

Interview 7, “Theresa”

Date: 2.4.2019; Duration: 43min; Setting: cafeteria of participant’s workplace

I = Interviewer, P = Participant

I: Here we go. So, could you just tell me a bit about your caring situation? So, how did that come about?

P: So, um, my mum is elderly. So, she’s 86, she’ll be 87 this year. Um. I think she’s probably been showing signs of dementia for many years but perhaps I was a little slow to see the signs. She doesn’t, or she wasn’t living in [location1], she was living up in [location2] and I live in [location1], so, we didn’t see her, you know, terribly often, um, but we moved her down to [location1] about two years ago and um, since that point in time, you know, we really realised pretty quickly that her memory wasn’t what it was and then she started beginning to forget arrangements, dates, times, um, forgetting to meet people, um, you know, she didn’t turn up for Christmas day, for lunch on Christmas day, um, so, at that point I spoke to her GP and we had her booked in for an assessment at the memory centre, um, and at the first assessment, um, I can’t quite remember what happened at the first assessment but they, she wasn’t diagnosed with Alzheimer’s at that first point in time, but we obviously had to go back six months later at which point they formally diagnosed it was Alzheimer’s, um, really, from diagnosis, which was just last July ‘til now, um, she’s really gone downhill very, very quickly in terms of um, memory and understanding and ability, actually. So, she’s gone from being somebody, you know, who was still getting the bus into town every day by herself, maybe meeting a friend for coffee or just having a wander around shops to now somebody who doesn’t even leave the house. So, that’s kind of how we’ve seen it progress if you like over the last six months or so

I: What would you say is the care that you do for her? What sort of...

P: So, I now have power of attorney, so I’m effectively running two households, if you like. So, you know, looking after her house finances, um, a lot of my time is spent speaking to the GP, um, and doing all of her food shopping, we’ve now got carers in so I’m doing all the liaison with the carers, just trying to keep on top of what they’re doing, um, and I visit um, actually, I only visit 3 times a week – I was going in every single day, but there comes a point when you have to think “I cannot sustain this - going in every day” so, I now go just three times a week. Um. That’s probably about it. Probably about it. She’s still physically quite able, it’s just mentally she’s not got the capacity to know which day it is or what’s going on.

I: Would you consider yourself to be her main carer?

P: Yes. So, I’m an only child, so, there’s just myself and obviously with the carers going in now every day, you know, that’s kind of employed caring support, but um, yeah, there’s only really myself.

38 I: So, the carer support, is that something from the council?

39 P: It is, yes. Yeah. At the moment. I've been looking at other options and maybe bolstering that
40 with some additional carers, but it's, it finally seems to be going quite well with the support
41 we've got. So, in a way I don't want to rock the boat. You know, it's taken her a long time to
42 accept the carers that we've got, so, we're just going to stick with that at the minute. She's
43 actually going into, well hopefully going into a care home on Friday for a week's respite (okay)
44 so that'll be the first time we've ever done that. Um. Assuming I can physically get her out of
45 the house to go, which is going to be the challenge, I think, on Friday.

46 I: How many hours do you think, on average, do you spend caring a week?

47 P: It's very difficult to quantify that. So, for example, you know today, I need to ring the care
48 home, I need to ring the doctor, I need to ring the bank. So, you know, it's little bits all over
49 the place. It's quite hard to tot it up and say "Well, actually, I spend 15 hours a week caring."
50 Um. I don't know. I mean, in terms of visiting I'm probably only physically there maybe four
51 hours a week, um, but then, yeah, you've got all the additional phone calls and conversations
52 and – it doesn't sound a lot but it has quite a big impact, you know what I mean? So, it's not
53 as though I go on a Saturday morning and spend seven hours with her. That, you know, I don't
54 think that would work for her either. You know. For either of us, really.

55 I: Are you having to check in with the carers every day or do they just check up with you when
56 there's something out of the ordinary?

57 P: They check up with me when there's something out of the ordinary. They obviously leave a
58 communication log in the flat, so, every time I go round, I can catch up and we communicate
59 through the log. Um. I've been speaking to them a bit more recently because we've had to
60 increase the care from two visits a day to three. Um. She's also stopped eating, so, we've had
61 quite a lot of conversations with the carers about making sure that they do actually feed her
62 because they um, she's a very strong-willed woman and she'll say "No, no, I'm fine. I'll eat
63 once you've gone" and they've been saying "Okay" and they've left and I know she doesn't
64 eat once they've gone, so, so there's been quite an intense period of conversation with the
65 care team just to say "Listen, you can't accept her word anymore" you know, because we
66 know that once you walk out of the door she won't eat. So, that's taken up a bit more time of
67 late, but yeah, I can't really quantify it

68 I: How do you, personally, feel about the care that you provide?

69 P: Oh, gosh. I feel grossly inadequate. I wish I could be there more often, I wish I could spend
70 more time with her. There's a lot of a guilt comes with caring responsibilities. Both in terms
71 of feeling as though I'm not supporting mum enough but then also feeling I'm not spending
72 enough time with my own family. I've got a child in primary school, separately I've also got a
73 disabled father who doesn't live in [location1] either but, you know, he needs some of my
74 time as well. So, yeah, you do feel very inadequate (I understand) actually, and obviously
75 trying to maintain the same level of work that you've always done in terms of the output, you
76 know, that you're producing when your workplace is really hard.

77 I: Can you talk a bit more about your work? So, what would you say is a normal workday like for
78 you?

79 P: So, I have kind of a strange role in that it's not 9 till 5 job, really, although I'm contracted to
80 do, you know, 37 and a half hours a week. Um. My job's very deadline-driven, so, if there's a
81 deadline, you just have to work whatever hours happen to be on that week to get the deadline
82 met. Um. I also, my team and my manager are in [location3] which is our head office, so I am
83 required to travel to [location3], [location4] and [location5], actually, with work as well, which
84 adds, you know, a bit of extra stress. Um. In terms of, you know, not being at home to be able
85 to go visit mum that night or even just, I mean last week I got home from [location3] at
86 midnight on Thursday night, so then, you know, come Friday I was so tired I don't think I was
87 performing at work or giving mum full attention when I got there either. So, I think my role's
88 about to change, but there's quite a lot of pressure and a lot of last-minute activities. So, for
89 example, this morning, you know, I had my day planned out, I then got an email in saying, um
90 "We need this budget breakdown", "That's fine, when do you need it?", "Today" (oh) Well,
91 that wasn't factored into my working day, my working week, even. You know. So, a lot of last-
92 minute requests, so, I know that to fit that in I'm going to have to do that after half past five
93 today because I can't fit it in during my working day, so, there's a lot of, it's a high-pressure
94 environment, actually. And I have a lot of support locally and the local team are lovely, but
95 ultimately, I'm reporting to somebody in [location3] who knows nothing about my personal
96 circumstances. So, um, and then I've got that conundrum of "How much do I tell her?" you
97 know, it's hard, isn't it, because she doesn't know me, whereas the guys here, you know, they
98 know I'm loyal, dedicated, I work hard, and that if I say to them "I need tomorrow afternoon
99 off to go see my mum" they'd be like "Go, it's fine. Absolutely no problem". Whereas I feel,
100 rightly or wrongly, to ring this new boss in [location3] who doesn't know me and say "Listen,
101 my mum's not very well. I need to go and spend the afternoon with her", I feel as though I
102 would get a black mark for that. So, a good example is Friday, actually. So, Friday I was going
103 to take that off as time in lieu, actually, for some extra work I did the other week to move
104 mum into the care home, um, but my boss in [location3], she's now put a meeting in my
105 calendar for 11 o'clock on Friday morning, so I'm not going to be able to do that. So, yeah, I'm
106 just sitting there thinking "Well, do I feel empowered enough to go back to her and say
107 'Actually, can we bump that meeting into next week?'" but again, because she's a new boss, I
108 feel a bit like "Oh no, I must do whatever she asks, cause she's new" so, yeah. I think I went
109 off topic there

110 I: No, that's absolutely what this is about, yeah, very much so. So, all of the travel that you talked
111 about, is that last minute as well, or are you able to plan for that?

112 P: Mostly it's planned. Um. Last week was probably a little unusual in that it was a very last-
113 minute request. Um. So, I can, I can normally plan the days I go to suit myself but when I'm
114 there it does tend to be either an overnight stay or a very, very long day, just to get through
115 everything I need to do when I'm down there. And I think cause the rest of the team don't
116 travel very much, I don't think they realise the implication, I mean [location1], you know
117 yourself from your travel, [location1] to [region1] is a long way (yes) you know, it's three and
118 a half hours each way on the train. Um. And, you know, I think they forget that. So, when I
119 walk out at half past five to get the six o'clock train home they're not thinking of the

120 implications for me at the end of the day there. Um. But yeah, it's, to be fair, it's not awfully
121 frequent, but when the travel comes, it all seems to come at once, so quite often I'll have a
122 busy, really busy two weeks where I'm all over the place and then it'll calm down for a few
123 weeks and then chaos. Um. But that's quite hard for me trying to maintain a routine. (I can
124 imagine) I sort of say to mum "I won't be in this week to see you because I'm away" you know,
125 she won't remember that, she won't, maybe she doesn't notice it so it doesn't matter, but
126 you know, I feel, I've not been to see her this week the way I had planned so I feel bad about
127 that.

128 I: That sounds extremely difficult (P laughs – it's challenging). Are you able to work from home
129 though?

130 P: I can. Yes, I can. We have, on paper, we have a very good flexible and agile working policy. In
131 reality, it's just not always possible. Um. It just depends. Again, it depends on the deadlines
132 I've got, it depends on the meetings I've got, um, next week I'll be able to work from home a
133 couple of days, so that's fine. This week I just can't at all cause I've got too much on.

134 I: And so, when you want to work from home, is that something that you can decide for
135 yourself?

136 P: Yes. Yes. Yes. I'm very lucky in that respect. So, I have the freedom. Nobody. Yes, I don't have
137 to ask permission, but it is just fitting it around my workload. Um. And we do a lot by video
138 conference, so obviously if I have video conferences on I can't be at home, so I need to
139 physically be here. Um. But, no, I do have the freedom and I'm very lucky. So, for example, on
140 a Friday I actually finish work at 2, so I quite often try and work from home on a Friday because
141 it means I can finish at 2 and I can be at my mum's by quarter past two, rather than finishing
142 here at two and then having get home and then out to hers. So.

143 I: Your mum lives quite close to you?

144 P: She does. She just lives ten minutes away now (oh, that's good). Yeah, yeah. So, that was one
145 of the reasons for bringing her down from [location2], actually, is that, especially how she is
146 now, I mean there's no way we would have been able to manage that whilst she was so far
147 away. Um. So, I was hoping we'd moved her in time, so I think we maybe just got there in time
148 so at least she knows where she is, she's aware of her surroundings, and I think the thought
149 of moving her now would just be very complicated.

150 I: Does that ever happen that your work and your caring collide? So, one of them interferes with
151 the other?

152 P: Yes. Um. Yes, it can do. So, um, for example mum was in hospital two weeks ago, three weeks
153 ago. So, I get a call from the doctor at lunch time saying "We're admitting your mum to the
154 hospital because she's lost so much weight. She's not eating" um. I had a full afternoon of
155 meetings, so what do you do? Do you drop the meetings and run to the hospital? You know,
156 it was just one of those, you know, situations where I wasn't quite sure and actually, as it
157 happened, the ambulance didn't come for her until 7 o'clock at night, so, from having called
158 it at one, it didn't come 'til. So, if, I could have stayed at work and done my afternoon's work
159 cause she was just at home waiting for transport. So, there are a lot of things like that.

160 Sometimes work does impact and phone calls, you know, that's the biggest impact, for me.
161 So, you know, even just trying to speak to her, I need to speak to her GP today. Um. They don't
162 have a message facility. GPs are very busy practices. So, it's not just as though I can take myself
163 away for ten minutes and make a couple of phone calls. I take myself away, oh, they're busy,
164 I have to come back to work then, I've still got to ring them, so I have to find time later in the
165 day. It sounds silly (no, not at all) but it's at the back of my mind all day that I must ring the
166 doctor, I must ring the doctor and then it's just finding the time. Cause of course this open
167 plan environment, you can't just sit there and pick up the phone, I have to find a meeting
168 room, make the call privately. Um. So, there has been a bit of that. There was um, a couple of
169 instances where she's fallen, so, you know, calls from carers to say she's fallen, so, and last
170 week she'd um, over medicated. So, you know, some other call to take when you're in a
171 meeting or whatever just to say, you know, and then there's that - is she okay? Do I need to
172 go? Do I need to stay? So, you know. Sometimes it, sometimes it can be quite challenging.

173 I: How do you make these decisions whether you need to go or not?

174 P: Very hard. It is very hard. I think, now, um, I think in the beginning I just dropped everything
175 and ran every time. I think now I understand a little bit more about what I'm dealing with and
176 perhaps I don't have to do that every single time. Um. So, now, you know, I can perhaps feel
177 more empowered to ask questions of the carers or the doctor or whatever to say "Actually,
178 do I really need to be there? Is everything under control?" and then what I will, so the one
179 with the over medication last week, for example, had the conversation I thought "Actually, it's
180 all fine" but then I just popped in to see her on the way home at the end of the day. So, for
181 my own peace of mind, I knew she was okay, but I hadn't felt as though I'd had to drop
182 everything and go home. Um. But it's really hard. There were a couple of times where I'd
183 literally just arrived at the [location4] office and the phone would go saying, you know, um,
184 "Your mum's double dosed her medication" or "she's fallen" and I'm thinking "I've just arrived
185 in [location4]", you know. I cannot physically, you know, I can jump on a train and come back,
186 but by the time I do. The only advantage I do have is that she lives in sheltered
187 accommodation. So, between 9 and 5 there is a manager on site (okay) so, um, I think, if, you
188 know, if I thought there was an emergency that I couldn't get to then I know I could at least
189 ring that lady and say "Can you just go up and check?" on mum. And she's very alert, actually,
190 to what's going on. So, there've been quite a few instances where mum's forgotten she's put
191 a pan on the stove, um, and they have a system where as soon as the smoke alarm goes off
192 the fire brigade just come. But, [site manager] who's the site manager's been brilliant. So, she
193 hasn't necessarily rung me, she's just gone up, dealt with the firemen, dealt with mum and
194 it's all been sorted. (That's great). Yeah, so that's kind of a conversation I've not had to have
195 on the day which has been really good. But, she will maybe ring me later on just to say "Just
196 to let you know the fire brigade came again today but it's all okay" so, (laughs), so, um, yeah,
197 so that's, that's an extra bit of relief, if you like. Um. And actually, now that we've got the
198 carers going in three times a day, I feel that has taken a bit of pressure off me as well. So, at
199 least I definitely know somebody's, you know, she's seeing somebody morning, noon and tea-
200 time, whereas before, when we didn't have that in place, you know, I was perhaps the only
201 person she was having a conversation with that day and nobody, you know, she'd fallen, who
202 would know 'til I got there at six o'clock at night? So, at least that is freeing me up a bit to be

203 able to concentrate on work (sounds really good) yeah, yeah, yeah. It's taken a while to get
204 there but we've got there now, so.

205 I: Is there any other support that you receive from the council, for example or from [carer
206 organisation], maybe?

207 P: No. [carer organisation] have been amazing, but I would say to you, um, and I've said it to
208 them, as well, actually, is everything on offer is absolutely outstanding. They just offer it
209 Monday to Friday, nine to five. And that is absolutely no good to me. So, um, that has been a
210 huge frustration, actually, because I mean I have worked from home a couple of days and, you
211 know, effectively just had to sneak out to meet them for a couple of meetings cause I felt that
212 I needed to have those meetings. They've got some amazing courses about understanding
213 dementia, you know, how to deal with all the things that are coming. I just can't get to them
214 because I have work. Now, have I gone and asked my employer if I can go do that? No, I
215 haven't. Why not? I don't know. You know. Because I'm thinking they're either going to say
216 no, or they're gonna think I'm slacking, you know, shirking my responsibilities at work because
217 I want to spend a couple of hours learning about dementia. Is that fair? I don't know. I'm too
218 scared to ask the question at the moment. So, yes, so, that's a challenge. So, [carer
219 organisation] have been absolutely amazing. [carer organisation employee] came out and saw
220 me at the house and ran through, you know, everything that's available to me through them.
221 I think their service is just superb. Um. You know, whether it's been counselling or financial
222 support or even just. In fact, they've just helped me fill in the attendance allowance form
223 cause I didn't even know about that. So, that was really helpful, but again, I had to, um, you
224 know, work from home that day and just effectively take an extended lunch to spend two
225 hours filling in form with them and then make up the time later on. Other than that, um, no,
226 the only other support I've had is I did um, I did have some counselling privately through our
227 work counselling service last summer. Um. Just in the early days, really, to deal with that guilt
228 (laughs) issue, which was really helpful, actually. Um. We only got, I can't remember how
229 many sessions it was now, but you know, there were a finite number of sessions I could get
230 through work. And again, I've spoken to [carer organisation], cause I know they offer
231 counselling service but actually again, accessing that is just not very practical for me. And even
232 if work said "Yeah, you can have all the time off you want", actually, that's fine, but my
233 workload doesn't go anywhere from having all that time off. So, that's the other thing at the
234 back of my mind, that okay, I could go to that course for two hours on a Tuesday morning, but
235 then I'm just gonna have to make up work elsewhere. So, is it worth it? Cause at the moment
236 I'm really busy. So, um, other support. I haven't really got any other support. Um. My
237 husband's great. He's been great, actually, helping out with mum when he can. Um. No, not
238 really any support at the minute.

239 I: Have you had a carers assessment?

240 P: We, I don't think so (laughs). I was about to say did we? No. Well, did we do that?

241 I: It should be done by the council.

242 P: No. is that an assessment of me? (Yes) See, I don't even know what you're talking about. That
243 is one of the biggest challenges with this, actually (Yeah) is understanding everything that's

244 out there and who you need to speak to and what you need to do and um, I mean [carer
245 organisation] have been good and [dementia organisation] have been good but they both sent
246 me piles and piles of leaflets and information and they're still sitting unread at home because
247 um I've either been really busy at work or by the time I've got home I'm so exhausted that I
248 don't want to sit there and read through fifteen different leaflets telling me. I do want to but
249 I'm too tired to do it. Um. So, no, nobody's spoken to me about a carer's assessment, actually.

250 I: And how about technology? Is there any technology that you are currently using to help with
251 caring?

252 P: I think the answer's no. Um. I'm a bit of a dinosaur personally when it comes to technology.
253 Um. Bit of a joke in our house cause my husband works in IT so he's very up on technology.
254 Um. What do I use? Obviously, I use the diary system of reminders on my phone, um, I would
255 like to have access to the GP and the carers through technology. I don't even have email access
256 to them, so that would be really useful, you know, that's quite basic technology, but at the
257 moment that all has to be done by phone and for me, actually, email's easier than phone,
258 especially when you're working. You can just bang out a quick email rather than having to go
259 and do the whole phone call palaver. Um. It would be useful to have some kind of platform
260 where um, you know, we had information about all the people that were involved in mum's
261 care or even access to her care plan. Um. You know, at the moment, it's just a file hidden in
262 her flat which, you know. Um. So, no, I personally would find that useful to have one place to
263 go for absolutely everything, whether it's the memory centre information, carers information,
264 the GPs information, the hearing centre's information. Because, you know, I don't know when
265 her next appointment is for her hearing aids cause I've not been, you know, she's been a very
266 independent woman since last summer, so I've no idea, you know. Even when's her eye test
267 due for renewal – I've no idea. You know, so all of these sort of things and I have now, I am
268 now getting her mail redirected to me because um, I just didn't have a clue if any paper work
269 was coming in, reminders, anything like that at all, you know, and mum didn't, she didn't know
270 what she'd received, what she'd read, what she'd binned, so, that's helping a little bit in terms
271 of me getting on top of, you know, what's out there, but, yeah, some kind of platform where
272 everything was in one place, that would be absolutely fantastic.

273 I: That's really good. Does your mother have, do you know, does she have panic alarms or
274 anything like that?

275 P: She doesn't. She wouldn't wear it. She's still quite vain, so, she won't wear her hearing aids
276 because she's vain, she won't wear her glasses cause she's vain, anything like that, but no,
277 because she's in sheltered accommodation they do a pull cord in some of the rooms. So, um,
278 theoretically that's available to her, but she's off that, I don't know how many [location1]
279 ladies you know of this generation, but they're very independent and strong-willed and um,
280 she would not pull a pull cord unless, you know, she wouldn't do it because that would be
281 causing a fuss and you don't want to cause a fuss. Um. So, the thought of wearing a panic
282 alarm of any description is just not, she just wouldn't do it.

283 I: So, you talked about her having had a couple of falls already (yes) yeah. Does she have any
284 way of notifying someone when that happens or is it just when the carers come in?

285 P: No, so, just when the carers come in (find her on the floor) and see her. Um. I mean, I'd say
286 the pull cord's there, but she wouldn't use it or remember to use it perhaps, now, I don't
287 know. Um. So, yeah, I think the last time, she managed to get herself up, so, you know, she
288 was fine. But then she, you know, within literally minutes doesn't remember that she'd fallen.
289 Um. But that last time it was just fortuitous that it was literally just as a carer was arriving, so
290 they got to her pretty quickly and then they just rang me, and I went straight over. Um. But,
291 no, um, that's a difficult one, isn't it? Because even if I said to her "Mum, you've got a pull
292 cord, you could pull it." How do you know she remembers that now? Cause we're at that stage
293 where, I don't think she would know what the red triangle in the corner of the room is for. So,
294 it's a good point. Yes. I mean if she was wearing something maybe she would be more likely
295 to understand that that was there for assistance rather than thinking "I don't know how to
296 call somebody". Um. Yeah, I don't know. Some voice-activated systems might be quite
297 interesting, you know, if she could even shout out "I've fallen" or "Help" um, you know. Cause
298 actually, if somebody does fall, you've still got to crawl to the corner of the room to pull a
299 cord, haven't you? (yeah) I think that might not always be possible. Um. That would sort of
300 give me peace of mind, actually, if she, if there was something out there that meant she could
301 get connected to somebody. Um. I mean, mum's, again, of that generation, um, where she
302 didn't grow up with technology, so, she couldn't even use a mobile phone before the
303 dementia set in, so, any new technology, now, is just almost a bit late for her. Um. She has
304 accepted dementia clock, so we've got one of those in now, that took a long time for her to
305 get used to but she's happy with it now. So, at least she can see what the day and time is. Um.
306 But, yeah, even when she was still out and about, a mobile was too much for her, she couldn't
307 work it or understand or, and cause she won't hear her hearing aid she couldn't hear it ring,
308 so it's pointless (laughs). Um. But, yeah, it's a very frustrating condition, I have to say, because
309 you want to help somebody so much but they're not capable of receiving the help. So, yeah,
310 it's, as you say, if you could go and say "Mum, here's a panic alarm to wear like a watch" but
311 she either wouldn't want it, wouldn't remember how to use it. So, yeah, it's hard (Absolutely).
312 Do they do dementia dogs the way they do hearing dogs or um guide dogs for the blind, I
313 wonder?

314 I: Honestly, I don't know, but that's definitely something I can (it's not a technology) it's not a
315 technology but it might be a solution

316 P: I was just wondering if they, mind you, I don't think she could have a dog where she lives, but
317 anyway. Yeah. I don't know, you've got me thinking outside the box a bit

318 I: That's very good because my next question is actually – if you had a magic wand (yes), what
319 would you like technology to be able to do for you?

320 P: Ah, gosh. Um. Well, as I say, I think to have all the information I need in one place would just
321 be amazing. That'd be amazing. I think to be able to make appointments and access systems
322 through one portal would be amazing as well, actually. And then I think if there was a
323 technology that could alert me to a fall or a need for assistance that would be fantastic as well,
324 actually. Um. Yeah, I mean, I suppose that single portal for carers, if carers were able to input
325 into that portal as well with a daily report, it also means on the days that I don't get to see
326 mum I could just log in and see what they've said today, rather than – I won't be there 'til

327 Friday now, so, that's a whole week almost that I won't actually see what they've said. So, I
328 know they would ring me if there was an issue – I know they would ring me – but, sometimes
329 it's useful just to see a little comment that they've put or sometimes they might write that I
330 need to collect more, I need to collect something from the chemist or more nutritional drinks
331 or something like that, so, yeah, that instantly accessible way, a portal where I could just sit
332 on my iPad at 9 o'clock at night and just have a quick look at that would be absolutely amazing.
333 Um. And also, that can be shared with the GP, that would be even more amazing. And I don't
334 know if I'm just really lucky in that the GP has sort of taken mum under his wing – he's taken
335 a real interest, I don't know if I'm just particularly lucky because he has, he knew her before,
336 I mean, he knows her now, so he's seen the transition and I think he's very keen to help any
337 way he can. So, I think, I think he would probably buy into something like that. I'm not sure if
338 all GPs would cause they're so busy and under pressure, aren't they? But um, yeah, I don't
339 know what, magic wand. Well, we have talked about tracking technology. Um. When she was
340 still out and about, um. Possibly late for us now, but that would have been useful, I think.
341 Cause I know my grandmother went wandering, um, she had dementia and I remember as a
342 child going out in the car with my dad looking for her. This is back in the seventies, you know,
343 way before any technology. Um. So, better tracking technology would have been, would have
344 been useful. My husband did look at some but they were, they were huge and also you kind
345 of thought "Well, I can't sneak that into mum's handbag" you know (laughs). If she had a
346 mobile phone I could hook it up with find my phone, um, so, something unobtrusive that you
347 could just slip in her handbag and at least if there was a problem you could track her down.
348 That would have been really helpful at the time. Um. I don't know. It sounds silly but any
349 alternative to mobile phones. The mobile phone was just too challenging for mum, so if there
350 was any simple way of being able to contact her, you know, ring her, um, I don't know, sounds
351 crazy cause mobile phones are really quite simple, but you know, it was just too much, so I
352 don't know if there was a way of just saying to her "Just carry this with you and it means I can
353 speak to you when I need to speak to you" (yeah). So, I don't know, that kind of thing. Um. I
354 can't think of anything else that springs to mind immediately

355 I: That's already quite a lot (Is that quite a lot? Okay) Yeah. It's really quite a lot, so that's really
356 good. Thank you. Thank you very much. Um, so, if you met someone else who's in a similar
357 situation like yourself combining work and caring for someone with dementia, what kind of
358 advice would you give to that person?

359 P: Oh, gosh. That's a really tricky question, actually. Um. I would say "Get on top of it early". I
360 was very slow to see what was going on. Um. I would probably say, probably say speak to your
361 employer at the outset, as well, cause I'm now in this position where I think "It's too late to
362 say anything. I don't know what to do". But, yeah, probably um, say that and then also, um,
363 yeah, just, just try and lose the guilt early as well, actually, because I think once you've lost
364 the guilt you can be more productive and more helpful. So, more productive at work and more
365 helpful to the person you're caring for, actually. But, that's very difficult, I think, women are
366 very good at guilt anyway, just generally. And um, so yeah, I think, especially I think when it's.
367 We've always got that childbearing complicated relationship as well, so, yeah, I would say
368 realise what you're dealing with and lose the guilt early. Those would be my things. One thing
369 which we're starting at work actually is the carers group (okay). So, um, I volunteered to be
370 the [location] representative of our carers group cause we're an international business, but

371 nationally we've got this carers group now, so I've only been to one meeting so far and it was
372 really interesting, actually, but, everybody, I haven't met anybody else with dementia, but,
373 other people obviously dealing with, you know, far more complicated things than I am. It's
374 just really interesting to know, there are so many of us in the workplace. Um. And you kind of
375 think you're the only one, don't you? You really do think you're the only one, which is silly,
376 cause everybody's got complicated lives. Um. So, that has been really useful as well, actually,
377 is to have a, a forum where we can get together and, we're not really sharing issues, but we're
378 just talking about what the workplace could do to support us better and actually I think we're
379 about to implement our – it doesn't sound very much – I think we're about to implement a
380 half day a year that anyone can take off, at any point, for any caring responsibility that they
381 need, which I think, given caring responsibilities that feels like a tiny gesture, but it's better
382 than nothing and not everyone can work as flexibly as I can. You know, some of our secretarial
383 staff are on very strict shifts, so they can't just say "I'm working from home tomorrow" the
384 way I can, so, I think probably for somebody like that it's way more complicated. So, I think to
385 be able to have that kind of half day off, no questions asked, is fantastic that they can do that.
386 It still feels like a small step, and I don't know how, you know, when I think of all phone calls
387 and appointments, you know, that I've had to do, some people are dealing with disabled
388 children, so they're in and out of the hospital all the time. I just don't know how they manage
389 it, actually. Um. A lot of it is down to line manager – your own line manager. So, they can have
390 a bit of discretion there, you know, I guess if you've worked here for years and have proven
391 yourself to be reliable and committed employee, they're gonna give you a bit more leeway,
392 aren't they? But, yes, that would be my other piece of advice is if there is a workplace group,
393 if there's a workplace group, you know, get involved because actually I have found that really
394 interesting and helpful.

395 I: So, we're almost done (That's fine, yeah). So, um, I would just like to ask you what are the
396 wishes that you have for yourself for your own future?

397 P: In terms of-?

398 I: In terms of your situation being a working carer or generally

399 P: General, gosh. Right. So, personally, I think I would really like for mum to get into a good care
400 home, because I think having twenty-four seven care and I think having, actually, that social
401 interaction will make a huge difference for her. I think she'll have a better quality of life being
402 able to interact with others. Um. The cost of a care home is absolutely prohibitive. I had no
403 idea. So, that's an interesting dilemma, but, you know, ultimately, I think it probably would be
404 the best thing for her to have that. Um. From a working perspective, I hope we can get the
405 carers group at work off the ground and working successfully for people. We're actually
406 working up to a carers week in June, so will have a week of information, I'm going to get [carer
407 organisation] to come in and speak and give out leaflets and things like that. Um. So, I kind of
408 want to spread the message across the offices in [region2] anyway that "You're not alone",
409 "There's lots of support", um, and we're going to get a proper carers policy in place where
410 people know, you know, what flexibility they can have in their lives, if that's what they need.
411 So, you know, hoping we can get that off the ground. We've got a date in June so we're gonna
412 have to get it up and running, the carers week in June. Um. And selfishly I hope my new boss

413 is as understanding as my old boss, you know, to give me the flexibility, you know, and I, I feel
414 I'm very happy to work 'til midnight one night cause I've got a deadline, but you know what,
415 on Friday if I wanna spend it at home with my mum, I want to be able to do that. So, as I say,
416 I'm very lucky at the moment I've been able to, I just hope that can continue as well. And,
417 actually, I think the modern way of working has to get away from this 9-5 at a desk. That is not
418 the way forward. It's not the future, is it? Um. Thinking about all these companies that have
419 gone to four-day weeks and things and have found their staff are more productive, which is
420 really interesting and um. So, yeah, I think, yeah, hopefully workplaces generally will become
421 more alive to people's situations. Um. I also think an extra generation coming through with a
422 different work ethic, as well, a different view of work-life balance. So, I don't think they will
423 welcome the strict regime as currently impressed because they will view things differently.
424 Does that help?

425 I: Absolutely. So, very last question (yes) that I have is - are there any positive aspects to being
426 a carer or being a working carer as well for you?

427 P: Oh. You know what, it has made me, uhm, it has made me think about what other people are
428 doing, you know, in their own bubbles cause life's busy, you know, we're all managing what's
429 in front of us, but it has made me, you know, look more widely at a way of. Perhaps try and
430 be a bit more sympathetic in my own team, so, um, giving people a bit of space and flexibility
431 and freedom. Um. I've met some really lovely people, particularly through [carer
432 organisation]. Um, so that's been a real positive, you know, to people I would not ordinarily
433 cross paths with, which is great. Um. I suppose it's perhaps brought the family closer a little
434 bit. Um. My mum does have a sister who lives in [location1] but, you know, busy modern life,
435 tend not to see each other very often, but, you know, we're talking a lot more now cause she's
436 concerned about mum. It's been a nice positive that's come out of it. And actually, her
437 daughter, so, my cousin, and I have become a lot closer which is really nice as well, actually,
438 cause you just grow up and you move away, don't you? But um, yeah, so, I think, probably
439 doesn't sound like a positive, but I think you kind of come to the realisation that actually, that
440 generation won't be around forever, so we're the next generation and we want to bring the
441 family back together again, you know, for our children, actually. So that's been a real positive

442 I: Thank you for sharing your story.

443 P: That's alright. It feels weird talking about it sometimes, actually, I think. Yeah. Everything. I
444 didn't, you know it took me a long, long time to realise I was a carer. And that's been quite
445 interesting as well, cause I just, you just kind of think "That's what you do" isn't it? (Absolutely)
446 I don't need a label, this is just part of life. So, that was quite interesting, just took me a good
447 few months of people saying "You are, you need to accept this label, because actually" that's
448 part of the learning curve as well. Once you accept that title then actually you sort of feel a bit
449 like "Right, okay, I can" you know "think about things differently now" rather than "I'm just a
450 daughter looking after her mother", you know?

451 I: Yeah, that's quite interesting. Could I, just for context, ask you a couple of very short
452 questions?

453 P: Of course, yeah.

454 I: How old are you?

455 P: 49

456 I: And, so, we've talked about all of this. Um. Yeah, so, the last question that's still open is the
457 level of education that you have achieved

458 P: Uh, so, I have a degree from [location1] university.

459 I: Thank you very much

460 P: That's okay.

461 END

462 Addition by P via Email after the interview: "One thing that did come to mind later was the use of
463 technology to remind people with dementia to eat. A simple alarm isn't enough as certainly with
464 Mum's case, by the time she's turned the alarm off or put the phone down and gone to the kitchen
465 she's forgotten why she is there."

466 Postnote after member checking via email Sept. 2019: "Appreciate this is after the fact but Mum no
467 longer leaves the house at all so I would welcome home visits from e.g., audiology and opticians but
468 these don't seem to be available - a website or technology solution to find services/contact details of
469 organisations that offer such things would be amazing."