm what I feel is fatigue. It's not a tiredness, a
520 tiredness as if you haven't slept. But that's not what I'm talking about. It's just your arms
521 and your legs feel weak sometimes that manifests itself sometimes when I'm feeding my
522 mom. And I go through periods like that and so like for instance when I've been able to
523 run properly that's when this happened on me. And what I've been doing long distance is
524 half marathon, marathon distances and on occasion recently I went out for four miles
525 and I couldn't even do four miles at an easy pace because I was feeling so fatigued. So
526 when I get to that point you just have to stop it. The problem with that is in terms of a
527 negative like there's no break from it. There's no break. Because as I said it's me and my
528 brother, who, my younger brother [2] who the burden is with. And. Again it's just a
529 reality. But the only way I can get a break is so I take a holiday. But then you're coming
530 back to it again. So that's kind of constantly on you. But that's just the way of it. What
531 can you do.

532 I: So what would you wish for yourself personally for your own future? Say the next year
533 the next five years (in terms of?) just anything, what would you like for yourself?

534 P: [pause] Oh I'm not so concerned about myself really. As I say, uhm my, my work
535 situation is fine. Uh. I have. Every job has it's negative and positive but I'm truly
536 fortunate with the work I have. And I'm as I say it, if I was, if I wasn't impacted in the
537 various ways in my life that would be good. But that's, what can you do. That's just. You
538 have to just get over that. That's probably the one thing I would say that's. A bit of a
539 negative that I am impacted in certain things in my life as I say my, my whole life's really
540 taken up with my parents' lives because that's just me and my brother tend to be up

541 there more than others. So it's just have freedom. No, more freedom maybe we'll be the
542 thing you know. But uh yeah that would probably sum it up.

543 I: So my final question would be if you met someone else who is in a similar situation,
544 combining work and caring for someone with dementia, what sort of advice would you
545 give that person?

546 P: We didn't get a massive amount of advice from anybody, at all. When this came to light
547 that she was diagnosed. They said it was early onset Alzheimer's. So no one really gave
548 us any advice. We got handed a few booklets here and there but particularly laterally
549 which so we've kind of had to pick things up as well. We've just dealt with it and so
550 we've gone as we've gone along the process so no one really gave us much advice. So if
551 someone was in the same situation as me I would tell them to, I would I'd be willing to
552 speak to them from my own experience if they were, if that would be of interest to hear
553 that I would tell them to speak to people who have gone through, people, people you
554 know particularly who've gone through it because it's one thing hearing it from someone
555 who has gone through it (Yes) and they've got their own experience or maybe expertise
556 but it's probably better if it's somebody you know as well who's gone through it. To
557 explain that. In what we did and how we dealt with things in X Y Z situation. Particularly
558 from a practical point of view that should be good because if someone had helped us
559 along the way with very practical advice because as I say the likes of the camera, if
560 someone had told us that from the outset that would have been a massive help and a
561 massive burden lifted straight away. So that's where technology definitely would be
562 massive. I'm sure there's so many other areas that haven't even crossed my mind as far
563 as technology goes that could be of benefit to someone in these situations but I would
564 try to share my experience with them. I'd try, I'd try to tell them to read up as much as
565 you can about it. Each situation would be different. No doubt. Like for instance at first
566 my mom was getting aggressive when the carers would come in and you're trying to
567 reason with her that they're there to help. And she's saying 'there's nothing wrong with
568 me'. Various situations like that along the way that are really difficult to deal with for my
569 mom and for making my dad and others and so on. So just you've gone through things so
570 you'd be able to give your perspective on these things how you tried to deal with it and
571 how x y or z helped you deal with it. So it's very much practical advice and so on. That's
572 just that would be the best thing for me if someone would have given me practical
573 advice. I'm not, so I'm not so personally me I'm not so for myself other people are
574 different I'm not so concerned about emotional advice and all that I'd rather just get on
575 with it myself and maybe other people won't like that but that's the way I would like to
576 deal with it. I'm not one to sit down and start going through you know emotions and
577 things like that but I would very much be interested in the practical side of the caring
578 element you know one area where you can help in that sort of sense.

579 I: So has the internet ever played a part in looking for this kind of practical information the
580 kind of technology and-?

581 P: Not technology. No I don't remember any of us, and that's probably something we
582 should have done really, looked online. It never crossed our minds to look online for
583 technology that might help. Whether. Whether there is much or not I don't know.

584 I: Bu also in regards to this practical advice that you were talking about?

585 P: Oh, I see, people's experience and that. No, we didn't. I have to say we didn't do that.
 586 And again that's something we've learned along the way we've learned a lot on the way.
 587 You know we probably would have done things differently along the way but we really
 588 weren't given. I don't think we were given enough support at all. We really weren't.
 589 We're great support for the carers. You know that's massive but in terms of our
 590 understanding of how to deal with it how to deal with the situation from a practical
 591 perspective and otherwise, we really weren't given any support.

592 I: Where would you have expected that kind of support to come from, the health care
 593 professionals, doctors maybe?

594 P: Yeah I would assume some sort, someone from the NHS that we would have been given
 595 some sort of help more. I mean the point of this probably I think there was an
 596 Alzheimer's nurse at one point. I don't think if she ever came up but there's been
 597 mention of various potential situations but we really weren't to kind of sat down and
 598 someone saying look you know we know there's gonna be a burden on your family and
 599 your mother particularly this is you could x y or z you can look at in order to help a
 600 situation. I don't think we really were. (Mm hmm mm hmm). So maybe the others might
 601 disagree. I don't know.

602 I: No no. Yeah. Great. OK. That was basically the last question that I had. So I just have very
 603 few very brief questions just for the context of the interview. So how old are you?

604 P: Thirty seven.

605 I: Do you currently have a spouse or partner?

606 P: No.

607 I: So how old is your mom?

608 P: My mom is 67.

609 I: And you said that she does have a diagnosis of early onset Alzheimer's? Do you know
 610 when the diagnosis was say uh?

611 P: Probably, roughly 2014. (OK) I was there when the doctor diagnosed her. (OK) roughly
 612 around then.

613 I: And the final question would be the highest level of education that you-

614 P: Degree, I have a degree.

615 I: OK great. Thank you. OK. That concludes the interview.

616 END

617 Postnote after member checking via email, Sept. 2019: "Finally, I would make reference to information
 618 on alternative treatments for Alzheimer's, in terms of the technology desired paragraph and peer to peer
 619 support. We recently started using coconut oil and coconut milk, after reading about it online. We have

620 actually noticed, particularly over this last week, that Mum has been more focused and has started
621 talking a bit more and even laughed this morning, when I gave her breakfast to her. Obviously we don't
622 know for sure if it is the coconut oil, but it would be good to know of real life practical examples of carers
623 who have seen improvements in the condition of loved ones suffering from dementia. I'm sure an app
624 could be developed to encompass a lot of practical information and videos etc, with those willing to
625 share their experiences. My sister who is married in [country] was a Scientist, before she had a family.
626 She came across this through research online, although a lot of it ties into her academic background. She
627 has done a lot of research into alternative/ natural treatments for Alzheimer's. She feels that a lot of the
628 alternative/natural treatments are largely ignored, as there's no money to be made out of this approach.
629 She also says that in general, with chronic health conditions, that pharmaceuticals are pushed on people.
630 She's not saying that pharmaceuticals should be eradicated, just that it's worth looking outside the box
631 and giving the body what it needs to function optimally and heal itself. We had nothing to lose, so we
632 took her advice on board and tried the coconut oil and coconut milk."