

Interview 9, "Sue"

Date: 10.4.2019, Duration: 121min, Setting: University cafeteria

I = Interviewer, P = Participant

I: Ok, there we go, right so, could you tell me a bit more about your caring situation- so how, how did that come about, how did you become a carer?

P: The two people I care for are my in-laws (yeah) my ex-husband lives in the Middle East (ok), although he's British he lives in the Middle East, has done for thirty years (ok). He has another brother and a sister. The brother lives in [place omitted], because we live in [place omitted] it's two hours away. He also works in [place omitted] he's a [role omitted] so his work is here, out the way, so he can't come back. They have another sister who lives about ten minutes away from her parents, who has nothing to do with her parents (ok). She can't cope, she can't cope with it which is just her personal issues. So, me and my daughter, one of my kids, in principle my four children look after my in-laws, mainly my other daughter who is 26, we're the main carers on an emergency basis and maintenance, all that stuff so that's why, that's why we look after them; we are their responsible, able people who can be around and do everything for them. They're 88 and 89.

I: So your mother in-law is?

P: My mother in-law is 88 and my father in-law is 89 (ok) and he is full on total dementia, has had for about ten years and she point blank refuses to have any help whatsoever, it's just a housekeeper that comes in for two hours on a Friday morning and she insists on doing the work with her (ok) and that is it and he's now virtually doubly incontinent and that's the situation we're in; she will not accept any help.

I: And your mother in-law, does she have diagnosis of dementia as well or?

P: No, just him (just him) just him. She's got osteoporosis, she's bent over, she is declining very quickly (ok). We got her to get an adapted bathroom put in, maybe about two or three years ago, a wet room (aha) thank god because now he's totally, so badly incontinent. That's been her saving grace and that's it, that's the situation really, this 'it's my husband until death do us part' (mm, mm). She won't even let him go to day care. So that's the situation we're in is that we, on a daily basis one of us is up there and we handle all the building, looking after the house, looking after the finances. She goes out every morning (your mother in-law?) She gets out virtually every morning as long as she's ok, because she still drives just in [area omitted] and she goes to Tesco's but she has a routine, certain day she buys certain things. Thursday is banking day you know there's that, so she'll go lift her cash (aha) and that's what she survives by because he thinks she's at church and that's part of, because she used to go to church every morning, so that's still part of his life, he can cope with that. So she's out of the house for possibly two hours every morning.

I: Ok and during that time he is alone?

39 P: He is alone (ok) but that's always been part of his life so that doesn't upset him (yeah, ok)
40 and if you phone, he'll answer the phone, he won't answer the phone if she's in the house.
41 He'll answer the phone and he'll say [Name]'s not here, she'll be back at half 12' (ok) so it's
42 dangerous because if anyone was watching the house, that's him, he's happy to answer it
43 because he knows and he doesn't move out. He sits in one sitting room, and she sits in the
44 other -laughs- (oh) so he sits in his sitting room and that's what he does, or he'll get up and
45 answer the phone and say 'she's not here, she'll be home at half 12' and goes back to his
46 seat.

47 I: Can you tell me a bit more about the care that you're providing?

48 P: The care that we provide is that we speak to him at certain times during the day, always in
49 contact you know if I can't get her at five o'clock because she cooks three course meals
50 every night (ok), then if I couldn't get her then I would know there was an issue. That's our
51 concern, is that something happens to her, he would just step over and go 'why are you
52 down there?' that's, so we have, she doesn't, she does know this but she doesn't know this-
53 that between me and my daughter we, or the others, who's around, you know, 'have you
54 spoken to your gran today?' while I go down, because we can't be too, we can be intrusive
55 but we don't like to be because it upsets her too much (mm) so if I hadn't heard her get on
56 the phone then I know that [name omitted] hasn't spoken to her or somebody then one of
57 us will go, because our concern is something happens to her (yeah). They've got a
58 community alarm which is in his name, but he wouldn't know, it's just that thing in the
59 corner that's got lights on it, you know so that's it, so we do the maintenance, we bring up
60 some of the heavy shopping. She will not allow us to do most of her shopping, she will only
61 get bottled water, so she was carrying that all the time, so we just went and bought 20
62 bottles or 30 and put them up and she just freaked, because it was taking up a space in her
63 house she didn't want used (ok), so she now buys them singly. So that's what we're up
64 against; we do as much as we can and we, most of our, we have to push everything on her-
65 the bathroom, it took me probably two years to talk her into that and she kept saying 'I can't
66 do this, I can't do that and it's gonna-' she's got a pulley for her laundry in the bathroom and
67 she used to stand on the edge of the bath to hang up because it was a fixed rope and I
68 eventually said one day, I arrived at the house one day and said 'here's a joiner and here's
69 the pulley and we're putting a proper old fashioned pulley that comes up and down' so that
70 she does not have to stand and she was doing that up until, the wet room was put in about
71 two years ago and that was in maybe two years before that but other than that, at 82/83
72 she was standing on the edge of a bath everyday hanging up laundry (oh my god). So she
73 could go out in the garden but she'd fallen in the garden not that long before and seriously
74 hurt her back. So things like that, we do sometimes just step in and say 'no, this is ridiculous
75 now'. When the wet room was put in we had to redesign part of the screen area because the
76 pulley wouldn't have been able to come down, so we had to redesign, the Council put it in
77 and then we had to redesign a bar at the top end. So at the moment we're trying to get her
78 to let him go in day care because anything out of his routine, the repercussion's awful he's
79 so unsettled afterwards. So he has a complete fixed routine, but the community alarm, she
80 can work, he can't, so that's my downfall, is if anything happens to her we've got no way of
81 him communicating with us.

82 I: So, the community alarm, is that like the pendant alarm?

83 P: The bracelet or diamond necklace.

84 I: And is she, so your mother in-law is wearing that?

85 P: She has it, she has it on, although it's in his name, he would just dismantle it, he would cut
86 up the rope and take the batteries out of it and he continually takes batteries out and
87 dismantles things (ok). So, he can't, he knows not to touch it which is probably to her
88 detriment, but if he was on his own to touch, he would dismantle it and then plug it in, she
89 would find it in a sideboard or something you know, so it's there. When it got put in he was
90 really, really, really um, because of where it is and the cables and the phone points, it's
91 actually in the sitting room he sits in, so that was kind of a risk we had to take but he doesn't
92 touch it now.

93 I: How do you explain him dismantling it, is it curiosity or?

94 P: Yeah, he continually dismantles his remote, TV remote and he'll sometimes come through
95 and say it's not working, and she'll go through, and he's taken every wire out, he's unplugged
96 everything at the back, he's unplugged all the lights, he's taken all the batteries out of the
97 remotes. He goes through phases of that, so what I did find out recently is there's a local
98 company, a local independent, it was a TV shop and now they do chairs for old people, you
99 know the ones that lift them up? (Aha). They kind of specialise in this and I think this guy has
100 hit a market and what we've discovered recently is she pays them because when he does
101 this to the TV, he then messes up all the settings (ah) so it needs re, reset, so what we've
102 discovered she's doing is she pays this company and the guys come up, a tenner a time and
103 they just reset your TV (laughs) and we've said to her 'we'll show you how you do it' and
104 she's like 'no, no, they come, the boys come' and literally this guy has obviously hit a market
105 because there's so many people (yeah) and he just, he'll just get a call '[Name]'s
106 dismantled it again' and the boys come up and I also think she's using them to do light bulbs
107 and stuff because she's trying not to ask us (aha). But we've noticed things and we're like
108 'how is this' and she'll let slip now (right). So I don't know how many times she's using this
109 company so, and there is the community people, part of the community alarm with the Care
110 and Repair Teams through the Council, they will come and do things for you but they've got
111 a waiting list you know and if her whole ceiling light's out, then she uses it, keeps it on at
112 night, then if we come in and we notice it, then we'll fix it (mm) but if she's noticed it, she'll
113 phone them. I think she's phoning [company] who come and do it that day rather than wait
114 for the Care and Repair Team because she's like 'I've got the money, I can afford to do this'
115 so-

116 I: So why, why do you think she does not want you or your family to-

117 P: Because we do other stuff for her, she's trying to limit (oh, ok). She's 'oh you work, you've
118 got your grandchildren to look after'. [Name omitted] my daughter, works between where
119 we live and [place], so like she's driving every couple of days to [place] and she's like it's
120 damage limitation, she's like 'I've got the money' that's what she says is she won't take, she
121 buys all the incontinence stuff for him, she won't take it off the Council and we're 'let us get
122 the community nurse in, get him assessed again', not assessed again, I don't think he's ever
123 been assessed. She says 'no, I can afford this, I just buy them in Tesco's' (mm). So it's very
124 much her, I think it's her clinging onto her independence, I can't take that away from her.
125 That's one of the things is we have to be respectful of what she wants. It's all very well, at
126 certain times we will sit her down and say 'enough's enough'. So from that, so we are there
127 and we bring stuff to her, we will bring stuff to her and say 'do you know you can get this, do
128 you know you can do that, do you know this is available?' and she'll say 'not doing it, not
129 doing it'. The bathroom was the big thing, the bathroom was a big, big thing and thank god
130 we got it done because he, we got it done just in time for her because she's showering him
131 down and he's covered because what he does is he gets up during the night, he takes off his

132 pads, shoves them down the back of the radiator, and then obviously he must be naked
133 from the waist down by then, goes to the bathroom which is next to his room and comes
134 back, but in the meantime he's kind of trailed (aha). So at least she's able to shower him
135 down and what very recently, I showed her how to adjust the head in the shower, you know
136 you can do it and get a spray, or you can get a very concentrated and she was using it on all
137 his clothes, because she was throwing stuff out, at first, she was throwing out shoes and
138 clothes. She says, 'I'm not putting them in my washing machine' and eventually it's got so
139 bad now, she realises she can't, and I said, 'have you used the shower head' she says 'what?'
140 I says 'use the shower head over the drain' and now I showed her how to adjust that so she's
141 got the hard stream and she can, because it's solid (aha) and she's like 'that's marvellous'
142 because she was trying to do it all in the hand basin (ah, ok) and I'm like 'do the solids go'
143 you know it was just something as simple as that and she was like 'that's the power in that
144 rather than me trying to do it in a hand basin' and of course she's that size her fingers are
145 like (oh dear) you know (aha). So, something as simple as that-

146 I: Made quite a big-

147 P: made a huge difference because she's so, it's breaking her heart putting soiled stuff in her
148 washing machine. She'd just got this thing, which is fair enough you know but I think just
149 getting the solids off and right down the drain (yeah). So it's, the shower or the body shower
150 for him has actually now become part of her laundry which is fabulous (great, great) but
151 she'd never, because she's never had a shower, you see in their house before they didn't
152 even have a shower, they had a bath and then because according to her you don't wash your
153 hair with warm water, she always washed her hair in the kitchen sink (oh, ok) because warm
154 water makes your hair greasy (ok -laughs) so she has never, ever, ever washed her hair in a
155 bath in her life, or in a bathroom, it always gets washed in a kitchen sink.

156 I: Does, does your mother in-law get any help with the personal care for-

157 P: No, refuses. It's there, we've had somebody up recently who I demanded, I, we got it set up
158 and it was to review everything that was available and then when the man phoned her
159 because he's, although I can put it in place, he has to phone her and she has to accept the
160 invitation to come up for him to visit, and she's like [*affects a very sweet voice*] 'no, no, it's
161 fine' and oh yeah, gets a bit tricky you know -laughs- and 'no it's fine, we cope'. So, the guy
162 phoned me back and he's like 'she said everything is fine, it must have just been- I was like
163 'no, no, no, no. Let me speak to her' so I phoned, and I said [*affects firm voice*] 'you've told
164 this guy your life's fine (it is). Last week you were demented. Please will you meet him?' So
165 ok, so she arranged, like she said come up and he came up and he spoke to her and he asked
166 where my father in-law is and we said 'do you want him to be in the room?' and he said 'aha,
167 yes' and we brought him in, who's fine and 'hi, how are you doing' and then of course he's
168 away with the birdies, he's no idea who this man is, sitting with him and the man then asked
169 or said, then asked or said, said afterwards 'I didn't realise how bad he was because she's
170 refusing everything. At first, that's why I said bring him through so I could speak to him' and
171 he was just looking at the guy -laughs- and the guy first thought he was being just rude and
172 then I was like 'I'm gonna have to speak to him [to father in-law] and I was like 'this is to help
173 her [mother in-law] and he was like 'why, what's wrong with you?' -laughs- he's looking at
174 her saying 'what's wrong with you?' and I said 'there's nothing wrong, she needs help
175 because she can't cope looking after you' and then it was clicking with him [visitor]- my god,
176 this is, he is so gone and he's like, he's saying 'you really do need some help you know, we've
177 got so much we can help you with' and she was like 'there's so many people'- she is

178 somebody who thinks everyone else needs it more than her (mm) so this is, it's making her
179 use what's there and she won't.

180 I: So, she did not agree to any of the help-

181 P: Well, eventually, there's a day care place and she kept saying 'I don't want to go there'
182 because it's breaking his routine. He was in hospital early on last year for about ten days and
183 she went through about a month of hell afterwards, wouldn't sleep, up during the night
184 walking around. She sleeps with the house keys under her pillows.

185 I: Ok, does that happen, does he-

186 P: He will try because when he gets really agitated, he'll go and try the doors. I've told her
187 about the door alarms we can get, I've told her about different things. She knows all this but
188 no because if he opens, if he does something and a buzzer goes off it'll frighten him. So, he
189 will be running around your street at two o'clock in the morning you know, 'oh, I'll hear him'
190 I've told her about pressure mats, you know, the alarms 'no, it'll frighten him' and I'm like
191 'but you'll be able to sleep, and you'll not be frightened in half an hour because he'll have
192 forgotten'. It's all about not aggravating him. He sits, he gets up in the morning and he's
193 dressed all the time because he used to be a ship's captain, he was deep sea freight all his
194 life, so he's dressed all the time with his shoes on, because he keeps saying to her 'have you
195 finished what you're doing because we need to go, you're taking me to join this ship'. So,
196 he's always got a shirt and tie on and dressed, ready to go out and that's when he's very
197 agitated; she has to let him have the shoes on. Sometimes she can talk him into having on
198 house shoes, which takes away the kind of, brings him down a bit about not wanting to go
199 out. He knows he's dressed because he's going, but he's not permanently like into her sitting
200 room saying, 'when are we going?' because if he's got his house shoes on it, it's a bit of an
201 understanding about I'm going but not right now. So, there's all those wee things that just-

202 I: And she's managing all of that (aha) basically herself (aha) mm.

203 P: Yep, absolutely and this is about, just, I don't think there's much more we can do for him
204 (aha), he's safe, it's the repercussions of her and how she is petrified of changing his routine,
205 his environment because this doesn't work, this can't cope. She doesn't want other people in
206 the house and mainly it's to do with people in the house because he gets aggravated by
207 people being in the house (aha). Like if the boiler breaks down, it's um, that really winds him
208 up, why are these boys in the house and tools and then of course up and down to their vans
209 fixing things. The boiler cupboard, we discovered a lot of things, one is the boiler cupboard
210 was him in, fiddling with the boiler, so the cupboard where the boiler is is now locked, that's
211 another key she has, so he can't go in and tamper with the boiler (ok) but he messed around
212 with it so much, there's always stuff getting fixed. It's only about six years old but we reckon
213 he just naffed it up so long 'til that, that's him taking things apart.

214 I: So, it sounds like your mother in-law has constant vigilance (yes) yeah.

215 P: She is exhausted, she is 88, she is exhausted, she is getting tinier by the day and it's to do
216 with, it's her exhaustion; he's happy, yeah, you know, she puts his clothes out for him in the
217 morning, she knows what he's put in at night, so therefore she knows what to look for in the
218 morning because he'll have taken something off. So, she knows maybe he went to bed with
219 socks on and underpants and a diaper thing and a top and bottom; so, she knows she's got
220 five items to find in the morning and that's what she has to find (aha). If she can't find the

221 pyjama bottoms, he must have soiled them, where are they, so she has to go on a hunt.
222 There's places now she knows he's got places and it's down the back of a certain place in the
223 wardrobe or down the back of the radiator. So, she knows certain places to go, like it's not a
224 huge house but she knows where to go look and that's why she has to because like vigilant
225 of what goes on, what have I got in the morning. She puts his clothes out for him and he
226 dresses. Again, she has to be vigilant about what's he got on, and what's missing and then he
227 stuffs stuff. He went through a phase once of food, he was getting thin and she was like
228 what's going on and then she realised he wasn't eating food, he was putting it in bags and in
229 his sitting room, in the sideboard and in the drawers in his desk, she found all these bags of
230 food you know so now she has to be more vigilant. She watches him eat, he has to keep, she
231 keeps the two sitting room doors open so she's watching him because he won't sit at the
232 table anymore. So, she does allow him to sit in there, but she has to watch him.

233 I: Aha, that really does sound exhausting.

234 P: Yes, that's my thing with her, is what you could give her. He's long gone, it's about her as a
235 carer; that is our focus, it's her that we have to look after. It's the damage on her, the wear
236 and tear of her and if she hurts herself, we think he would just be like [asking her] 'why are
237 you there?' We don't know, we know he wouldn't know how to lift a phone now and or
238 what to do (aha) and that's why we have to have this permanent contact.

239 I: So that brings me to my next question, so regarding your work and how you're able to
240 reconcile caring for both your in-laws and working (aha), so can you tell me a bit more about
241 your work, your job?

242 P: I work principally eight 'til half three. I only work ten minutes away from where they live,
243 other side of the town from where they live. So, I'm very close but I also have my own
244 business as well, so after my work I can barely look in our flats, I have to go look after them
245 (ok). So, I can be called away to do different things after work, so that's why I work it with
246 my daughter. She's still living in the town, my two boys live in [place], they're not so handy
247 (aha) so we'd, we can be there. I principally I could be there, I've got a niece on her side, my
248 mother in-law's daughter and the woman has nothing to do with her. Her husband will
249 sometimes help if, if I phoned and said, 'can you get there' and if she didn't need the car
250 then he would be allowed to take the car and go. She would come first, not her mother. My
251 niece also can help sometimes, on their side, on my mother in-law's own, her daughter's
252 side but again, they own a pretty big business, she's got three kids; they're limited. So
253 principally it's me and my daughter, but she now works in [place]. So, we can get to them.
254 My work are pretty good about it, I work for quite a big, because I work for the Bank I don't
255 work in a small office, there's a couple of hundred people in the department I work in, so for
256 me to be able to say 'I have to go' I'm very lucky that way and I'll say I'll make my hours up. I
257 don't think they've ever said no to me. Between me and my two daughters like we went to,
258 we got them to go to a day care centre the other day, we got them to go. He was none the
259 wiser where he was, she could only find fault with it and afterwards she said it was
260 wonderful, but you know, so afterwards [daughter 2] went with them because it was really
261 getting them to see the place, so she went with them. So depending I can work, sometimes I
262 can work up to eight o'clock at night, so I can work a late shift, I don't start until 12 so I can
263 do appointments sometimes in the morning, (ok) so I can do that, I can swap my shifts I
264 work, I will work in a big department, I work in a smaller team of about 15 folk and we're
265 quite special, not specialised but very, we can swap our shifts. So, if I've got stuff to do then I
266 will try and swap my shift and do it in the morning.

267 I: So, are you flexible on the day, or do you have to let them know?

268 P: Generally, my manager knows the situation, him, he knows that um, so as long as I can swap
 269 my shifts in amongst the girls I work with, or the people I work with because -laughs- there's
 270 one boy among 14 girls, then they're happy for me to do it you know. Different things like
 271 when I was away at the weekend here, just now (aha) earlier on, my neighbour phoned to
 272 say they've had to go into my flat and turn the water off because something had happened
 273 with the cistern in my toilet and it was raining in my downstairs neighbour's flat -(laughs) so
 274 I have now phoned and I'll swap, I've been able to phone my manager and say 'I'm gonna
 275 swap with [name omitted] because she's on a late shift tomorrow' (ok). So that's the kind of
 276 arrangement I can do for something. If it had been to do with my mother and father in-law, I
 277 could've phoned and said look, one of the other girls is on late, I phoned her, I'm gonna do
 278 her late, she's doing my early' and that's fine. So, I've had to stuff for them like 'this has
 279 happened, I've managed to get an emergency appointment, I'm gonna take them tomorrow
 280 morning (yeah) and I've done it; work is fine.

281 I: For you to find someone else-

282 P: Er, well yeah, see if I've phoned and said 'look I can't, this is happening and I don't have time,
 283 like I can't come in tomorrow' it has happened (yeah) doesn't happen so much, but it has
 284 happened and I'm like 'I've got to take them somewhere tomorrow or something's
 285 happened' or whatever, I've been called out. He gets up during the night and wanders
 286 sometimes and then will fall over and can't get up-

287 I: Aha, but that's still inside the house or?

288 P: That's in the house (yeah) now she won't tell us when this has happened, she'll call the
 289 people from the community alarm and it'll take them in the middle of the night, three or
 290 four hours sometimes. So, in the meantime she's got him a cover, he's sleeping on the floor
 291 and she's sitting beside him wide awake.

292 I: Did you say three to four hours until they even get there?

293 P: Yeah, the community alarm people can take about three hours sometimes to come and get
 294 him up (ok) but she has said she's been sitting there, and he's woken up sometimes and
 295 whatever he's done, he's actually got himself up. So things like that, a couple of times when
 296 this happened at first I did go out and that was during the night and then it was a whole
 297 palaver and so I was in late the next day, that's not an issue with my team, that that is like ok
 298 and I'm like 'I don't want the time, I'll work it back' but that's why I'm gonna come in like
 299 about, I normally start at eight and I was like 'I only got home at like three o'clock or
 300 something, four o'clock; I'll come in but I'll be a couple of hours late' and that's ok, that's
 301 kind of like-

302 I: So, when you would make up the hours, would that be working late that day?

303 P: What it is, is we do, because of the type of calls we do or the work I do, like when I left work
 304 on Friday I should finish at half three, but because I was dealing with a particular issue, I
 305 really didn't leave until half four, but then I trying to explain, to get someone else to finish, I
 306 was like 'look I'm doing this' so I'm owed what's called an hour's lieu time (ok, yeah) so
 307 we've always got these fifteen minutes, half an hour because of the people we deal with, so

308 we could put in lieu time because it's much more practical for us to finish and go with that
309 customer.

310 I: Mm, so you keep a note-

311 P: So that's kept, I just email my deputy at the end of the shifts and say I had an hour. She
312 knew, she was involved with it, and I was 'I'm happy to stay' so (yeah) so I will, so and things
313 like that I will just say 'take it out of my lieu time', that's what I would use my lieu time for.
314 I've got holidays but you know, you kind of, because of my flats, because of my
315 granddaughter, I kind of have to be a bit precious with my holiday time because I've got
316 other commitments. So, from my work, I'm very lucky. If I worked in a small office or a shop
317 or a much smaller environment, then it would be, it would have, I would've had to I don't
318 know, I really would have to stand our ground more that they would have to use social
319 services (mm, mm). We would really have had to force that point for her protection; it's all
320 about protecting her [mother in-law].

321 I: Aha, aha.

322 P: I'm lucky because of my job my daughter actually also works for the [place omitted], just
323 pure coincidence. So, we're very lucky. She couldn't walk out as much as I did because of her
324 job, she couldn't walk out as much, it would be me principally that would go in an
325 emergency, her department weren't as understanding because of the type of job she did.

326 I: So, when an emergency would occur, during your work time, how would you, how would
327 you know? Would your mother in-law call you?

328 P: She would, she would phone, if I knew, if we were aware there was something going on if
329 people hadn't whatever, I would say to my boss 'I'm gonna have my phone, there's
330 something going on' and that would be fine, because we're not supposed to have our- data
331 protection and all that, we're not supposed to have our phones out (aha) but I would have
332 my phone out and I would be continually checking it. She has my number direct, I'm very
333 lucky that the team I work in has a number direct to us and she would literally just say 'I
334 need to speak to [name omitted]' Don't think she ever has done she just uses my mobile so
335 really the most that she would phone and nobody would notice it would be an hour to two
336 hours, because between me checking my phone or [daughter's name omitted], we
337 continually check our phones; we do do that.

338 I: Does that happen often? Does she call you often at work?

339 P: She'll leave a message and she'll say 'hi, give me a phone when you can' and you're like
340 'hmm' (something's up) it's a phrase she'll use or something and you'll go 'hmm, that's it'
341 and you know right away, I've just got to phone you know and that's it and we phone and
342 then she'll be like 'well this happened or that happened or you know, nothing important'
343 and you're like 'really?' -laughs- (so what-) um, that can be things like um, what did he do, it
344 will be the boiler mainly you know, in the winter because he's been through a big spell with
345 that, with the boiler. I now have a picture of the boiler on my phone (aha) because it will
346 happen so I will have this picture of the boiler and we can talk her, if we can't get there, we
347 can talk her through how to (ok, aha) how to do it and we'll say 'look, if you turn the switch
348 off, do that, do this, you'll see it flick through the numbers' because she'd be like 'oh, it's all
349 flashing at me' and we're 'it's gonna do this, like go and have a cup of tea, come back and it
350 will be done'. So, stuff like that. What else has he done? The remotes, I think that was where

351 this company, that's where they come in about the TV. I think he broke the TV and then, why
352 did we get them? We go through phases of problems with whatever he's doing (ok) what,
353 cleaning stuff, we'll find out about cleaning things and things like that, if some, if he starts
354 doing something, what can clean certain things up and we'll do a bit of research in it and
355 we'll go get it, bring it up to them but you're talking about getting calls out, we get called out
356 it would be mainly the boiler. It's the heating, is a big one but we're on damage limitation
357 with that, as in the cupboard's now locked, he can't get at that (aha) because it's the
358 cupboard where she keeps hooovers and cleaning stuff and all that and he was always
359 polishing and things, so it's a cupboard he would go into, but he's not allowed in it anymore
360 (ok). Moving things, all the lights, he went through a thing where he was turning the
361 electricity off and we had to show her how to reset the lights; things that she'd never dealt
362 with, if your lights trip out, your circuit board, things like that. The locks, she won't have
363 door locks. He did stuff with the locks for a while we had to have, how did we do it? I'm
364 trying to think what we got called out for; mainly the boiler, the heating and the lights when
365 he was messing with the power board or stuff like that. Her, her neck, she's really bad
366 recently and she can't move so well, she won't take medication; she takes paracetamol and
367 ibuprofen that's it. My oldest son's a doctor, so we'll say 'well [name omitted] says, he says,
368 he suggests' and then she'll maybe listen (ok) so things about medicine sometimes she'll say
369 'I've been down to the doctor today, I've got medicines. They've only give me part of the
370 prescription, could you pick it up later' (aha). That's saving her having to go back in the car
371 and go back out because that's upsetting his routine, if she went back out in the afternoon.
372 So she'll maybe say something like that to bring something up; that's happened a couple of
373 times. It's mainly heating and lighting.

374 I: And so, when you said you all have now this picture on your phone of the boiler (aha) does
375 that mean you are able to handle these situations over the phone or does that mean you-

376 P: Yes, it means that if we can't get there, then I've got a picture of her boiler on my phone and
377 I can say 'right, go and stand in front of the cupboard, push this button, push that' because a
378 good few years ago, she actually had the book and we had it open in a folder and she could
379 look at it and she could do it herself (aha) but now she's getting more wary of touching it
380 and so she's not as confident and I think she's more scared of breaking it and making it really
381 bad so a good few years ago she would've just switched it on and off. Now she's more wary
382 as she's getting older and more concerned that she's gonna screw it up (yeah). So that at
383 least is (raises her confidence) the confidence thing is that we've got the picture (yeah). She
384 will not use a mobile phone, she cannot get her head round, because as far as she's
385 concerned they give you ear cancer (mm, ok) so if we could get her to use a mobile, she's
386 fallen a couple of times in the path (she's fallen?) up, they live on a hill (ok) with bungalows
387 all up the one side and on the other side of the road is garages, so there's no way right
388 across the road from her (ok). So she lives in a bungalow, so you go in a gate and you go up a
389 path to it, right (aha) and it's, we got her to get a handrail in, I think we more or less
390 demanded she was getting it put in, the Council came and put that it and she's fallen, it's her
391 that falls now (ok) and a man, she says she just lay there first of all until she heard somebody
392 coming. It's quite, not a busy road but it's not a side street and she shouted and she heard
393 someone coming and I think the guy was just like (laughs) and she was lying on the path and
394 she said 'could you help me?'

395 I: So, the community alarm that she has would not have-

396 P: She wasn't in the house at the time, the comm'-

397 I: So, it was out of range?

398 P: Yeah, she wouldn't have had it on (oh), that's something, that if the community lot, but
399 then, if she fell in the town or in a shop that's fine but you've got that dead space between
400 public areas and the house (aha). So, if she fell on the pathway, she didn't have it on because
401 she won't wear it outside the house. I don't know if it would've worked, I don't know what
402 the range is but there is that dead space from your garden area, how much, what is the
403 range, don't know, but she didn't and she was coming in with the shopping and she turned
404 round and lost her concentration and you come down the path and then there are two steps
405 to the gate (oh my gosh) and she said she knew exactly, she said 'I forgot about the steps
406 and I just stepped straight off the step, I was-' (oh) so this man came and took all her stuff
407 up; that's one. She did it again a few months ago and then eventually something must have
408 clicked with him time-wise and he must have come to the front door, or she, we don't know
409 if he came to the front door because of the time or if she, he heard her shouting his name
410 (aha) and then he's suddenly looked down (laughs) because from their front door there's
411 five steps, so it's close to the steps and then the path does that and turns and goes down the
412 way and she was lying on the path and he said, as soon as he opened the door he said 'what
413 are you doing down there?' she was like 'I fell' because she said I was literally lying on my
414 back on the path [both laugh]. She said she tried to get round and she had a hand on the
415 handrail but her knees, she didn't have the purchase (mm) so she said she was considering
416 bumming her way down the path and hoping if she got to the bottom steps, she might be
417 able to use her hips, that's the point she was at. So, she was in that dead space where the
418 community alarm, she didn't wear it because she's out the house, but she wasn't in a public
419 area (aha). So, there is that, that is something we've been conscious of because as I keep
420 saying, it's gonna be her-

421 I: And of course, she does not have a mobile phone to-

422 P: She will not, she cannot get her head round mobile phones, she's a clever, switched on lady,
423 mobile phones, no way. So even if she had something that triggered. It's more, it's like a
424 community alarm that would, you wear all the time. There probably is something, there
425 probably is because you've got all the stuff epileptics wear, if they fall over, the motion
426 things (aha) and that triggers an alarm doesn't it, they wear the brace thing don't they, with
427 the sensors on it. So that, that, because if she was putting her car, she has got a garage over
428 the road she can't put her car in anymore, she's lived in this house for 43 years and the car
429 got put away every day, right and then the last year she can't, it gets parked outside the
430 house. 43 years she put her car away and now she doesn't, so if this had happened to her, if
431 she'd tripped in the garage getting out of the car and fallen in the garage, he, I don't know
432 what would happen (aha) but that's where we have to phone so-

433 I: So, when you are at work do you do check-up calls?

434 P: During the day (during the day) we don't (mm), it's more like, like when I finish work, like
435 late afternoon once of us will be- 'have you spoken to your gran today?' you know (yeah)
436 one of us will be. We don't check on her all day because during the day she does do stuff. It's
437 more like we just need to check that she is ok late on in the afternoon (yeah, ok) because
438 also it's now getting so tiresome for her standing up, she won't let me put cordless phones in
439 (aha). She has a phone in all the hall, so she has to get up. I got her things called um, I don't
440 know if you've seen this, it's plugs, you put your lamps into a plug and the plug goes in the
441 wall and it's a remote so you've got these in the lamps now, so she sits with that remote and
442 plugs it and turns all her lights on, turns her TV on (aha) but that lives in her face cream jar,

443 that's this size because if he [father-in-law] saw this remote he'd want to, he'd want to take
444 it apart. So, she has, where she sits, she has a table on her left-hand side, got a lamp on it,
445 but she used to have to get down on her hands and knees to turn on and off at the switch
446 until I gave her the, put the remotes in for her. I literally had to say 'you're gonna sit and
447 watch me, I'm putting these in'. 'I don't need that'. 'I'm putting these in'. Then put it all
448 through, 'there's your remote' and she was like 'ok, I'll have that' (laughs) but that's literally
449 what we had to do because other than that she was under a coffee table that sits at the side
450 of her chair and having to put lights on. So here is a grey face cream jar about that high and
451 it sits there so that is something recognisable to him as hers, but it's all cleaned out and the
452 remote for the lights is really thin and it lives in there because he would take it apart if it
453 would be a remote and he would be trying to take it, he'd be fascinated by it because it's a
454 different remote-

455 I: Aha, that's really clever.

456 P: it, it's her way of surviving. She has to keep any changes secret from him so that it doesn't
457 disrupt him or give him different things. She's always having to buy new desk lamps because
458 he, he takes apart the desk lamp. I don't know how he hasn't set the house on fire, I don't
459 know how he hasn't blown the place up, well I think now we've showed her how to reset the
460 meter, he probably does but we don't know (aha) and I think that's why, as I keep going back
461 to this company I think she's very dependent on them and we're only finding out now just
462 how much and these, as I say this guy's hit a niche market. How many people are there that
463 don't have me, my daughter or my family who have no one (mm, absolutely) they can phone
464 and say 'can you come and do my light bulb, can you come and reset my TV' (absolutely)
465 because they can't, Care in the Community do all this stuff, but they've got a waiting list
466 (mm) and I think that that, this guy's hit a market and he never had, [father-in-law] he does
467 break his TV, they will, they know exactly what kind of TV she's got, what he's used to and
468 they will bring her a new one and put it in (that's good). They must just have a file, I don't
469 know how he just knows all his customers that well, that he's I know he's done a couple of
470 times, had to replace the TV or she's said, 'he's got me a new TV; done'. They bring it, they
471 unpack it, they set it up.

472 I: So, talking about work again, how many hours do you on average work for the bank and
473 how-

474 P: I work 35 hours (35), 35, so we both work 35 hours.

475 I: And the business you were talking about, how many hours on that, average per week?

476 P: Oh my god, depends, I've got five flats, if they're fine I can go for weeks and there's nothing,
477 and then I can go for weeks where I'm working four or five hours every night (ok) if I'm
478 looking for new tenants or something's damaged or if there's hassle or if I'm working in
479 them, I maintain them myself, I don't use a letting agent, I do all the work myself so, I would
480 say I probably am working a long with the maintenance, the accounts, I could be spending
481 another couple of hours every day (mm, mm) mainly that gets done at night, late on at night
482 but I can, it's flexible, I fit it around what I have to deal with her.

483 I: Mm, has caring ever interfered with that business?

484 P: Yeah (yeah) yeah, because I have to a lot, get to do get to do with my kids or get to do
485 something and I go to pick stuff up, I have to go deal with them first of all, well, because

486 come she gets him to go to bed about half nine, ten o'clock and there's routine (aha) and if
487 he goes to bed and she can get that done he's fine, he'll go. She pretty much knows if he's
488 agitated, she's gonna have a bad night, she'll know from the daytime something's gone on
489 and she knows, she's kind of prepared. So sometimes yeah, I'll have to go and do stuff after
490 work and I'll not be able to do the flats, I'll have to do that, or I'll say, if it's something I've
491 got to do, then I'll get my older daughter to go do it, or my younger daughter [name
492 omitted] she's good, she's good but she's not ever been as flexible. Yeah, absolutely yeah,
493 we have to, they're the priority you know they can't wait, and the flats can wait, I can tell a
494 tenant 'look, I've got to go and do something' or you know, no it has happened.

495 I: So, your tenants know about the situation?

496 P: I kind of, my tenants are, kind of been people I've known for a wee while, not known for a
497 while but I, because I do all the stuff, I interact with them, I interview them, I put them in
498 you know I, I, they can call me any time, so I've never been, I've always been I can say 'I've
499 got to go do this first' or something, but yeah the stuff, mainly it's probably more to do with
500 maintenance, like maybe if the flats were empty of something but yeah absolutely they're
501 the, yeah, yeah, I've had to- absolutely yeah they're the priority because they, if she, if she
502 asks us for something, it's important (yep) because she's tried to do something herself (mm).
503 She recently got ripped off financially (oh no) and we're dealing with that just now. Her, in
504 her sitting room she has three wee two seater sofas and they have loose covers on them, a
505 company called [name] and they're famous, and it's stretchy, you put them on they're dead
506 easy to go on right and she has beautiful blue curtains, which she loves, she loves these blue
507 curtains and went up to see her and I was like 'have you got new covers?' and she was like
508 yeah, just phoned my lady at [company] and the lady comes out and there's special designs
509 and she's like 'this is what you need, you pick the pattern, that's it' and they cost, these
510 three sets of stretch covers cost 1800 pounds right (wow) ok, one thousand, eight hundred
511 pounds (woah). Part of the charge, now these people provide a service and I understand,
512 you know and they're good quality and they go in the machine yeah, yeah, but part of this
513 service is that they pay, you pay them to put them on for you and I'm like 'really? because
514 you've put them on yourself, you take them off and wash them, they go in the machine, they
515 hang up for half a day, they're practically dry and you put them back on yourself. But you
516 paid this lady 45, no, 90? 45 or 90? Was it 45 or 90? to put these on the sofa because they
517 were new ones, three sofas and a matching single chair and she actually paid the woman to
518 put these on. I saw the bill, the only reason I saw is because what happens is she ordered
519 them, the lady comes to the house, brings all the books, that's it, she brings them up and she
520 put them on and I'm like 'you paid for her to put them on? You put them on all the time
521 yourself'. She was like 'I know, she did it, she was really nice'. I don't give a shit, and while
522 she was there, she brought up, now she bought these loose covers with a blue bit through
523 them to match her beautiful blue curtains. While she was there putting these on, the lady
524 said, 'you could do with lightening up the room a bit, how about, are your curtains ok?' and
525 she talked her into getting curtains (oh no) yeah she bought these covers to go, because I
526 remember I saw them, I said 'you've bought new covers and I like it, they're blue, the same
527 as your beautiful curtains right?' and she was like 'yep'. She didn't tell me at that point she'd
528 ordered curtains so the next time I'm up, I drove past the house and I was like I can see
529 really white linings you know -laughs- and then I was in her house later on and I was like
530 'you've got new curtains'. The woman talked her into buying white curtains (no) right? They
531 cost, because then I saw the receipts because I went mental. They cost 663 pounds. The
532 woman again they come they bring the, the books, all that and they hang them for you (ok),
533 she paid her 90 quid to hang these curtains and she has a bay window and then low, it's a

534 flat and then the window. The curtains weren't on the edge hooks, so they were just
535 hanging, they were two and a half widths- how much do you know about curtains?

536 I: (laughs) Not a lot.

537 P: When you get curtains you need that much space right, so you have to get so many widths
538 of material to make that width, so she had two and a half widths of material. So you've got
539 that bit sown, another bit the same size is sown and then half, ok? So, you don't see the
540 seams when the curtains are open, but when they're closed you can see the seams and
541 when you hang curtains if you've got two and a half widths, the half width goes at the far
542 sides (aha) so that when your curtains are drawn, you've got a big wide part, the big wide
543 part and then this other seam right, so I'm looking at the curtain, I'm like 'hang on a minute',
544 the two half widths were here so when your curtain's closed, you're still seeing the seams.
545 That's not how you hang curtains, now this woman has done this for thousands of years and
546 I'm like 'that is totally, I'm furious' and she was like 'oh, she's so busy and she's so kind to put
547 them up' You paid, right, I said 'ok, we have- I didn't know the price of the curtains at this
548 point 'but I know you've paid money for these I said I know that they're not hung properly,
549 so as you keep closing these, they're gonna creep, right, you haven't got linings in them,
550 proper dark linings because her, she absolutely needs curtains because of the way the sun
551 hits their house. She uses her curtains all the time to block the sun during the day, wherever
552 it's coming from. I said so 'they're not up properly, that's hung on the wrong way and there's
553 no proper linings' she said 'oh I don't, she didn't ask me about linings' I was like [gestures
554 frustration] (oh!) why? 'Oh, she said it will make the room lighter' I said 'but you bought your
555 new covers to go with this' and she said 'I know, I loved my blue curtains' I said where are
556 they, please god don't tell me she's got them? If they're round here, I'm gonna take them to
557 the cleaners I said 'I will take them to the cleaners' so I left the woman a voicemail and I said
558 'I know you do this, everything when you come up, but, they aren't hung, the seams are in
559 the wrong place, the linings are useless, they do not cut out the light; you do know that she
560 is partially sighted, she has issues with light and you have not provided your normal service'
561 and she phoned me back she says 'oh, I'm coming up to see her next week' I says 'you're
562 damn right you are'. So at the moment they, so that, that, why did I get on to the curtains?
563 (laughs) Why did I get onto this? About people taking her, why did I get onto it? I was
564 demonstrating a point of how, I can't remember why I got onto that, what was your
565 question?

566 I: Well, we were talking about how caring interferes with your work.

567 P: That because that has taken me on another mission just now as in, this lady, I said to her 'I'll
568 give you the opportunity to come' but I'd already spoke to my manager and said 'I, if this
569 isn't right then I'm gonna have to go and meet these people, I might have to start
570 rearranging some issues next week because I'm not letting this woman do this' (mm, mm) so
571 I was telling them about it and I said 'I can see me having to go and meet this lady. I'm not,
572 I'm giving her one chance to come and fix'. So that was one of the things that interferes in
573 my work in as much as someone has got her during the day and influenced her (mm) and I
574 wasn't there to protect her and me or [daughter] and there's where she will do things where
575 she tries not to involve us, to be independent, but she's been totally taken advantage of. 660
576 pound curtains (right) you know, that is where we will make the effort to change my shifts or
577 [daughter] will to be there to protect and that's why she did it without us knowing and this
578 woman got her and the second time she, she, 1800 pounds. I was like 'you could have
579 bought three new sofas'.

580 I: Incredible. I really hope that you are able to resolve this.

581 P: They're a very good company, so I'll give the lady her chance, but I will then go above her
582 and say 'you're taking these curtains back' (yeah, yeah) ok.

583 I: Yeah, I was also going to ask you about being able to work from home, is that something
584 that you can do?

585 P: No, erm, I, we could, it's not something that's offered with the type of job I do. My eldest
586 daughter does, she can work from home, so she could take her laptop and if necessary be
587 down in the house (aha). She could, generally she could work from home, she could do it
588 more than I could. I don't have that, mine is more just being flexible with time.

589 I: Is it something, so are you not able to work from home because of the kind of job that you
590 do or-

591 P: Yes, I could work from home, I've got a home office I've set up because of the business
592 (yeah) I could physically if my job allowed me, I could physically work from home no hassle
593 but my actual job, my role just now isn't a work from home role (yeah); it's not something
594 we do so whereas there's lots of people that do work for the Bank, huge amount and
595 probably a small, very much a small percentage of people who can't.

596 I: Aha, can you explain a bit more what it is about your job that doesn't allow you to do that?

597 P: Erm, mainly it's just never been done because we, I worked in a contact team where people
598 are phoning in all the time; we're the front line (ok) and then I work in a specialist, not a
599 specialist, that's a bit dramatic, I work in a team where people are referred to us and we sort
600 out what they need to stop it going to complaint (ok). I work in that kind of team where,
601 yeah, 'look mam, I'm really sorry to hear about that, I've got access to other stuff people
602 don't normally have, let me see if I can move someone's diary, let me see if I can do this.
603 Here's my direct number'.

604 I: So, you are a trouble shooter kind of-

605 P: Yeah, we're a kind of like, someone will say 'look, I've got this team, customer support team
606 we can maybe like speak to who could possibly...' say you've got an appointment with a
607 mortgage advisor and whoever's booked it put in the wrong phone number (aha), so you're
608 supposed to get a call at half one, you don't get it, so you phone in at 2 o'clock going 'no
609 one's phoned me' they'll come speak to us and we've got people who possibly aren't fully
610 signed off, they're under training, so they can still do some appointments but they're not,
611 they've got open diaries. So, we're like 'oh yeah, we've got someone' we don't say that
612 actually they're training (laughs) (mm, mm). 'We can get someone to speak to you in half an
613 hour, are you still available' so that kind of, we, because of the job we do, I think we could,
614 our job could be done remotely but I don't, we still interact a lot with each other, there's a
615 lot of human contact in our, in our department. So I don't think, it could be done if you're,
616 not experienced, it's not rocket science to do this job, um, it's just not the kind of job you
617 would do, it's a glorified call centre job. Call centre people don't work remotely, they work in
618 a (yeah, yeah) in a big floor with thousands of desks.

619 I: Do you sometimes wish that you could work from home?

620 P: It would be convenient (yep) but not so much my carer's role because more I need the
621 flexibility of just being able to leave, so if I lived with them I think yeah, it would be good but
622 from the kind of caring I do, where it's to go help (yeah), it's a reactive one (yeah) a reactive
623 one then. I need the contact and I need the flexibility because I work in a big department,
624 although in that small specialised team, then there's enough people if I go it doesn't have an
625 impact (yeah) right, me disappearing and nearly 200 people in the bit that I'm in, it doesn't
626 kill the business (aha) that's where working for the Bank has been my saving grace, is that
627 yeah, that, working from home wouldn't, it wouldn't help.

628 I: Yep, yeah, I understand.

629 P: It's the flexibility of going.

630 I: Yeah, that makes sense. So, in terms of support that you receive for your care role, so you
631 already talked about that you basically have quite a large network of people who are
632 helping, your children for example, or your niece, that can help out with caring. Do you get
633 any support from the Council, for example, for caring?

634 P: We could get more, I think there is more, but she won't allow us (aha) to use it. We, there is
635 a day care that we're still pushing for, we took, my other daughter took him up there the
636 other week, mainly for her [mother in-law] to see it. Unfortunately the day they went up all
637 the men were on a day trip out the place, so all that was left was about 12 ladies who
638 weren't fit for going out, playing bingo (oh, ok) so she was like 'really, it's all women', I was
639 like 'ah, ok', they told us to come at half one on a Thursday because that's a great day to go,
640 the lady had forgotten the men were all out on a day trip (oh dear). So he [father in-law] was
641 bewildered, he was none the wiser where he was and she was quite derisory about it. I was
642 like 'yeah, I'm gonna take you back up on a day when all the men are there' and she's now
643 accepting that maybe she would let him go because it would give her a few hours (yeah) just
644 to not have him walk in and out the door because he will, some days if he's agitated then
645 he'll just go back and forward, go back and forward, walk around. So yes there's that service,
646 they would come in, the guy came a month or so ago, you know we can have carers come in
647 and dress him and she's like 'he can dress himself, I just put the stuff out' and they can do
648 the personal care and wash him down and she said 'but if this has happened, if I hear when
649 he's had an accident at five o'clock in the morning, I'm not leaving that 'til a carer comes
650 through at half seven/half eight. I have to deal with it there and then' (yeah). So, yes, I think
651 there's some more social work services and dementia, is it [dementia organisation] that's
652 the- (dementia organisation?) [dementia organisation], I had him on a list for that for ages
653 and I can't, I said a while ago 'I haven't heard from them for a while' and she said, 'oh they
654 phoned me, I told them I didn't need it' (laughs) he's been on the list for two years (laughs)
655 and she says 'Oh-' I was like 'oh Christ' (oh dear). So yes, there are things, there are carers
656 that could come in but she says no; there's day care, she says no; there is respite, she says
657 no, because the repercussions when he comes back, it's ruined his routine (mm, mm, I
658 understand) and the carers coming in are strangers coming into, because it's not the same
659 person, she doesn't want strangers in her house. She will not order a taxi from here, if she's
660 going out somewhere, not now, a few years ago when they were more mobile, she would
661 not phone a taxi to go out if they were going to her family, she would actually ask us to take
662 her. She would get a taxi home, she didn't want a taxi knowing that her house was gonna be
663 empty. That's what she, and she doesn't want people seeing her and him coming down the
664 path and thinking they're older people getting into a taxi (mm, mm, I understand). So it's ok
665 for us to take her and for a taxi to take her home; so it's stuff like that. So it's all about

666 safety, perception of people watching them and that's why she doesn't want people in the
667 house because she doesn't know who they are.

668 I: Yeah, that makes sense.

669 P: That's part of it, that she has no control over who's coming in and who'd be looking at her.

670 I: Have you yourself had a carer's assessment from the Council?

671 P: No (laughs) I'm registered at the alarm, the community alarm thing (ok). I tell you what I did
672 get, I got a call a good few months ago and I noticed the call on my number and it came up, I
673 don't know how good your phone is but mine, my Samsung says 'suspected spam' (oh, ok)
674 right and it says 'suspected spam' so I was like oh, and it came up as a [place] number (ok) an
675 0141 number right and I thought oh right, ok and then something had happened, why had
676 the alarm gone off? It transpired it was actually the community alarm people trying to get
677 me but because it flagged up as an 0141 number and it flagged up my phone as, because, it
678 must be because it's a, it comes from an auto dialler number (aha, aha) my phone come up
679 as and then I think by then she'd got [my daughter] and then I think I got the voicemail later,
680 because I'm thinking it, voicemail, because you see it come up like half two you know,
681 suspected and you think oh right and I listened to the message and it was I think it was 'this
682 is so and so from comm' just trying to get you' (ok) and I was like oh my god!

683 I: That's interesting

684 P: Yeah, so I didn't and the fact it flagged up as spam (laughs) or suspected spam, but again
685 probably because it came from a remote auto dialler, but whoever on that switchboard was
686 trying to get me (yeah) was using a programme and a computer that says oh yes, there you
687 go, there's the contact so it's they're doing it and it's an auto dialler.

688 I: If the situation had-

689 P: [oldest daughter] had dealt with it, whatever it was, she had, they'd got her (ok). I think
690 [mother in-law] had gotten because whatever had happened with the community alarm,
691 they will try and get me but in the meantime she had got her but that was I was like 'woah',
692 that was dangerous (yeah) yeah but for me, so they, so the community alarm know, that's
693 what I'm saying about this carer's assessment, they know I'm down as the main carer, the
694 main contact, the emergency contact. She, I don't know if I ever had a carer's assessment. I
695 know that I did something with my doctors which seemingly very recently they said
696 something about 'oh, you're down as a carer'. It must mean if I ask one of the nurses for an
697 appointment, I get it, so that I don't get sick (aha). There must be something there because
698 she said something recently about that (laughs) I was like oh, ok.

699 I: But there was never anyone sitting down with you and asking you about your needs as a
700 carer?

701 P: Possibly when I got Social Services in ages ago, when we got her to do the bathroom and all
702 that when I, because part of the thing is I'm trying to force is that if anything happens, then
703 my father in-law needs to go into Care. I don't think we could safely care for him in his
704 house, he would be too agitated. He would freak if I was staying in her bed or my kids or,
705 even my son. We kind of had him on standby but he's a doctor, he works mental shifts in
706 [place]. The other son, my father in-law doesn't like my other son. So, he could never be part

707 of helping his papa, he's ok, he's not as bad now, so my big thing was we need him assessed
708 so that if anything happens to you, where would he go, because of how bad he is, because
709 they can only go certain places (yep). So I think that's when I got her talked into- 'we need to
710 do this stuff, to mean that we've got this fall back because if I was living in your house with
711 my daughter, he would be absolutely demented'. So it's not right that we should be in the
712 house, if we take him out altogether, somewhere that was 24 hours with the floor alarms
713 and we could keep him safe from himself and not confuse him in his own house and maybe
714 got, no because that's when I got her into it; I was put down as a carer then more of as I
715 think a next, I felt as though taking my own numbers as a back-up (aha, yeah). I don't think, I
716 know a wee bit more about caring because a friend of mine has two boys who have got
717 special needs, although they're grown-up men now, they've got the mentality of six-year-
718 olds. So, possibly I knew what I was talking about a wee bit more, the carer world and maybe
719 they were doing this, I don't know, I don't think I've ever had a personal assessment. I'm
720 down as all the emergency contacts and I'm the, the, you know, if she got taken into hospital
721 it would be me they would be and they would know that my father-in-law is there, there is
722 that but I don't know, I dunno.

723 I: So you mentioned your friend who is also a carer (aha) is that something that you, an
724 experience that you talk about, that you share?

725 P: Yeah, yeah, her boys, one's got cerebral palsy and the other one was damaged at birth, two
726 boys. Two years apart in age, both totally different needs and she lives on her own, her ex-
727 husband's dead. She has no family (oh) yeah (that sounds very tough). That's spectacular
728 (laughs) that is spectacular, that one here. So, yeah, I'm, I'm their unofficial guardian, we've
729 gone through guardianship just now because she's got no one else. Yeah, that's another one,
730 but, so maybe I don't think they, do they do an official carer's assessment?

731 I: Um, that's something that you would actually be entitled to as a carer, so yeah (laughs).

732 P: I, maybe because I know about the caring world because of my friend, then maybe stuff
733 didn't have to be explained to me (mm) and we take my mother-in-law, my daughter and I
734 we'd take her to things because we, my daughter used to work for, [charity], what's the
735 charity up in [place omitted], it is a big charity, anyway, she works, before she went away
736 she went away to [place omitted] for a year, she works for this big charity in one of their
737 houses, a residential unit. So she knows quite a lot about, that's why she could talk to her
738 gran about safety mats and door alarms and (oh, ok) the stuff that she knew through the
739 ones that had epilepsy, the motion alarms and all this stuff (ok) so sometimes if it doesn't
740 work with me, I'll say '[daughter] will tell you' or '[son], the doctor will tell you' (laughs) and
741 then I'm just gonna insist. [Business name omitted]

742 I: That's the um-

743 P: They're a massive thing down just on the outskirts of [place] (oh, ok) and they have big
744 residential houses, people leave them big houses like those, that kind of house you know
745 and then they turn them into residential houses for like mainly five/six grown adults, my age
746 that will live there. So that's how we know quite a lot about what's available.

747 I: That's really interesting. I was gonna ask you about that, so the community alarm that your
748 parents-in-law have, is that also something that you came up with-

749 P: My mother had had it, my mum had Parkinson's (ok) so my mum had it, fondly referred to as
750 her diamond necklace (yeah) or her diamond bracelet; my mum had them.

751 I: So, your in-laws got it on your initiative, you said-

752 P: Yeah I, we, that was, I just demanded at one point, I said 'you're getting this' (laughs) she
753 didn't want the phone wires and I was like 'you're getting this' right (yeah) 'you need this'.

754 I: Is there anything from your point of view, how, you would like this service improved? I mean
755 we've already talked about her only being able to wear it in the house (yeah) um but how
756 else would you, would you like-

757 P: Something that was further afield so (yeah) because older people, we got her the phone
758 with the big buttons, we've tried, but as I say she just, mobile phones to her just don't
759 register, which is a real shame, they don't register. If there was something, a community
760 alarm something like that that was further afield, a personal panic button yeah, absolutely,
761 imagine if that had worked when she, she's told me twice, three times she's fallen in the
762 past you know if she's not on the street, she's listening for somebody. [father in-law] can,
763 did kind of see her but if she'd been able to do something-

764 I: So generally speaking, you were happy with the service, it just needs to have a wider range-

765 P: It's fabulous it's a fabulous service and it works (aha) but it works if somebody can work it
766 (yeah) and I know you can't cover everything, you can't, but for her, she was in that lost
767 space in her garden. She wasn't in the house so therefore she doesn't wear it, she puts it on
768 when she comes back into the house. So should there be something, there's that dead space
769 between public areas and inside your house.

770 I: Do you think it's a danger maybe that she forgets to put it on again when she-

771 P: My mum didn't wear it, [mother in-law] knows to wear it, she knows to wear it because, I
772 can't remember, something did happen, and she knows to wear it and she's quite particular
773 about it (ok). My mother didn't and that's what I used to say to her 'yeah, yeah' if my mum
774 was stuck in her bed but it was over in her trinket box on the other side of the bedside table,
775 how the hell does she get to it, that's how I sell it to her [mother in-law] is 'you have to wear
776 it, you have to, you have to'. The, I've also told her there's a bracelet one you know but she's
777 ok wearing the hanging one. When my mum died, we'd only recently got her the bracelet
778 one, they'd only come in, because she would forget to put the necklace or she would put it
779 over, but she could wear the bracelet one at night (yeah). So [mother in-law] does wear the
780 necklace one, we're lucky there but only when she comes back into the house (yeah, yeah)
781 so you've got that dead space but then there's this stuff that epileptic folk have, the motion
782 sensors so maybe there has to be a version that, but then if someone sits it doesn't move, I
783 don't know. There is that, there is that worrying space that is, her garden is a worry for me
784 (yeah), her path and her garden and her garage.

785 I: So, you're still thinking mainly about her without these-

786 P: Because I don't think, so she would be lying on the path if this had happened in the snow,
787 she'd be on the path, she would very quickly have hyperthermia, she's really skinny right, he
788 is looking at the front door, he can't see her, by then she can't shout, so he'll go back in and
789 he'll forget (mm) and then he will eat his breakfast five times a day if he wanted to because

790 he has this perpetual (laughs) he hasn't got the capacity for time. She gives him his medicine,
791 she tells him 'you're going to bed/this is your lunch' he'll come back through and say 'I
792 haven't had my breakfast' and this is at five o'clock when I'm visiting and she'll like 'you're
793 gonna get your tea in an hour' and 'huh' and he'll go back through saying 'I need a drink of
794 water' and you know he's had five drinks of water while I've been in. So he's got no concept
795 of time so we don't know, my worry is if we didn't check every day, he could be in that
796 house actually, we don't know what he would do, how quickly he would scavenge for food
797 or, it's not gonna happen with us, we've got the back-up, right, we've got that infrastructure
798 as they're never gonna be more than 12 hours without somebody speaking to them you
799 know in a worst case (yes, yes) but, it's the, the time that I could be travelling, my phone
800 dies, my daughter could be out the country; that one time when you miss somebody
801 speaking, is the time that she's fallen over and she's lying on the floor and he's just saying to
802 her 'why are you there?' He was back in his room and forgets that she's lying on the floor. So
803 you've got him demented, him messing with the electricity, him previously messing with the
804 boiler but now that's locked off, him then scavenging for food you know, that, that, it's she's
805 not there to control it, that's my, that's our risk (yes, yes). That's our risk is we have to keep
806 her safe because she runs the place and it's that, he, I don't think he would have the, I don't
807 know if something would kick in with him to phone and say 999. If you ask him where he
808 lives he'll say whatever they used to live in the house they lived in 41 years ago, he'll tell you
809 that. He doesn't remember his address they live in now, if you ask him where he lives that's,
810 he lives in the other house. So that, if somebody spoke to him I know phones now have got a
811 recognition, I don't know if the police or the emergency service have got that, they can tell
812 where you're phoning from but if somebody said 'where are you phoning from' he'd say,
813 he'd say what was it [old address omitted] not [current address omitted] so I don't know,
814 we've got them registered for things if there's power cuts, Scottish Power will phone you
815 and say you know 'we've got a power cut and it's gonna be..' all that. I got a letter in recently
816 to check about that, so came up to their house, saying 'we're just making sure you still need
817 this service' and all that and that's great, 'if anything happens we'll let you know'. If you get a
818 power cut, your phone doesn't work. How the hell are you gonna phone and say we've got a
819 power cut for six hours (yeah) (laughs) I was like what am I reading?! (laughs) (yeah) no, they
820 can't phone her, because her phone doesn't work, there's no electricity, god's truth. I
821 presume what they mean, I don't know, that was, that was weird and it must be again for
822 the community alarm; there isn't one if you get a power cut.

823 I: It's a very good point, it's definitely something to think about.

824 P: They're fabulous because they work on electricity, but your phone line's gone because you
825 don't have electricity, you might have a battery back-up and the battery in the alarm. So
826 that, the other week was quite amusing I was like 'oh, they're great these ideas but no'.

827 I: Yeah, yeah, ok. So, I was wondering if your daughter didn't have this connection with that
828 organisation where she learned about all this technology, where would you expect this
829 information to come from, where would you go looking for it or-

830 P: There's a place in the town called the Carer Centre, again I know that because of my friend
831 because she relies very heavily on them (yeah) and I know that the service is there about,
832 they've got the therapies and the massage for the carers (yeah). She [mother in-law] won't
833 take it because other people need it (mm, mm)- 'I'm fine, I don't need it' I'm like 'ok'. So I
834 know about that. [dementia organisation] again I know about that, I just do. My problem is
835 she won't accept help because she's got the money to pay for it, she's capable, but where
836 would you know about it, the Carers' Centre, I got her to go there once and I know that she

837 did use them a couple of times, she did phone them about some stuff but if she needs
838 things, she'll go to these bloody awful independent living shops where you pay 70 quid for a
839 stool you know that the Carers' Centre get you from the Council independent living depot
840 for nothing (aha). She will go pay 70 quid for these now because she had all sorts of stools
841 set up for getting him in and out the bath and I'm like 'we can get a lift'. I got a chair an
842 electric chair that lifts him up and swivels, we had to buy that privately, she wouldn't allow
843 me to get it through the Carers' Centre. So how did I know, I knew about a lot of these things
844 because of my friend and stuff through my daughter and she would say to her 'look, you've
845 heard me talking about [Name omitted], he was a guy who's the same age as me and he
846 lives there and she knew the family and she said 'we know when he's got out of bed because
847 the alarm and it doesn't go off, he doesn't know it's gone off'. I think she thinks it's, she says,
848 'he doesn't know it's gone off, but we do' you know and things like that and she wouldn't, so
849 the Carers' Centre, I don't know how you would publicise that, you see it in doctors and stuff
850 don't you but then she won't let the doctor be called out. She'll take him to the doctor, so
851 they won't come out because they're too busy.

852 I: So, this fairly big network of carers that you're having with your family all playing their parts,
853 how do you usually coordinate?

854 P: Me and [eldest daughter].

855 I: For example, you and your daughter or if you need any assistance from someone else, like
856 your niece for example or other-

857 P: This weekend we were away because my son's going to live in [place omitted] so all of my
858 side of the family, there's 27 of us away this weekend (ooh wow) so all my brothers and
859 sisters, all my children, we were all at this big house and I told my niece, I said to her 'we're
860 away, are you around' and she said yes, because they've got a caravan 'yes, we're around'
861 and I said 'so you're, she's yours this weekend' (ok) and I said so we're not here. She's got a
862 brother, he does bugger all, but we could phone her brother and his wife, if necessary,
863 they're periphery but if it was, if it was a, something had happened this week and my niece
864 couldn't get, she could have phoned them to get there. So they are on the back burner but
865 this, I had to make sure with her and say 'you need to know I'm away, we're all away' so
866 that's but she's very limited to what she can do, her kids are 6, 4 and 2 so she's very limited
867 to how much she, but she will, she has in the past literally, she is good, she will go 'yes' and
868 she will take the kids, put them in the car and she will at least get there and she's done that,
869 she'll get there if I can't until I turn up, or me or my daughter. So, yeah, we've got, we've got
870 that but this weekend was very unusual in that all my lot were away (yeah) but so we have
871 then.

872 I: So, so you and your daughter, are you usually just calling each other to keep each other
873 updated?

874 P: Texting, I will just, if I can't, if I can't get her (yeah) I generally speak to her when I leave work
875 every day, when I'm driving into work every day, I'll be phoning her and saying, 'how are you'
876 and if I'm going to the gym, you know if she needs anything I can go there on the way. So, I
877 will, I particularly use a gym which is where I work but is a gym and near my house and then
878 my mother in-law's house and then another gym. So, I go to the one in [place omitted]
879 because I am driving past her house, so I don't go to one here, I drive to her house and then
880 to the gym, or to the gym and then to her if I have to. That's my reason for using that gym is
881 I'm going in that direction so I can go before or after if I have to and then I speak to her as

882 I'm driving, so that if I think anything at all, I just think oh bugger it and I just go up there and
 883 she answers the door and I'm like 'I don't believe you let me in, you sound awful, what's he
 884 done'. So, I principally am the one that does that or I'll say 'I'm on a late shift, can you phone
 885 your gran'. My other daughter's on a placement nearby and I will phone her and say 'when
 886 you finish work can you go by your gran, I don't believe her' (mm). So principally I am-

887 I: You are the coordinator.

888 P: I am the person that does and if it's not gonna be me, I'll be like 'you guys', I'll text them and
 889 I'll say, 'one of you two needs to pick up with her, there's something going on'.

890 I: Aha and does that work well for you or would you wish for something-

891 P: Do you know what makes the difference? WhatsApp (yeah) WhatsApp because that's
 892 literally a group that is my four kids, everyone's got different groups and principally I've got
 893 one that is my four kids and me and their four partners and I will put into that, because that
 894 gets their attention because they're that age (yeah) that gets their attention; 'somebody
 895 needs to stop by your gran's' (ok) or 'I've had to go to [place] to one of the flats, can one of
 896 you pick up with her' and that's generally it and they will, one of them will tell me to bugger
 897 off and another one will say 'yes we can do it' you know, that's principally, that's our saving
 898 grace just now, you don't have to send different texts (yeah), one group, one, that makes a
 899 difference.

900 I: Yeah, yeah, yeah, um, so thinking about, I got a bit of a weird question, so if you had a magic
 901 wand, if you could wish for anything, what would you like technology to do for you?
 902 Particularly for making it easier to combine work and care but also-

903 P: Something that allowed me to speak to her (yeah) other than mobile phones, as I say she's
 904 got this thing (aha) so something that'll allow me to speak to her which at the moment my
 905 main thing is I'm actually just gonna probably just break into the house now and put cordless
 906 phones in (aha) because she's fought me on them and she won't let me do it because I need
 907 to move a phone point but I actually am about to do it, that's my next project, the curtain
 908 thing interfered with this because that can sit beside her (yeah) and I'm gonna force my
 909 point on this, is that 'your mobility's getting worse because your back's sore, your neck's
 910 sore; I'm doing this and that's it, I don't care', because it's being able to speak to her because
 911 she has to get up and walk from here, say from your front door, to in here to get to her
 912 phone and I, her um, her, she's got much harder to move and also if she's in the kitchen, it's
 913 even further to come through. So, for me it's being able to contact her without disrupting
 914 her or making her 'oh, I've got to get up' (right) that's mine, to know she's ok.

915 I: So, what's her resistance to these mobile landlines?

916 P: Well, you know girls keep their phones down their bras (yeah) right, well she'll maintain
 917 they're all gonna have breast cancer now and we're all gonna have ear cancer because
 918 phones give you cancer (ok, so it's-) and everything gives you cancer to her. So mobiles,
 919 we've tried, we've tried the big buttons, it's just not in her remit, it's and she's really clever,
 920 it's just something I can't get her to connect with and she doesn't need it. She's, she just, I
 921 think we just missed the boat getting her to be, because lots of folk have got mobile phones
 922 and your age doesn't stop you, just we missed the boat with her, getting her to use this. That
 923 would be wonderful; if she had a mobile phone in her handbag when you're lying there on
 924 the path you know, (laughs) 'if you had a mobile phone in your handbag you'd be able to

925 press a button, dial 999, do something', you know, phone him in the flat and he'll go 'nope,
926 she's not in' and you can shout out 'no, I'm lying on the path'. So it's that blank space where
927 you can't connect with her or to connect with her, to force a connection with her. Is there a
928 speaker I could put in the house shouting her name (laughs) Big Brother voice.

929 I: Do you think that would be something that she'd accept?

930 P: I don't think so because if I had to use something like that, it would mean she's actually
931 incapable of getting (mm). She has a phone in the hallway-

932 I: So she wouldn't see it as a help, she would see it as-

933 P: I think for in that situation, because I know some, there's a thing you can get where you put
934 on your, a lot of people have it on their TVs, it's a motion sensor (yeah) and that's part of the
935 community alarm isn't it? the community alarm will phone people and say 'I haven't seen
936 you move' or 'there's been no-' (yeah, yeah) there's that, they both move (yeah) so that's
937 not realistic. It's something about contacting her but not disturbing her (aha), that's where I
938 think I'm gonna force putting the cordless phones in (mm). I think that, at least I know when
939 I phone her she's sitting there (yeah) because it's all about putting phones in and wires and
940 stuff and she just gets paranoid about that and again that's having workmen in the house,
941 we can get under her, there's a trapdoor and we can actually get under her house and do it
942 very easily, so I think I'm just gonna force the point now. [Name omitted] will probably do it,
943 my son's an electrician and I'm just gonna say 'we're coming up', maybe I'll get the girls to
944 take my father in-law out while we're doing it, but the problem is she's very limited with
945 where she'll let him go now in case he soils himself (mm, yeah). He doesn't do it during the
946 day really, it's a night time issue. He gets to the bathroom but when he does get to the
947 bathroom he's making a real mess, he's not, he doesn't realise he hasn't cleaned up properly
948 so when she does have to take him out, she likes to do it and it's only for an hour or so, so
949 from that. It's a contact thing, it's the worry about her (yeah, yeah) and what he would do.
950 How many people do have their carers fall over and how long does it take someone to find
951 them? What happens to the people?

952 I: Yeah, absolutely, absolutely. So, if you met someone else who was in a similar situation, so
953 combining work and care for someone with dementia, or their loved ones, what kind of
954 advice would you give to these people?

955 P: Your employers need to know (yeah); they need to know the situation you're in, they need
956 to know that if you got up to walk out the door, it's for a good reason (yeah). There's gonna
957 be people that take the- I don't, you know I, I always come back and say I want to make the
958 time up, more often than not they'll say no but if it happens on a regular basis, so it's
959 different if you work in a small place (mm) you know if you work somewhere in a shop or,
960 there's only so many people, a small independent business (yeah), that's a world away from
961 what I've got, work for a big company is what I'd say (laughs) work for a big company that's
962 local but (sighs) but yeah. You have to learn, you have to learn what's out there and I think
963 maybe my background with my friend, I've got an advantage (mm), plus my parents, I had to
964 use it for my parents and I don't know, but you have to let your employers know what's
965 going on, you have to be honest and say 'this is the situation and I am the carer, I'm
966 responsible for these people'.

967 I: That is really good advice, yeah.

968 P: And find out what is there, community alarm's the best thing ever. You use them so
969 infrequently but you use them when you need them; they're good and the maintenance part
970 of the house, that is, that's a big thing, the community, Care and Repair Team that's there
971 from the Council, they need to have, you need to be able to use them because you can't go
972 up ladders and put light bulbs in when you're 90, we can, but she doesn't want us to do it,
973 she doesn't want us to do more than she's doing. So to know what's there but you can't wait
974 for three/four weeks to get a light bulb in your home (that's true) so there has to be
975 something and that's where this other company I think has found this market (mm). He's a
976 good guy, there must be lots of people out there who are bad guys taking advantage of folk,
977 so you have to know what's available and there's also a thing with the Council, it's a trusted
978 traders thing. She did something with the front door lock and she called the trusted traders
979 team and they recommended a joiner and he came out. I found out about it afterwards
980 because I saw the stuff on the carpet, I thought oh what's going on here (laughs) I saw the
981 wood (aha), she hadn't hoovered quiet right and I was looking and she was 'how did you
982 notice?!' and she said 'oh, the lock had to get fixed' and he came out and fixed the lock for
983 her. Now that was through the Council list, trusted traders because she's like 'I don't know'.
984 My niece that I talked about, her husband's a joiner but she doesn't want him to come and
985 do it for nothing and not get paid take time out. So she was able to phone that team and
986 they sent somebody. So (yeah), that you need to know that these people are around.

987 I: Yeah, yeah, absolutely. So to sum up a bit what we have been talking about, what would you
988 say are the most negative and the most positive things about doing your work and caring,
989 for you?

990 P: The positive is that she's still living in her home, that's all she wants is to live in her own
991 home and look after him. She doesn't want him going into a home. She went round all the
992 nursing homes, we told her about some and unknown to us she actually went and visited
993 them and she said 'oh they're lovely but I don't want him to go there' she doesn't want
994 anyone else, that's it and she hates him, as soon as he was with dementia, she hated him!
995 (laughs) (mm) what! They have two sitting rooms with, I mean, they fought, but it's her
996 husband. So, the positives are that she has him in the house, she's doing her honourable bit
997 and she's old school, you know- this is my husband, I'll do it (mm). Another thing we also
998 think now is that it's company. If he wasn't there, she would be very isolated because she's
999 very limited to what she can do now, most of her friends are dead. So from that the benefits
1000 are you can give her what she, she looked after my kids you know, she looked, it's what we
1001 can do for her, so it's not a burden; so it's the respect from that. The downsides of it are
1002 where to draw a line between being respectful of what she wants and saying 'you're being
1003 absolutely ridiculous' you know, 'you're missing out on something here which is detrimental
1004 to him because of your views' and that's kind of being disrespectful, but as I say like even the
1005 simple thing about cordless phones, I'm just gonna stand my ground now and say 'I'm
1006 putting them in, I know it's your house but I'm putting them in' and then afterwards I said
1007 with the remote (laughs). The other thing is the tea, you know when you lift the kettle it's
1008 heavy and there's a thing called the one-cup, where you just, you fill the tank and it's very
1009 light, you can actually bring a jug over and fill it and then you put the cup in and it just
1010 dispenses one measure of water (mm). I had them for my mum when she had Parkinson's,
1011 now they're common place, they were extortionate then but it meant she wasn't having to
1012 lift the kettle in her, with her shaking and all that (mm) so that, because her hands are so
1013 bad with arthritis, him, the kettles and stuff like that again I was like 'we need to get you one
1014 of these' [and she said] 'it doesn't match my kitchen' [and I said] 'I don't care' (laughs). It's
1015 where to draw the line where you eventually say, that's the hard part, the downside (yeah)
1016 is to, and also for me it's to stop my kids having to, not a burden, that's not the right word

1017 but, she doesn't like putting upon them but she, I said 'there's me and [younger daughter]
1018 within ten minutes of you and both partners, right so there's five adults who could get to
1019 you within half an hour to put his clothes on at 3 o'clock in the morning, stand him up, put
1020 him back to bed, but you choose to sit on the floor with him for 3 or 4 hours until the carers
1021 come' and that's what I said to her is 'I, I don't like that' I said 'because you're denying
1022 [father in-law] the right to have him put back to bed' (mm) but she also, her view on it is
1023 that's taking away his dignity that you have to come lift him up off the floor. So I, I'll fight
1024 with her about and I'll say 'but your taking away his dignity leaving him lying on the floor'
1025 and she's like 'he's sleeping' (laughs) I'll go in and he's sleeping' and I thought but we don't
1026 want you knackered and sitting up. So there's that- who's right and who's wrong? (yeah)
1027 completely different perspective in that and I got really annoyed with her and said 'I want to
1028 come lift him off the floor' and she's like 'I don't want to get you out of your bed because
1029 you've got work to go to'. So there's no right and wrong (yeah); that's what the difference is,
1030 there is no right and wrong (absolutely) it's her values and my values, there's no right or
1031 wrong.

1032 I: What would you wish for yourself for the future, for the next year to five years maybe?

1033 P: Erm, in an ideal world I would've loved her to go to a sheltered housing you know (aha) that
1034 kind of where she could help, people around that we don't suddenly realise- 'oh my god I
1035 haven't spoken to her, my daughter's away for the day or something you know, shit, that call
1036 at nine o'clock at night and then actually wake her up, you know that kind of erm, she will
1037 not move out that house. It's a bloody awful house for somebody in her condition but she
1038 will not move out that house and that's what we've had to accept so we have to work round
1039 and make it as safe as possible. So that's what you could say to her- 'if you hurt yourself, you
1040 cannot get in and out of this house. It's a bungalow but it's up a windy path (laughs) and
1041 then six steps. Once you're in it you're fine you know but if you've hurt yourself you can't get
1042 in or out it (yeah). So, there's nothing we can wish for, it changes us nothing we can really
1043 wish for because we have to work within what she'll allow us. I'd love her to move to
1044 somewhere, erm, a better house but it's not gonna happen. That's not been, that's not
1045 something I even fight with her about. I don't know, I don't know, there's nothing, I, I don't
1046 know. It's the contact, it's, I think it's the contact, it's the how do we keep in contact with her
1047 or know if she's hurt herself. That's our big thing, everything else we can work round. It's, I
1048 think that, the communication.

1049 I: Thank you so much. This concludes the questions that I have (laughs). Is there anything that
1050 you would like to add (erm-) that we maybe haven't talked about?

1051 P: Um, no, mainly it's, it's the communication (yeah), that, that no go, that lost area between
1052 public spaces and if her car broke down at the bottom of the hill, just that kind of, there's
1053 nothing, [no] one thing. There's no register anywhere, um, I look after all her bills; Council
1054 Tax, Gas, Electricity, all that. My niece, this is the one thing she does do, their family own a
1055 Garage so she looks after her car and she recently was talking to me about something, she
1056 was 'oh my god yeah-' and I couldn't work out what was going on, my niece had forgotten
1057 about her MOT (aha) so I don't know if she got a letter through, I'm not quite sure but
1058 there's nothing, if there's a register that could be put, if somebody put who looks after the
1059 Gas/Electric, there's no monitors for my carers, not me the carer, an outside agency but see
1060 if through a register with having someone with dementia, does anyone look and see who's
1061 looking after the Gas and Electricity, their Council Tax, are they getting the Council Tax
1062 benefit? If you're diagnosed with dementia, why is that not automatically notified by a
1063 doctor to the Council? But they've got money right and I keep saying 'please get the discount

1064 and donate the money to a charity of your (laughs) you know- take the benefit you're due
1065 and give it to your charity' but you know, so if someone was diagnoses with dementia, why
1066 is that not automatically, there's something in your forms you fill in that flags up to the
1067 Council that that person's entitled to 25% discount (aha), even though there's two of them
1068 you know, now you get 25% discount in Council Tax if you're a single person who lives in the
1069 house, but if you've got someone living with dementia, you're also entitled to 25% (yeah) or
1070 incapable or somebody who's got special needs. Why is that not automatically notified and
1071 who looks after somebody's Gas and Electricity. Not so much her car and stuff, that's just an
1072 older person, if you're that bad you shouldn't be driving! (laughs) but there doesn't seem to
1073 be anything to pick up, it's all, a lot of it is to do with family but if you don't have the family
1074 who the hell does it? (Yep) I switch her Gas and Electricity all the time because their gas is on
1075 for like 20 hours or 21 hours and at 90 degrees and she's still got on her cardigan. The
1076 amount of that that they're using. Bins; I arranged for the Council, they come up to bring the
1077 bins and they give them special bags, they don't have wheelie bins anymore because the
1078 men come up the path, so they have bin bags now with old fashioned bins (ok), you know
1079 the tin ones with the lids on them (mm), they've got them and they have to put the stuff in
1080 bin bags and that but the bin men come up the path and take them, empty their bins for
1081 them, so they don't have to take the wheelie bins down to the street any more. It was the
1082 simplest thing to do; if she doesn't have to fight with two wheelie bins every week. Why if
1083 you've got someone over a certain age do the Council not, I know everything's too perfect
1084 but is there not something that picks up on these things (yeah) those kind of services?

1085 I: It's a very good point.

1086 P: That is to do with money isn't it? They're not gonna offer a service, it's there if you ask but
1087 that kind of, but-

1088 I: That is a, that is an excellent point. Again, thank you very much, I just have a couple of very
1089 quick questions just for the context; so how far away would you say do you live to your
1090 parents in-law?

1091 P: I can drive door to door, if there's no one between us, if it was an emergency I can literally
1092 from my car to their front door I can do in about six minutes.

1093 I: Six minutes (yeah) ok. How many hours on average would you say do you care for your
1094 parents in-law, everything considered?

1095 P: Um, I'd say phone calls, arranging stuff, I speak to them probably half an hour every day and
1096 probably there every day or second day (aha). Again that's to do with privacy, I don't want to
1097 be on her doorstep every day and she doesn't want that. So I would say we're talking and
1098 being in contact at least half an hour everyday but actually being up there, I will be up there
1099 every second day for an hour or so and so will my daughters and stuff so it can range
1100 anything from five, six hours a week to ten, twelve, you know if we're doing stuff, if we're
1101 sorting stuff. It's more to do with phone calls, the work we do in the background (yeah, yep)
1102 you know I'm doing stuff for them the insurance and [eldest daughter] does their banking,
1103 not their banking, she goes every Thursday to get her money (yeah) but my daughter
1104 monitors her bank account. It was her who flagged up, she got a text the other day and she
1105 emailed me at work and she was like 'are you doing stuff with gran's bank?' and I'm like 'no'
1106 and she said 'I've just had a text through saying thanks for arranging your overdraft' and
1107 something or other and I really went into full panic, we couldn't get her, transpired she was
1108 in the bank (ok) and what it was um, and my daughter's like 'I know gran's got ten grand in

1109 that account, why is there a thing up saying you've arranged an overdraft?' and it transpired
1110 because it's a new tax year, the girl in the bank had said 'Mrs [Name], you should be moving
1111 some of this into a new ISA' so my daughter knew, she had this plan to do them but the girl
1112 in the counter had got her and as it's a Thursday morning she's in the bank and the bank
1113 have got her (ok), so the girl in the bank and they'd taken her away and they'd got her and
1114 part of this must have been that they, they get points for doing different things, so they've
1115 set up an overdraft for her. The woman's got ten grand in that one account, they've not got
1116 money problems (laughs) but that was, we saw that flag up or she did immediately because
1117 it's her email address connected to the bank account but we were into full panic, we thought
1118 someone was trying to (yeah) so, who does that (yeah) you know, the Banks need to take,
1119 well what do the Banks, they do, they do take responsibility for that, they do flag this up erm
1120 so, that frightened us. What was the last question?

1121 I: How much time do you on average-

1122 P: So days like that (yeah), days like that, that took us a good few hours because we, one of us
1123 was about to leave and go to the house; we thought what was going on (yeah) and then it
1124 dawned on me- Thursday, bank day, she's in the bank and we agreed we leave it 'til half 12,
1125 1 o'clock and then [my daughter] could see money being moved, she could see online and
1126 then we got her later on that afternoon and she was 'I was in the bank' (laughs) oh yeah, ok,
1127 we know (yeah). So it can go anything from 5/6/7 hours and go sometimes hours (yep).
1128 Lawyers and stuff like that, power of attorney. My ex-husband lives in, he now lives in [place
1129 omitted] and my, the brother, my brother in-law lives in [omitted], they've got power of
1130 attorney (mm). They're not there! It was put in place years ago, they're not there so we have
1131 to work round that stupidly (aha). We went to put it in place for [my daughter] to do all her
1132 financial stuff recently and then that's where we found out that actually power of attorney
1133 was in place for [mother in-law] as well. She thought it was just in place for [father in-law] so
1134 she wanted my daughter to sort her money out for her, couldn't. So it depends on hours, I
1135 couldn't put sometimes it can be hours and out fixing things as well, we can be out fixing
1136 things, fixing windows on Christmas Day- they broke the window, we had to go board up the
1137 window; he tried to open the window and it was bent and he forced it.

1138 I: Oh dear, did he hurt himself?

1139 P: No because it just cracked it, the whole thing cracked. He's not supposed to touch windows
1140 but something had got into his head (ok) so I ended up boarding up-where are you gonna
1141 get a joiner on Christmas Day, Christmas morning?

1142 I: So, it's quite unpredictable how much time (yes) you might have (absolutely depends) to
1143 spend?

1144 P: So that was Christmas morning, I was up, instead of getting ready to go to my son's, I was
1145 down getting stuff out of my garage, which actually happens to be up near their house,
1146 getting boards that I knew I had and boarding up their bedroom window (mm). That can
1147 (take a long time) where else you're gonna deal with that (yeah) yeah.

1148 I: So, can I ask you how old you are?

1149 P: I am 59 and a half (laughs).

1150 I: And a half, ok [both laugh] and what's the highest level of education that you have
1151 achieved?

1152 P: I've got HND in Computing, HND, that's one.

1153 I: Ok, good and yeah so I think we have touched on everything else, so just the final question-
1154 your ex-husband is he in anyway still involved with the care of them?

1155 P: He actually probably does more for his parents than the brother that lives [closer] and the
1156 sister that lives nearby (ok) because when he comes home, he used to stay in the house, he,
1157 but doesn't now, he used to sleep on a sofa bed and what's [father in-law's] office, or his
1158 sitting room, so he can't do that anymore but he will come and he'll do maintenance. She
1159 will, we know that he's down and we know that he's spoken to him and he'll tell us she
1160 wants us to fix this, she thinks we don't know (laughs) so she'll have wee things lined up for
1161 him (ok) one of them being that window, which wasn't opening right so she, she had signs
1162 on it saying 'do not open this window' so that was one of the things he was to look at and
1163 normally he would say to us sometimes like 'I don't think this is going to last until I come
1164 home' and he will do bits and pieces that are ridiculous because he's the most unhandy
1165 person in the world. So he will actually do some stuff for them although he comes home
1166 maybe twice a year for a week.

1167 I: Yeah, so it's restricted to when he's actually physically present.

1168 P: Yeah he'll do some stuff or she'll talk to him on the phone now and he'll order stuff from
1169 Amazon and have it delivered to her (ok) he'll do that, he's done that before and that's a
1170 more, that's more pretty things you know, she'll see something and then he'll send it to her
1171 but yeah she used to use him to fix some stuff, rather than bother us.

1172 I: Mm, does he check back with you or with your daughter?

1173 P: He checks with [daughter], he checks with her. He does sometimes with me but he knows
1174 that we've pretty much got it. If he picks up on anything in the phone call, then he will email
1175 or text us and say 'I think there's something wrong with the front door or' you know, just
1176 weird things then he will sometimes feed that back but he can, he's 8 hours away on a plane
1177 (laughs) (mm, yeah). The other one in [place], we have asked before, 'come and clear stuff
1178 because we're getting the loft insulated', there used to be an attic room (aha) and we've like
1179 'we can't get this insulation put in for your parents because all your stuff's there'; he's 6
1180 months younger than me (laughs) 'because all your stuff's there from university, you still
1181 need and it's still in your parent's house but we can't get the insulation put in because it's
1182 still there and if you need it, come and get rid of it please, to your four storey town house'
1183 (laughs) but he still keeps all his uni stuff at his mother's (laughs) so yeah, stuff like that; he's
1184 not fabulous at helping and he'll make ten million times he's gonna come and then
1185 eventually he'll come but you know, but no, don't ask about him (laughs).

1186 I: Does that lead to conflict in your family sometimes?

1187 P: We don't ask anymore, there's no point (yeah), there's no point and that's to do with his
1188 wife, his wife doesn't want any contact, erm, so it's not worth the hassle for him. He's got a
1189 demented life with her so, we know it's not really him it's just not worth it. So we don't rely
1190 on him, if he turns up fair, but if he doesn't (mm) and he doesn't. Most of the time we think
1191 when he does come to visit his mother, he's actually managed to sneak off, she doesn't

1192 know. He's the same age as I say, 6 months younger than me. He's a high flying [post
1193 omitted] and the wife is a [omitted] who owns two [omitted] and she denies him the right to
1194 have anything to do with his mother. So there's no point in fighting with him, he can't, so no,
1195 it's a shame. Done?

1196 I: Done (laughs) again, thank you so much-

1197 END

1198 Postnote: After completing the interview and switching off the recorder, participant told me that
1199 wandering was an issue with her father in-law. He would often get dressed, asking when he could
1200 leave for the ship (he used to work in the navy); his wife would try to switch out his shoes with
1201 slippers and tell him that he'd already been outside whenever he wants to leave and most of the
1202 time he seems content with this; participant mentioned that a device to keep track of him would be
1203 helpful but it would have to be connected to her rather than the wife as she doesn't trust technology
1204 (as mentioned in the interview); it would also have to be something unobtrusive as he would
1205 otherwise take it apart (as mentioned in the interview);