

Interview 16, "Rose"

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I = interviewer, P = participant

I: So, to start the interview. Can you tell me a bit more about the caring situation, so how did caring come about?

P: It came about as a natural process. Um. [ex-husband] he's my ex-husband and. Um. We were still living together. And about 10 years ago. And he lost his job. And he was about 58. But prior to that we had noticed that he was a bit grumpy, bit more bad tempered. Anyway, losing his job, he went into deep depression. So, we went to the GP. And he saw different people. And eventually was put on anti-depressants but it didn't really help, his memory was pretty terrible, and he was falling. Not often but falling nevertheless. So, I pursued the doctor which took a long, long time because they put it down to lots of different things. And eventually he went to the [hospital] and he was diagnosed with Asperger's syndrome. So, from there he went on to different places like [specialised group] for Asperger's in [city]. But his condition just kept deteriorating. So again, I had to push and push and push. The doctors, he had lots and lots of tests, lots and lots of scans. And only last year was he diagnosed with frontotemporal lobe dementia. And a right-side weakness, they call it. But it's like wandering limbs, so his, his arm will just go out for no reason or he'll clench his fist. And his leg will just throw itself out in front of you. And so, it took nearly ten years to get that diagnosis, up until that point we just had to get on with it and we did have some input from physios. And OTs that came out to the house and, and they were fantastic support, I have to say, they really were, but it was limited what they could do without a diagnosis. Unfortunately, I think it's the same no matter what condition you think you might have, or you've clearly got a condition, but it's not got a name, not given a title. There's no services there, there's none whatsoever until you get that diagnosis apart from the very basic, your GP who is vastly overworked and OTs, again overworked. And, but they got us a bath chair to get him in and out of the bath because you couldn't get him in the bath to get a wash. And they got handrails outside the house for us so you can get up and down the steps and it's very simple things but it makes a massive difference, not just to our lives but to him, you know, he was getting to the point where he was in the house all the time because he couldn't get out. They provided us with different walking aids to try and help him. And, so, it was just a progression because he was getting worse. And we were all living together that, I couldn't have not looked after him, you know. And, because [ex-husband] lost his job, and obviously the income into our home dramatically reduced, I had to start, consider seriously- So, I think in working, I did work anyway, I have always worked. But more hours, you know, at the beginning I did have to work my full 10 hours plus overtime [per shift] for a good few years, but now we seem to, financially, just be able to cope with it all now, as long as I do my one or two extra shifts a month. We can just, we can cope

41 with it. So, it was a progression that wasn't something that I just suddenly thought 'Oh
 42 well, he's ill, I'll move in here and look after him' you know. It was a fact that, it's
 43 somebody that you loved at some point, still love, you know, and I mean you get to take
 44 care of, and there's no services to take care of him anyway.

45 I: So, do you still live together?

46 P: Yeah. Yeah but you are we're not together. We're divorced, divorced. We divorced a
 47 decade or so ago.

48 I: That was before all of that started? (Yes.) And so, in terms of the kind of care that you
 49 provide, can you tell me a bit more about that?

50 P: Well it's everything, from the minute he gets up in the morning. Helping him down the
 51 stairs because we don't have a stair lift or anything, he can manage the stairs but very
 52 slow, methodical. And he's incontinent and so, it's a bed change every morning and
 53 cause, so that's another service that's sadly lacking, incontinence products. We're in the
 54 process of sorting that out. So, he gets up, he's generally wet, and so he goes to shower,
 55 we now have a wet-floor shower room installed. So, that's helping him downstairs, into
 56 the shower, has a shower and gets dressed, comes through to the living room, and get
 57 him sitting, and then I go through to the kitchen, prepare his breakfast. And make sure
 58 he takes his tablets. And put the telly on, he sits and has his breakfast, he then has to get
 59 a freshen-up because he's sticky from the toast and honey. And, generally from there he
 60 is all right for an hour or two, he'll sit and watch the telly, he'll potter about and then
 61 he'll go, if he has an accident sometimes, he'll go [to the toilet], if his bowels have an
 62 accident. But it's getting a bit rarer at the moment. So, we seem to be managing that.
 63 But he wears incontinence products through the day. So, go to the toilet to change, then
 64 lunch, prepared his lunch, giving him his lunch and more medication. And in between all
 65 this I'll be picking up tablets, taking him to appointments and OTs will be coming in and
 66 social workers will be coming in that fit in some new gadget or another. And then. Again,
 67 in the afternoon you know maybe come into the garden with me if it's nice. And if I'm
 68 working and I try and get some sleep, I just put my head on the couch, there's no point
 69 to go to bed anymore, and then prepare his tea, give him his tea. Gets ready for, he goes
 70 up to bed quite sharp, he does like it, he has his SKY and everything up in his room. So,
 71 about seven o'clock he gets a freshen up, brushes his teeth, puts his incontinence
 72 product on and I take him to bed. (Mm hmm). If I'm not working I'll take his tablets up
 73 about ten o'clock and if I'm working, and there's always someone with him at night,
 74 whether that's his brother or our daughter. (Mm hmm). And they'll give him his tablet.
 75 I'll go to work and as soon as I come in in the morning, he's generally pottering down the
 76 stairs. So that's a 13-hour shift and then I start again. (Mm hmm). Do breakfast, getting
 77 washed, dressed, get settled. I'll go up for a couple of hours sleep, I get up for his lunch
 78 come back down, give him his lunch, tablets, make sure he's dry and comfortable. And
 79 then I'll go back and try and get another couple of hours sleep (Mm hmm) before I get
 80 up and prepare his dinner. And then I make sure he's sorted before I go out to work, so,
 81 and I'll put his incontinence products and so on, I leave for work about ten past seven
 82 and he goes up about seven o'clock. So, he's safe in his bed. He has a falls watch, so we
 83 set all that up. And, so, that, that is, that's a, that's a day that we are just in the house.

84 But life's not like that. You know, he does have appointments he has to keep. And it's
85 more difficult to get him to the dentist, it's more difficult to get him to the doctor's, it's
86 very difficult to get him out of the house now. (In terms of his mobility?) His mobility and
87 the fact that, because of his condition he is becoming, not, not aggressive that's not it,
88 but he gets agitated about going out and meeting people. Once he's there it's fine but he
89 gets very anxious, so he can get quite grouchy, not so much with me but with his brother
90 and [daughter]. He really can be, and again his condition, his inhibitions are going
91 through, the swearing, he kind of swears a bit now. (Mm hmm) So is, his condition is
92 quite rapid which in many ways is a blessing. Because the end won't be 15 years from
93 now, it's more likely to be five years from now. And. But it's still very difficult, very
94 difficult to cope with. It can be quite aggravating. You know. And. But this week, this is
95 my week off, I finished last Thursday morning, I have ponies, so sort my ponies out,
96 when I finish they get a full muck-out and things. And then 'Bye' and I'm in the house
97 and it's washing, ironing, cleaning, shopping, paying bills, taking [ex-husband] to
98 appointments. Anything I have to do, or take the dogs to the vet or, you know. This is the
99 only afternoon I had nothing booked in for, for the whole week. And it's like that every
100 week, you know. He now has, because he's got his diagnosis and because I contacted the
101 Red Cross in [place], there was a lady there, and [support organisation] she just
102 happened to mention 'has anybody registered [ex-husband] with Alzheimer's Scotland'.
103 And I said 'Well, not as far as I'm aware. I've never had any literature from them'. And
104 they've been fantastic since they've been involved, that's obviously how you got my
105 number. And he now goes to, Monday morning and Brain Gym and every other Tuesday,
106 when I'm off I take him to the group in [place]. But again, that comes with stress to try
107 and get him to his groups on time, pick him up from these group. The Tuesdays are fine
108 because I'm off on a Tuesday afternoon. But the Mondays, his brother is supposed to
109 take him and I pick him up but that can be a bit, but he does get there and he just enjoys
110 it. So that's two things that he's going to, he's on the waiting list for an afternoon and at
111 [organisation] as well. And. So that's a waiting list for that. So, you know, that he has a
112 life and but it's, other people are having to, don't give up their lives but alter what they
113 would be doing so we can get [ex-husband] to do something. Otherwise he would just sit
114 in the house 24/7 and go nowhere.

115 I: Is it possible for you to put a number on how many hours a week on average you would
116 provide care for him?

117 P: Oh well, it takes about, it takes a good hour in the morning and, and it takes, I suppose,
118 does that include stripping beds, washing beds? (Yes) There you go, it's got to be, it's got
119 to be four hours a day if not more. And if you've got appointments to go to or anything
120 like that, but it's certainly four hours a day by the time I've done the morning round with
121 him, cleaned up after him, after the washing, washing of the bed. Lunch. You know.
122 Often, his incontinence, that's a change of clothes in. So, yeah, four hours, that's only
123 one day.

124 I: So, you briefly mentioned at night, when you are not there, there would be someone
125 else with him (Always, there's somebody in the house). Would he get up at night?

126 P: He used to. He used to get up at night and. But he doesn't now, he has a urine bottle in
127 his room and as I say we have, now got the district nurses on board. I don't know if
128 you're interested in all that saga with them. (Yes) To get any incontinence products now,
129 because they are so expensive, you have to do a 3-day fluid-in, urine-output. So, we did
130 that. And. Then it was sent to panel and goes to a panel, they decided that [ex-husband]
131 drank too much coffee, not enough water and so they refused him incontinence
132 products. So, we were just buying what you could buy which was costing about 22, 26
133 pounds a week for those, for day and night. And my GP got involved and they wanted
134 him to take a urine sample to the doctors they wanted a prostate test done, bloods
135 taken, they wanted him to stop drinking the coffee and drink more water. Well, my GP
136 was not impressed. And so, she wrote a very strong letter to say that [ex-husband]
137 wouldn't tolerate an examination, we did take the blood and we did get a urine sample.
138 And but still we heard nothing. And again, it was outside of [support group] on a Tuesday
139 afternoon that had district nurses that were coming in to tell us about the incontinence
140 products. And they made it sound like it was simple, you just filled in this form for three
141 days and you'll get what you need. So, I explained that I filled in the form and certainly
142 didn't get what we need. So, they got involved and they pushed things along. So, we've
143 had a trial now, of night incontinence products. So hopefully. And I've said that you're
144 fine but it's a twelve-week waiting list now before we actually get them. A twelve-week
145 waiting.

146 I: Do they deliver the products or give you the money for you to get them yourself?

147 P: Delivery. You'll get a pack a month. Well, again, that's ridiculous because it's 28 per pack
148 a month. Well, apart from one month, you know, two or three days a month you're not
149 actually going to have that. That's beside the point. The point is, it's still 12 weeks from
150 when they agree to provide them to actually get them. And these are the things. And I
151 know that the health and social care is falling to bits. I work in it. You know that's, that's
152 what I work as, in a care home at night. So, I know what it's like. We're cutting back on.
153 And. But. There has to be a line where people have to be respected and they have to be
154 allowed to have dignity. Now, in [ex-husband]'s case, maybe because I work in the
155 industry and I look after people like [ex-husband] every day. Yes, it's difficult because
156 you're more involved, you're more physically, mentally and emotionally involved with
157 [ex-husband] but I still know what he's entitled to. But trying to get through all the red
158 tape and all the people to actually get it is absolutely ridiculous. There's, too many
159 people involved. They don't talk to each other which is the biggest problem. You have an
160 OT, she gets you a piece of equipment, then she signs you off. So, if you ever need an OT
161 again, you have to phone back into the service, you get given another OT that comes out
162 and you have to explain everything again. It's madness. The whole system's madness.
163 But I start ranting, I'm sorry. But yeah, the incontinence products, we've got that,
164 hopefully, in twelve weeks.

165 I: In terms of the appointments that you were talking about, is that usually something that
166 you can plan for, plan ahead, or is that something that might come up and you would
167 have to rearrange them?

168 P: Yes. Yeah. Well, both, both, and the appointments at neurology have now stopped
 169 because there is no, there's no treatment for what [ex-husband]'s got. None at all. And
 170 they wanted him to go to the memory clinic but he's well past that and he's not going to
 171 tolerate it. He doesn't like going to the hospital. I think he's convinced he'll be kept in
 172 because he was very ill and had to be kept in, 18 months ago he had his gallbladder
 173 removed. And. So. The hospital appointments are not so bad because they're quite far in
 174 advance but things like the District Nurses, they just turn up on your doorstep and
 175 expect you to be there. And twice they did that now and got me out of bed.

176 I: They didn't even give you prior notice?

177 P: No, no. They were in the area and just thought they'd pop in and see us.

178 I: What if you had been at work?

179 P: Well, exactly, well, they know I work nights (okay) but I was sleeping. And the OTs and
 180 things, if they come in with equipment, the equipment service, they're not very, again,
 181 they're not very flexible. On Monday they deliver to [home area] and that's it. You know,
 182 so, and they'll just turn up with stuff and the OTs are limited because a lot of them are
 183 part time. So, ours is fab and she is she's wonderful. She knows I work nights and, mostly
 184 everybody that's involved will contact me on my mobile. If I don't answer it, leave a
 185 voicemail and when I'm on my week off, or coming up to my week off, I contact
 186 everybody. But then of course that means that my week off is absolutely block on block
 187 with things and people coming in and out again. But it's quite calm at the moment. The
 188 bathroom's done, he's got his new wheelchair, he's got his walking aid which we used
 189 yesterday. I'm trying to think what else is in the offing. Their coming to put a ramp in at
 190 the front of the house so that'll be an awful lot of disruption. And they'll just come and
 191 do that, I don't have to be there, they just have to measure up for that. (Mm hmm.) I
 192 think that's it at the moment. You know we have just been told that we have a package,
 193 of care. Well actually, we were given the package of care last August. But there were no
 194 carers available to provide the actual care. And they apparently, Midlothian council had
 195 no carers and they put it out, this is what we were told, they put it out to an agency but
 196 they had nobody either. It was only for three mornings a week, for 45 minutes to give
 197 him a shower. And that was on a Tuesday, Wednesday, and Friday, because the way my
 198 rota works, I work on Monday night, Tuesday night, Wednesday night, but I wouldn't
 199 work a Thursday. But the next week again I work a Thursday, Friday, Saturday, back to
 200 back, so it's Friday, Saturday- Thursday, Friday, Saturday. Sunday off. Work Monday,
 201 Tuesday, Wednesday. So out of 7 I work 6 [days]. So that, that's what we agreed. So,
 202 when I'm coming in in the morning I don't need to shower him, somebody could do that.
 203 And when I am off it's fine, I would do it then myself. And so, nothing, nothing, nothing.
 204 (Almost a year?!) Yes. And, and I probably abused my position as a [council] employee.
 205 But I had a bit of a meltdown at work. To be fair it wasn't [ex-husband] that the
 206 meltdown was about, it was about issues at work. And I was explaining that it's not just.
 207 13 hours in here, you know, people have a home life. And I look after somebody at home
 208 with dementia, which they didn't know. I don't really tell people. Because it, for one, it
 209 shouldn't and must never really affect my work. And also, I have quite a few health
 210 conditions myself and didn't tell work either. Anyway, my boss said to me 'Email this

211 lady', she's my boss's boss, well she's my boss as well and her boss 'And explain that you
212 work here and that you're finding homelife very, very difficult. There's a package of care
213 but no carers to carry it out'. So, I did, and she got back to me a couple months ago,
214 because I did this in January. And, and she wanted some more details, and said that she
215 can't promise anything. And she hopes that in the future, you know, we'll be able to get
216 care for [ex-husband] as soon as possible. Never heard another thing. You can't really, I
217 didn't expect it to be honest, but suddenly, last week we were told that we'd be getting
218 the care that we wanted, and an increased package of care provided by the council. So, I
219 don't know if she had anything to do with it or not, but it seems like it. Three months
220 ago, we were told there was nobody at all able to give us care and then now we're
221 getting it seven mornings a week. Seven afternoons a week. Well. It's supposed to be
222 afternoon, but I used to work in the community too, you can't be everywhere at the
223 same time. So, they'll come in in the morning and between 7 and eight. Again, he only
224 gets 3 showers a week from the council because that's all they provide. But just fantastic
225 as far as I'm concerned because that's three days I didn't have to do it. I can maybe you
226 know get a shower myself and get to bed early and lunchtime, they're saying eleven
227 o'clock which is a bit sharp for lunch, but I'm not arguing that, the fact that we're going
228 to get it and that starts on the 16th of July, that's soon. So that's what I'm in the middle
229 of just now. I'm having to do literally a bullet-point step by step ' [ex-husband] does this,
230 he'll need help with this'. Yes, they'll write it all down, but being here and doing that, I
231 know what it's like to go in blind into a house you've never been into before and have no
232 idea of the layout of the House and what you're going into, you know, because it's, it's so
233 beautifully packaged, you know, this person likes this, that and the other, but they don't
234 actually tell you about their passion and their attitude and how they'll be towards you.
235 So, I started that last night for the carers that are coming in. But hopefully, with it being
236 in [council area], I'll probably know the girls anyway. So that would be good. So that's,
237 that's brilliant. What we do have is animals in the house, so that could be an issue
238 because there will be some that will say that 'We're not coming by because you've got
239 dogs', so it might take a month or so for it all to settle, but it will, it will all settle down.
240 So that will be great when it starts.

241 I: So up until now it was just you and your family that provided care? (Yeah, yeah) And to
242 be precise, it was your brother in-law basically and your daughter? (Yes) Is there anyone
243 else that helps?

244 P: Well my brother, in the beginning when [ex-husband] first started to take unwell. But
245 when [ex-husband]'s condition was, what's the word, incompatible with going on holiday
246 and things like that, my brother would come and stay, and I'd get away on holiday. And,
247 but not now, he isn't, he can't be cared for by anybody else. No. No. He is too, he's gone
248 too far down the dementia route. They need to be around somebody that really knew
249 what they were doing.

250 I: So, with you, your daughter and your brother in-law caring, do you, is that something
251 that you have organized or are they helping out whenever they can?

252 P: Yes, basically it is. I do not like to put more pressure on [daughter] and [brother in-law].
253 [brother in-law], I think sometimes thinks that [ex-husband] is not as ill as he is. And

254 they've always had a bit of a, it's not love-hate, but they have always wound each other
255 up as brothers. And [ex-husband]'s always had characteristics of Asperger's but
256 obviously when he was a boy it was never heard off. And. So, they've always had this
257 sort of love-hate-ish relationship and they wind each other up, but they love each other
258 dearly at the same time. And so, if [ex-husband]'s been in the house all day and he's
259 lonely and [brother in-law] comes in from work, you know, he'll say things like 'You're
260 just like your father' and that just annoys [brother in-law] and he will fly off the handle.
261 But, he's there and he will look after him. He doesn't like showering him. And [ex-
262 husband] has got very used to me doing it all. So, if we go anywhere he won't go without
263 me and he prefers me to give him a shower. He likes the way I do his breakfast. So, I'm
264 trying to say to [brother in-law] 'Can you just do it like I do it, because it's not a break for
265 me if you do his breakfast and then he says it's horrible'. You know so [brother in-law]
266 can be a bit prickly at times. [daughter], she, she'll go in and just give him a shower. She
267 doesn't bother, but she's only 29, she has a life of her own. So, it's generally just me.

268 I: And you all live in the same house?

269 P: Yes, we all live together. [daughter] had to move back and she had rented a little place
270 but financially it was killing her, well it was killing us trying to keep her going. So, she's
271 moved back in. But it's a bit overcrowded but we get by.

272 I: So, in terms of you three coordinating the care for [ex-husband] is it, do you usually do
273 that on a day to day basis?

274 P: Generally, a week. You know, I'll say to [brother in-law] 'What shifts are you on this
275 week'. And, he has learnt that if he's going to do overtime he has to actually say so
276 because I've got it all on the calendar, my days, his days, because he does days and
277 nights. So, I have it on the calendar, so I can see instantly if somebody phones up to see,
278 you know, we've got an appointment for [ex-husband] to see blah blah blah. 'Can you do
279 it'. Yeah, I did that, I do that for the whole year at the beginning of the year but [brother
280 in-law] was very bad at just taking an extra shift and not telling anybody. And I have had
281 to take emergency annual leave because of it. But now he'll say 'can I do such and such'.
282 So yeah, we organise it like that and I'll see to it. When we look at the month where we
283 had, [brother in-law] and I are both on nights together, so [daughter] knows that she
284 can't work on Monday, Tuesday, Wednesday night shift and because obviously we are
285 not, we are away, and he goes up at half past 7:00. (Mm hmm). So yeah, we work it
286 between us but again it's me that organizes that, they don't come to me and say 'you
287 know I'm going out blah blah blah. Are you here?' So I don't have a life. Well actually I
288 went for a hen-do on Saturday. And. I was, I can't remember the last time I went out,
289 and I just felt a bit, you know I'd rather be at home. I just, it's terrible because I was the
290 life and soul of the party, you know, I mean I would, I would enjoy myself and I would get
291 the night bus home we used to get a night bus. But not anymore. It's all well organised.

292 I: So, to talk about your work a bit more. So, you said you have night shifts?

293 P: I do permanent nights, yes (No day shifts?) no day shifts anymore. I used to do the odd
294 day shift. But I can't leave [ex-husband] for that length of time anymore. So, and no I just
295 do nights.

296 I: And you have a fixed rota? (I do. Yeah.) And you said you were picking up extra shifts?

297 P: Extra shifts. Yeah. So, I try and do that when I know that [brother in-law] has, [brother
298 in-law]'s off. And twice, two weekends of the month. So, I'll try and work a Saturday
299 night shift and in the course of, having finished up on Thursday morning, so I'll have the
300 Thursday night, Friday night at home, do a Saturday extra, and then I'm not back till
301 Thursday night. So, it's not so bad.

302 I: Okay. So how does that work with the extra shifts? Can you rely on that or is that
303 something that-?

304 P: You can always get extra shifts (Okay). They're always desperate for staff. Yeah. Yeah.
305 Definitely.

306 I: Can you say that on short notice 'I want an extra shift'? (Yeah). OK. Yeah. So, you said
307 you worked at a care home? (Yeah, yeah) Do you have, like, the ability to take breaks
308 when you need to, or do you have fixed breaks?

309 P: Fixed breaks. We get one 20-minute break (One 20-minute break?) in 13 hours. Well, we
310 get 10 minutes as an extra comfort break. So, we get actually half an hour. But we don't
311 get paid for it.

312 I: Wow, that's intense. So, for example, when you would get a phone call would you be
313 able to take that when you are on shift?

314 P: I would need to, we're not allowed mobiles. It would be in my bag. And, they do have,
315 the home I work in has different areas, there's five different 'streets' they're called. So,
316 my street is the fourth street. The home has my street phone number. So, if that rang
317 then I would be able to answer that yes. I don't know, if it was an emergency I would go,
318 erm, but in saying that I don't suppose I'll be allowed to go if we were short staffed, so I
319 don't know, I've never been in that position. Touch wood.

320 I: Has that ever happened, that there was an emergency and-?

321 P: No, someone else...no. Oh, imagine there's some, people have gone but it's not left us
322 short staffed. You know they've been quite lucky, that was at a time we were fully
323 staffed. But often it's not, we're not fully staffed. Again, it's the council. It's a council run
324 home. So, you're supposed to have ten staff at night. Often, we're only eight. So, if I left,
325 that would make seven. You know. As far as the care inspectorate goes, that would be
326 very bad.

327 I: Just out of interest, how many residents are there.

328 P: 60 and one respite, sixty permanent. Twelve in each street, apart from one, forth street's
329 got 13, one is a respite.

330 I: So, every night you would be responsible for twelve-?

331 P: Twelve, twelve residents with lots of different types of dementia, not just dementia but
332 complex needs, behavioural problems. And schizophrenia. The whole caboodle. No, (It's
333 usually not quiet), it's not quiet. People think there is a lull, you know, but we hit the

334 ground running when we go into work. We go for a report at half past seven, we're on
335 the floor by 8:00 and it is just absolute manic till about 20 to 1, we normally finish. And
336 then I get a bite to eat, at two o'clock we start again, doing incontinence rounds. When
337 we finish until we start again I've got all my paperwork, that's a nightmare, all the
338 paperwork to fill in, from when I came on shift, get something to eat, stock my trolley
339 up, do another incontinence round, that's about three o'clock before we finish that.
340 We've got duties to do at night as well. We've got cleaning duties, filing. You name it.
341 Anything you can think of, clean microwaves, anything you can think of they get us to do
342 at night. Because they're still convinced that we're doing nothing. And then we'll go for a
343 break at five o'clock. Then start again. And finish at 8. So, when you do your last round,
344 we call it, you do your incontinence round from one end of the street to other then you
345 have to start giving out the pre-morning meds and then obviously there are some on the
346 street who want to get up and have a shower. So, you toil to finish up by 8:00. So, it's a
347 quick night. It goes by fast.

348 I: Just coming back to emergencies very briefly. So, you said that hasn't happened yet. But
349 how would you, how do you think, if something were to happen and you would be
350 notified of that at work, how would, then think, that you would react in that situation?

351 P: Well, we're supposed to have a practitioner who is a grade five and on at night, so she
352 would be my immediate boss at night. So, if it did happen I would go and see her, and I'd
353 say to her you know that, I don't know if they would know, but I would tell her that I'm
354 [ex-husband]'s primary carer. 'It's an emergency at home and can I go?' and I'm sure if
355 we were fully staffed she would say 'absolutely. Off you go'. But, again working for the
356 council, there's not always a practitioner. Because. The rotas are done so badly. And in a
357 month, you can guarantee that half of my shifts we won't even have a practitioner. So, it
358 would just be care staff, grade 3s. And. So, if we were fully staffed I would go to my
359 colleagues and I would say like, you know '[ex-husband]'s had an accident'. Cos my, my
360 colleagues I work with on my rota, they all know about my home situation. And they
361 wouldn't hesitate if we were fully staffed and probably even if we weren't. They would
362 muck in and take over. And, I don't know if there would be any backlash from that,
363 because as I say it's never happened. But I'm sure if we had a practitioner on, it wouldn't
364 be an issue. I would hope it wouldn't be an issue if we were fully staffed. But I don't
365 know, if we weren't.

366 I: Would [brother in-law] and [daughter] be able to handle emergency situations when you
367 are at work?

368 P: [daughter] probably better than [brother in-law]. [brother in-law] kind of panics,
369 everything has to go through me, you know. I think [daughter] would step up to the
370 mark more than [brother in-law]. And but she would still expect me to appear at some
371 point just to make sure it was all done right. [daughter] also has cerebral palsy, a mild
372 form of cerebral palsy, but obviously she's had it all her life. So, you know, I've always
373 been a carer. You know for [daughter]. But she's done pretty well for herself.

374 I: So, when you think about combining work and care, other than obviously when you
375 come home and you would like to sleep after a busy night, can you think of any, any

376 other instances where caring and work sort of collided? Where one impacts on the
377 other?

378 P: Well yes. When we couldn't leave [ex-husband] at one point, you know, because he was
379 getting up and he was falling over. And that still happens now. I mean I can go up to my
380 bed. And as I say we do have animals, so they go to doggy day care a couple of times a
381 week just to take the pressure off us for walking them and things. So, I'll wait till doggy
382 day care's come, which is about, half nine, quarter to ten, [ex-husband]'s had his coffee,
383 I'll go to bed. Um. And I could be in bed half an hour and [ex-husband]'s alarm go off
384 because he's fallen and it's an intercom system, so you can hear it all over the house,
385 and, so, then I have to get back up. (Mm hmm). You have to make sure he's okay. Check
386 him over. Put him back on the couch. Organize him. No point going back to bed because
387 it's lunchtime, so I'll make his lunch. And so that day I've got no sleep at all and I have to
388 go back to work that night. That happens quite a lot, actually. Yeah. Um. And even if I get
389 an appointment with a GP, it always, always falls on when I'm on my night shifts. (Oh
390 boy) so she is fantastic, our GP, she really is, she's a fantastic doctor. She looks after all of
391 us. She knows the whole family and has done for 15 years. And, you know, you go to the
392 doctor, you never, you're never on time, so you're late. She'll spend a good 40 minutes
393 with us. So again, it's 11:00 before we're back home. Then I'll give him his lunch. So, days
394 like that I would get maybe an hour and a half before I have to go back to work. So yeah,
395 at least three, three times, four times a month that'll happen. Or even if it's an
396 appointment for myself. You know, if I'm going to the doctor for something, because he
397 forgets that you work. You know he doesn't remember that. You're coming in in the
398 morning and you've actually just come in from work. And he thinks you just got up. You
399 know. And then. When you come down in the afternoon he'll go 'Oh, hello' as if he
400 didn't even know you were in the House. Although we're in the house, he's downstairs
401 on his own. The minute you hear a bang and knock or something you're up. I now lock
402 the back door to stop him go out the back door. Because of the dogs, he lets the dogs
403 out, obviously, for toileting, he lets the dogs out. Nine times out of ten he won't attempt
404 to get down the back stairs, but he has done, and he has fallen down the back stairs. But
405 that's where this falls alarm is fantastic because it picked it up, set it off and so we find
406 him, pick him up. On. That is an excellent thing, the falls alarm.

407 I: But the falls alarm still goes to the call centre? (Yes) And that would then wake you?

408 P: That wakes me up. Yeah. It sits in the hallway and it's a big stone open hallway so the
409 minute I hear dialling, because it's an old-fashioned dial tone. You remember that? I
410 don't know if you know that. Yeah. And that's what it does. The instant I hear that, I
411 know that he's fallen so that sends me up.

412 I: Would you prefer that you just would not be woken up and people would come and pick
413 him up as it would usually happen when you're not at home? Is that something you
414 would like?

415 P: No. No, because I can get him up and with just two of us there we can get him up and I
416 wouldn't want the girls to come out and, you know, if we weren't there. That would be
417 different. But we are here. And. The system's under that much pressure. It wouldn't sit

418 well with me calling them if I know I could have just done it myself. (Even if it costs you
 419 your sleep?) Yeah. Yeah, because, yeah, no I wouldn't. Yeah I wouldn't call them out for
 420 that, not if I was in the house.

421 I: So, have you had a carer's assessment for yourself, for your own needs as a carer?

422 P: Somebody, then my social worker, I think she did something like that. That was a while
 423 back. And. That's when she gave me information about breaks and things like that. But,
 424 to be honest, my memory is bad. And, I don't think anything came of it. I don't think
 425 anything came out of it. Because again, you know that they say that they've got these
 426 places for carers to go. But you have to arrange for somebody to be with the person that
 427 you're caring for, so you can go out. And you know sometimes it's just not worth the
 428 effort. You'd better just stay at home. Or going for a walk. If [daughter] is in the House, I
 429 get more value from going for walks and, I don't mean this to sound derogatory in any
 430 way but, the [support group] in [place], they're all a bit elderly and really, I don't really
 431 have a lot in common apart from the fact that we all look after somebody with
 432 dementia. So, although the information they give you is beneficial and the people that
 433 come and have a talk is beneficial, I can't see myself having a relationship with anybody
 434 there. Or making an effort to go and have a coffee with someone. (So, it's not the right
 435 peer group?) Yeah, yeah that's the word. It's not the right peer group for me. And.
 436 They're all very nice. And they're all going through the same thing as I am. No. But.

437 I: Would you be more interested if the group was a bit more like yourself? Would that be
 438 something that you would then like to attend?

439 P: I think so. Probably. Yeah, yeah, a bit more, more my age. Yeah. You know. There are.
 440 lots of young people who've got dementia. And. But. I just find that it's more of a hassle.
 441 And it's of no benefit. To be fair.

442 I: So, talking a bit more about technology, so this falls alarm that, that he has, is that, does
 443 he have it on his wrist?

444 P: It's like a watch. Yeah, well it's just like a fit-bit. Yeah, it's just a white screen and it
 445 doesn't come up with anything.

446 I: OK. And he wears that?

447 P: That's no issue. No, no, he likes his watch. He like it. Oh yes. Cause, and he's always had
 448 a watch [ex-husband] and due to all these accidents, it must have about 30 watches in
 449 the House, they are all broken or in one state of another of repair. And the last one
 450 we've got on him is a talking watch and so he presses a button and it tells him what the
 451 time is, he absolutely loves it. And so, he has his falls watch on this wrist and he has his
 452 watch here. So, he did have the pendant, but he kept taking it off. Yeah. He kept saying
 453 'I'm not wearing a necklace' [both laugh]. Yeah. And so again the OT managed, she, she
 454 instantly said 'right. Okay then we'll get you a wristwatch'. So that's terrific. It doesn't
 455 pick up every fall. About 80 percent it picks up. It's not 100 percent there yet which is a
 456 bit unfortunate. But again, when we hear the bang we know what it is. You know, he fell
 457 a lot in the new bathroom because it's always, he goes in to the toilet. It's fine, it's flat,
 458 but the minute he goes to the side, because it's a wet room, the floor slopes. So, he kept

459 falling that way. And so again, we had to have the OT back just to see what we could do.
 460 And so, we've got a couple more hand grips on the walls for him. It doesn't look very
 461 fashionable but it's essential. And you know he's not fallen in the bathroom since.

462 I: So, the falls alarm, was that something that you came up with? (No, it was the OT) The
 463 OT. How long have you had that?

464 P: Not that long, maybe, maybe a couple of months. We had the button before, we pay for
 465 that. I'm sure we don't pay the full cost of it but we pay to the council quarterly. They
 466 send us a bill and we pay.

467 I: So, when you say you had the pendant before that was something you had to press
 468 yourself? Was he able to do that?

469 P: No, he never did. He never did. It was, we found him out in the garden. He had fallen
 470 and because his biggest problem, one that he falls because his balance is terrible but
 471 because of the right-side weakness he can't actually get himself up anymore. And so, he
 472 fell, we used to have hens at the bottom of the garden. And so, he'd gone down to see
 473 the hens. And the garden slopes and there's a sort of levels off, and a slope and it levels
 474 off. So, the slopes coming back up, he couldn't do it so he fell. But he managed on his
 475 hands and knees to get to the table. But he still couldn't get himself up. So, he just
 476 stayed there until somebody found him. Broke our hearts. It really did. I mean it was a
 477 dry day thankfully.

478 I: And he never thought to press?

479 P: No. Never. Never pressed it once. And then the man from doggie day care who is a lovely
 480 fella. And he's found him on the floor when he's brought the dogs home because we've
 481 got a key safe obviously. So, [man from doggy day care] just comes in and I heard his
 482 voice saying 'Oh [ex-husband], you're alright?' I was sleeping upstairs. And I came down
 483 and [ex-husband] was in the hallway 'I just can't get myself up. I just can't get myself up'.
 484 I said 'How long have you been there'. 'Well I knew, [man from doggy day care]',
 485 because you know he seems to have been able to work out that someone will eventually
 486 turn up. And he said 'I knew that he was coming'. Well, he doesn't give the dogs names,
 487 he can't remember them, but he knew the dog was coming back and. So, he said 'I,
 488 I knew, I knew the dog was coming back'. So, [man from doggy day care] and I got him up.
 489 That's happened a couple of times. So that's, that tends to be what he does is if he falls,
 490 he just stays there until somebody, you know, thinks 'Where is he' and will go find him.
 491 (He won't go calling for help?) No. No. No. He will literally just sit there or lie there on
 492 the floor.

493 I: Can you think of anything how you would like to improve that falls sensor that he has?

494 P: This is, this may be a bit far out but, you know how all our fit-bits and mobiles and
 495 everything are all connected. It would be good to think that, if you have an I-watch that
 496 has a phone in it and you can talk to people and everything on it. It's expensive but. If he
 497 falls thing that he wore was, the 99 percent that it could work out that you'd actually
 498 fallen over, but that you could communicate through it. (Mm hmm) That would be a
 499 good thing. Yeah. You know because, although if he's out in the garden it's supposed to

500 pick up. The only time he's fallen in the garden since he's had it and it didn't pick it up.
501 But he can't hear them because they're [intercom] here in the house so they don't know
502 what's happened. They don't know if it's an emergency or, if this is an emergency
503 because he's fallen. But if rapid response is for emergencies, how do you decide which
504 ones are important? And you can't communicate with them. And even if it could
505 communicate with the family you know. So even if it could, even if he could just say to it
506 'dial [participant] or [brother in-law]'. That would be a great thing.

507 I: Do you think he would be able to do that? (He would) Would he be startled by suddenly
508 voices coming from his wrist?

509 P: No, I don't think so. No because we get him to set his alarm off anyway and he speak to
510 the call centre as a test and they just say 'Oh well Mr [ex-husband], it's blah blah blah
511 from the call centre, is everything alright?'. And he speaks to them lovely. And I mean he
512 had his talking watch. He loves that. You know. I think if, if there was a device that he
513 could communicate with us when he fell, even if it's just because he knows we will give
514 him the reassurance and. With the best will in the world, there are times I have to leave
515 [ex-husband] on his own, even if it's just to go shopping or, you know, I don't even go to
516 the hairdressers anymore, the hairdresser comes to me and. But, you know it just
517 happens that he is on his own, you know, for the shortest time he can, he can manage,
518 but he's still left on his own. He can't work the phone anymore. The phone's a no-no.
519 (So, even picking up an answering?) No, he doesn't do it anymore. He just lets the
520 answer machine take it. Unless he sees our names, because our names come up on the
521 phone. So, say for instance I've been taking [daughter] for a new pair of shoes and
522 [daughter]'s been 'No, no I don't like them, I don't like them'. She's 29 going on 6, you
523 know. So, I've said I'll be two hours but I'm not, you know, we're still sitting in [area]
524 trying to decide do we want that colour pink or this colour of pink. And then I'll phone
525 him, so, my name comes up on the phone. So, if he doesn't answer it the first time, I'll
526 speak to the answer machine 'it's just me, I'll phone you back in a minute'. And, because
527 his eyesight is not fantastic anymore. But if he reads your name, [brother in-law] or
528 [daughter] or [participant] he would pick it up. Because often it maybe takes two
529 attempts because it's the button, he doesn't know which button to press. And he never
530 hangs up. But that's fine as long as he knows that we're on our way home. Yeah, but
531 yeah, something like that. Something that you could say 'phone [participant]' and it
532 would work. (Yeah). You know that, you know, I can speak to my iPhone. And when I first
533 got my phone it was fabulous. I could just say to it 'text [friend], I'm going to see her in
534 15 minutes' you know, and whatever, and it would do it just like that. But since you had
535 all the upgrades on these things it doesn't understand a word I say anymore. So, it has to
536 be pretty good technology. So, um, see, accents are difficult, not that [ex-husband]'s got
537 an accent because he actually hasn't got an accent. And. Yeah, that would be terrific.
538 And the fact it would be fool proof. So, when he did fall, it would definitely know that
539 he'd fallen, and not just 80%. Because I've actually thrown it on the floor and it hasn't
540 worked. (Mm hmm, that's weird) It is. Yes. Yeah. (Have you told the OT about that?)
541 Yeah, they said that it's only 80 percent. And, you know, that it only works 80% of the
542 time.

543 I: Is there any other technology that you are currently using? (No, nothing) So, a bit of an
544 abstract question, if you had a magic wand, if there were no limitations whatsoever,
545 what would you like technology to do for you? In regards to caring and combining work
546 and care?

547 P: Well, I suppose, being able to see, when you're sleeping, being able to see that he's
548 actually okay and talking to him, you know. You see these adverts on the telly with
549 somebody coming to your door with a delivery of whatever, and there's a camera. That,
550 that would be superb. Not to spy on him, because that's not what it would be about at
551 all, but it would be nice to know that he's safe. He's in his bed and he's watching the
552 telly. And even to be able to do it from downstairs to upstairs, you know, that I don't
553 have to go, it's just walking up the stairs 25 times that day you just think, you know 'Oh
554 no. [ex-husband] come on, what are you doing now?' And then you get up and you
555 realize he's not fallen at all, he's just tried to open his bedside cabinet and that's what
556 you've heard banging. You know, so even for his room to my room, you know, if I could
557 even just put my phone on, I take my phone to bed, you know, you can get a wee screen,
558 can't you and see 'Oh, he's fine' and then you can rest easy. Yeah. Just like a baby phone.

559 I: Yeah. So, that will be something that you would use at home when you are sleeping, not
560 at work?

561 P: Well yeah, I could. Yeah. That's the thing, I could do it wherever I am. It would be nice
562 just to dial up your house and it shows you that the dogs are behaving, because they run
563 rings around him for a packet of biscuits. And see that he's ok, that he's watching the
564 telly or sitting, or, you know, is not in any discomfort or what have you, and that he's
565 okay.

566 I: So, if for peace of mind?

567 P: Yeah, exactly. That would be terrific. Because, you know, we do phone home. He doesn't
568 always answer the phone. And then the buttons get a bit dodgy, and there's no point in
569 having these phones that have the big buttons. They don't have cordless phones. So,
570 well that's a pointless thing because my generation, I mean, I remember when you were
571 stuck just sitting at a seat beside the phone table. I mean. He doesn't even remember
572 that now, he picks up a phone and expects to go wherever, he'd pull it down from the
573 wall.

574 I: Can you think of anything else that would make it easier for you to combine work and
575 care? It could be technology, or it could be not technology related?

576 P: To combine work and care, well, I'm, I would like to be able to work less. And, and to do
577 that we would need financial help from the government. And we don't get any. Well [ex-
578 husband] gets his pension and, and [ex-husband] always paid upper-rate for his
579 insurance. Because [ex-husband] used to have a very good job, years ago anyway, he
580 worked in the print trade. So, he earned a lot of money. And we were always thinking
581 about our future, that was very important to us. And. So he gets, he always paid over
582 and above. You could pay the lower rate, or the ordinary rate or the higher rate. And he
583 always paid the higher rate. So, his pension's a bit more than your average. And, we now

584 get PIP, Personal Independence Payment, and again that was a total fiasco. I can see why
585 people don't even attempt to do that. The form itself is like War and Peace to go
586 through, it's mundane, it's repetitive, it almost feels like it's trying to catch you out on
587 different questions, you know, because you're answering the same thing in a slightly
588 different way. Every bit of it. And then he was told that he wasn't going to get it. So, we
589 had to appeal against it. They came out to the house and da-da-da-da-da. Anyway, it the
590 end we did get in and that's how we got the car. Which is absolutely fab, we can get the
591 wheelchair in the boot, we can get his walker in it and stuff. It's been brilliant. And again,
592 we got the OT to put all the equipment in so that we can get him in and out the car, so
593 he's got a turntable and a hand grip and such like. We had to buy them obviously. So,
594 that's it. He gets his pension and he gets PIP, because I, I work full time and [brother in-
595 law] works full time and [daughter] works full time, we aren't entitled to anything. Yes,
596 we all live in the same house but we all have lives and our money is all put together
597 which is a bit unfair really because [daughter] doesn't earn a fortune. I don't earn a
598 fortune. I work for the council. I mean yeah, it's better paid than a lot but it's not
599 fantastic. So, financially if I could go to part time, that would make a massive difference
600 to my life. But then we would be losing six, seven hundred pounds a month. I couldn't do
601 that. No. So, we don't have a lavish lifestyle. It's pretty basic. We don't go anywhere on a
602 weekly basis. I mean, we were at the Highland Show but that's an annual event for our
603 family because we love animals. We love the Highland Show. And it always comes down
604 to money, at the end of the day, everything is about money. We leave lights on in the
605 house, so, it costs more electricity. The tumble dryer's never off because of the washing,
606 the washing machine's never off. Ironing. You know. All these things. And if you think
607 when [ex-husband] finished his work to now, what we pay for gas, electricity, telephone.
608 [ex-husband] wasn't earning a bad wage 10 years ago, and I've had to work more and
609 more and more and more to pay for all those things because of all that but his pension
610 hasn't gone up. (Mm hmm.) So, the only thing that keeps us afloat really is the car. The
611 fact that we get the car and we don't have to pay for the car. (Mm hmm.) That is a
612 godsend. But my daughter applied for a PIP because she had to have her car, and she's
613 just been refused her car. She went to appeal, and she was refused again. So that's been
614 very difficult. But there is no financial support for us. No. And. It's. It's not like we earn a
615 fortune. And it seems a bit unfair, you know, it seems really unfair that all our savings
616 have gone. Any savings that we had have definitely disappeared, even for just day-to-day
617 living, you know. And he goes through his clothes like nobody's business. But. Anyway.
618 That, that would be the only benefit to me, to be working part time, not having to work,
619 actually I'm not sure I could not work at all but. Because it's an escape as well, and I
620 know it's an escape to the same thing, but you've got your colleagues and you know, you
621 talk about different things. So, although you know, so I'll come back to work tomorrow,
622 you think 'oh no' but once you're there it's different. But part time would be brilliant,
623 two nights a week that would be the ideal. But apart from the finances, there really isn't
624 anything else. You know, we rub along all right. We booked a holiday, we've got a place
625 that we could take [ex-husband]. And this is all [ex-husband] orientated, as is our whole
626 lives. And that can take its toll. And, like [daughter] and I are escaping in November for a
627 week's holiday together. I'm so looking forward to that. But our family holiday, we
628 always have a family holiday, every year, and we try and do it with extended family as

629 well. But this year it's just the four of us. And, again it's [ex-husband] orientated. 'Where
630 would you like to go?', to Longleads safari park. So, a few years or a couple of years ago
631 now he wanted to go to Chester Zoo and we stayed there for a few days and he loved it.
632 So, we rented a property down in Somerset which is all on one level for him. He's got his
633 own bedroom, his own wet room, everything that you could want. And so, we've taken it
634 for a week, so we've got two days at Longleads for him and a few other things, so that's
635 our family holiday. But then [daughter] and I are going off to somewhere in Spain, warm
636 anyway. But we had a big family holiday last year. But it was difficult with him, it was
637 difficult. Because it was all, all our nieces and nephews. And last year, because they miss
638 the [ex-husband] that they used to know, because he was so much fun you know, and
639 they remembered him as being, you know, the daftest person on the planet. He used to
640 take them in the car and take his hands off the steering wheel and they remember things
641 like that. You know, he used to push them down the hills in shopping trolleys, I hadn't
642 known anything about that. But they remembered. I mean, unfortunately, one of our
643 nephews was diagnosed with terminal cancer last year (Oh no, I'm sorry). And, so we all
644 put into the kitty and all went to Cyprus. Took a big villa in Cyprus. It was a struggle
645 getting [ex-husband] on the plane because he was adamant that he didn't need the
646 assistance. And, because actually his condition is hidden, you know, you take his arm and
647 he's walking, yes, he's slow. You probably, today, seeing him today, think that there's
648 something not quite right there, but last year you wouldn't until you spoke to him. Just
649 looking at him he was like any other ordinary person getting on a plane. Hidden
650 disabilities can be very frustrating. Extremely frustrating when you're going through
651 security and he's not doing what he's told. (Oh dear.) But anyway, a very nice lady from
652 the airport came and I explained and she, they actually have lanyards at the airport,
653 green ones, so that would show the security people that you have a hidden disability. I
654 didn't know that existed. (That's really good to know) Because he wouldn't do what he
655 was told. At least we weren't in America (Oh my god) [both laugh]. That would have
656 been a different issue altogether because that was his favourite holiday actually, was
657 Miami, Florida and New York he loved. No but a, (Yes, many things that you don't ever
658 think about really), you don't know, because you just take your case you put it on the
659 thingy belt, take your belt off, take your shoes off. Whereas he's going 'Why do I have to
660 take my shoes off?' 'Because it's security' 'But what's security got to do with my shoes?'
661 '[ex-husband] you just take your shoes off' 'No. I'm not taking my shoes off. I can't get
662 my shoes back on if I take my shoes off'. Which is true actually, it's very difficult for him.
663 And you know, they were getting a bit stressed about it. And we thought, we can just
664 walk through, we had all the extra bags checked in, you know, we didn't have to carry
665 anything so 'Just do that [ex-husband], you have to walk straight in front of you, and
666 then a man will come and say come on and you just walk right straight through'. And
667 then he had his trainers on, and the guy said 'Will you take your shoes off' 'No, no'. He
668 went trough and it went beep 'Have you got your belt on?' 'Yes' 'You have to take your
669 belt off' 'I'm not taking my belt off'. Really anything just to be aggravating. And then he
670 refused to have assistance to get onto the plane. Well it was quite tricky. (Did you have
671 to go up the steps?) Yeah. But that's what he wanted. We didn't want to stay in a
672 wheelchair. We wanted to go up the steps. Now, I mean, it takes 15 minutes for him to

673 go up the stairs. Now he couldn't attempt the steps actually, he just couldn't. But last
674 year. Anyway. We got to Cyprus and we got home again.

675 I: Sounds like quite an adventure [both laugh] (It was worth it though, we all had a good
676 time). Yeah, I can imagine. So, I just have a few more questions, if you met someone else
677 in a similar situation, who was also combining working looking after someone with
678 dementia, what kind of advice would you give that person?

679 P: Don't accept what you're being told. And by anybody, and that includes professionals,
680 anybody. Right down to the incontinence nurse. If you feel that there's something wrong
681 with that person, keep going. And you know them better than anybody else. You know if
682 there's something wrong. And access as many services as you can for yourself. Don't
683 wait, because I was maybe a bit slow and expecting things to happen and they didn't. It's
684 tiring, it's frustrating. But, get your GP on board and get yourself a social worker as soon
685 as possible. So, contact the council and ask for an emergency, cause that's what I did in
686 the end for [ex-husband] in the house. I go, I phoned social services, and I explained that
687 I needed somebody to come out and assess [ex-husband] because he was falling all the
688 time. And she said to me 'would you class that as an emergency?'. I almost said no,
689 because again you go back to work, and you think 'can I go or would that be an
690 emergency? No, actually it wouldn't'. But then I went 'yeah, yeah it's an emergency'. So,
691 we got an emergency and referral, and somebody was out within two days. So, do that
692 because actually it is an emergency for you. You know. And. So really, try and access as
693 many services as you can. And don't give up. And. Write everything down, (That's good
694 advice) everybody that you speak to, write it down, ask for the name, write down the
695 time of the phone call, why you phoned, what the outcome of a phone call was, did you
696 feel as if you've been fobbed off. All of it. Because I wish I had done that from the very
697 beginning, because I can't remember. I don't have a terrific memory. I used to have a
698 spot-on memory, it's changed. Maybe you're just losing brain cells. But my memory is
699 not what it was. I could remember a conversation word for word a few years ago. But
700 not now. So yes, that would be my best advice. (That's really good advice) Write
701 everything down, when you phoned, what time you phoned, who you spoke to, how
702 long, everything, because they can record all of these calls. So now I've done that, I've
703 done that with a certain District Nurse, I've said to her 'If you record the calls, you go
704 back to when I spoke to whatever her name was two weeks ago, you know, and she
705 didn't say the same as you'.

706 I: Hmm. Mm hmm. Mm. Hmm. That isn't really good advice. Thank you for that. Um. Can
707 you identify any positive aspects as well of combining work and care, being a carer?

708 P: I think the only positive coming from it is, I know what's coming. And we are future-
709 proofing the house. And. So, as a family we, we have discussed that [ex-husband] will
710 not go into care unless medically we can't provide for him at home. But even, you can
711 get a hospital bed at home now. So even if he did need, you know, I.V. fluids, although
712 we have discussed all that, we don't have a DNR in place, but we have an anticipatory
713 care plan in place. So, basically, if [ex-husband] needs to be resuscitated, if it's not going
714 to benefit him, it's not happening. So, if he's already got to the stage where he has no
715 quality of life he wouldn't be resuscitated. So, chances are [ex-husband] will end his life

716 at home. I can see the future. I know what's coming so we have planned all that. And the
717 fact that I can talk to people at work and they understand. And I think I'm just maybe
718 more aware of, he's not aware of what he's doing. And I can see that for some spouses
719 and family members, they must think to themselves 'This is crackers, just madness. How
720 can that person turn into this person'. And I can see that that's fine, because that's what
721 happens. No, they're not the same person. That person is no longer there. And the fact
722 that I just look out for things that maybe people wouldn't, you know, check his teeth,
723 nails, skin. Oh. I'm on the ball with all that, and all that. I know how important very small
724 things are. Because then people are ill they forget bedsores, or they get sores of any kind
725 and they don't heal like they would for you and I. You know, that, that's, that's a benefit.
726 And I think, that dealing with professional people as in the doctors at the hospital, the
727 nurses at the hospital, all of them, they don't, erm, they don't intimidate me. I talk to
728 doctors all the time at work and you know CPNs, and they don't intimidate me. So,
729 they're just people who can make mistakes too and they often do. So, yeah, I think from
730 that side of it, I think I've benefited from that. I don't feel like I need to be a little mouse.
731 Yeah, I can be 'Well actually no, I don't agree with that. Yeah. Why do you say that. Why
732 do you think that? No, I'm not doing that, or [ex-husband] is not doing that'.

733 I: So, to be a bit more assertive? (Yes, exactly, that's right) So, we're nearing the end of the
734 interview. Is there anything that we haven't talked about that you think would be would
735 be good to speak about? Have we missed anything?

736 P: [long pause] It was really all about communication, isn't it? And I think, we talk about
737 dementia on the telly all the time. But it's always very basic dementia and there's a lot of
738 dementias as you know. I don't think it would be a bad thing for people to be aware that
739 it's not just old people, it's not. Young people get it. And it doesn't make them bad
740 people. We need, we need, we don't need care homes. This is my biggest problem here.
741 You think of a care home, you think of elderly people all sitting in a semicircle in front of
742 the telly. And that goes back to when I was a young girl. And that is still happening today.
743 They're still sitting in a semicircle in front of the telly. People with dementia aren't going
744 to sit watching the telly. They're going to get up, they're going to wonder about, they're
745 gonna pick other people's things up, they're going to put them down in other people's
746 rooms, they're going to get undressed, they're going to be incontinent, they're going to
747 spill things, they're going to shout, a lot of them don't like loud noises, and in care
748 homes the volumes of the telly are a hundred because of so many deaf people. There
749 has to be an area where people with dementia are with demented people. And that area
750 is safe. So, we don't want, we don't want it clinical, we want pictures on the walls, but
751 we don't want idiotic cabinets, glass cabinets that they can smash. Ornaments that they
752 can pick up and hit people with. They need, they need a safe environment. Almost like.
753 Um. Like the homes for youngsters, they've all got their own little flat but there's a
754 communal area. That, that would be beneficial. Putting demented people in with people
755 that aren't demented it's actually quite cruel. And that's one bit of my job I find very
756 frustrating. I don't, it doesn't bother me working with people with dementia. I mean, it's
757 taxing. It's challenging it's all that. And there's days that I wish I had worked in TESCOs.
758 But, I feel more compassion for the ones that are in care homes that don't have
759 dementia for having to live with it every day. Through no fault of their own apart from

760 the fact that they're just old and they need care. So, I think we have to be more aware
761 and don't bundle everybody in together. And. Because there's nowhere for people with
762 dementia, apart from care homes. And care homes haven't got qualified people to deal
763 with it. And they don't, really, really don't.

764 I: That's an excellent point. Just to finish up, I just have a few brief questions for the
765 context of the interview. Can you tell me how old you are? (53) And how old is [ex-
766 husband]. (He's 67). Quite an age gap. (Yeah, yeah. There's 15 years between us.) What's
767 the highest level of education that you have?

768 P: None. I don't have any. And I have severe dyslexia. And my schooling was non-existent.
769 It's a difficult topic. My dad died when I was very young and, and I was the fifth child
770 from my mom and dad but 23 years younger than my oldest brother. So, they had grown
771 up and left home before I was born. And. I'm not sure why my mum didn't do something
772 about my dyslexia but anyway she didn't. We moved from a very, very rural, rural as in
773 the middle of nowhere, to [big city] when I was eleven and I was put into secondary
774 school which was very difficult. I was told I was stupid. To be fair, all my school life I
775 don't remember a good day unless we were doing sport. I was good at sport. And we
776 used to get the belt in those days as well. You know so. Oh yeah. Yeah. So, they'd give
777 you homework, I couldn't do it, 'come and get the belt and sit in the back of the class'.
778 Given more homework, couldn't do it, got the belt. I mean, it was just a constant thing.
779 So I would try to avoid school at all cost, anyway, down South I walked out and said I
780 wasn't going back. With it being [big city] there was much more options around rather
781 than just going to school, so I went to a home tuition centre which was actually for
782 young girls that have babies, and they all had babies. I didn't have a baby and I was never
783 doing that. And I did it once [daughter], anyway and so they managed to get me to pass
784 very basic English. I did English, maths and child development, and to be fair, it was
785 really them that did it. And from the time I left there at 15 and a half I have, on my own,
786 nobody else has helped, tried evening classes. A big plus when I came back to Scotland,
787 because I lived in [big city] for over 20 years before we came to Scotland, did lots of
788 evening classes, trying to get somebody to help me because I knew I wasn't stupid. But, I
789 wanted a job, I wanted to earn money and it was all rubbish jobs, cleaning jobs, bar
790 work. And again, I have a good memory, my memory was terrific when I was younger.
791 And it was amazing how much I could remember. Numbers, always brilliant with them.
792 Letters, you can just, you know, throw a bunch of letters together and I couldn't even tell
793 you, but I could spell words backwards, but I couldn't spell. You know even to this day I
794 still write certain words backwards. But, a few years ago, well, ten years ago, I had
795 another dead-end job, a cleaning job. It was horrible. And I've heard that the
796 government were doing schemes to help people with dyslexia. And so, I thought 'Right,
797 I'll get myself down to the job centre', cause I've had it, you know, even most my family
798 still don't even know I have dyslexia. Down at the job centre, they got me an
799 appointment with an educational psychologist, sent me to a consultant, so I went there,
800 they did an IQ test. I was above average intelligence with my IQ test, so they took me in
801 to test me for dyslexia. And the report came back that my dyslexia was so bad that there
802 was really no hope for me to have career. And that the job that I had as a cleaner at that
803 time, that that would be the best I could, I could achieve in my life. And unfortunately,

804 that knocked me for six. And for two years I didn't do anything. I went into deep
805 depression, didn't eat, didn't sleep. And my neighbour next door, she said 'Why don't
806 you join the [organisation]?' And I was a qualified nanny all those years ago. And. So I
807 thought 'Looking after old people, why not? I'll try that' because I'd worked for agencies
808 in [city] doing the same. So, I got a job at [council]. And it was much better paid. So, I
809 thought 'This is great. Now I'm going to pay for a dyslexic teacher. I am going to have a
810 career. I'm not listening to any of this rubbish'. So, I did. She lives 10 minutes from me, I
811 go twice a week. And she again tested me for dyslexia and said it was really terrible. And
812 she could see just by the way that I was writing that I taught myself to write because I
813 don't do it like other people, I don't write like other people, you know, even to write
814 numbers. Certainly, I was never taught to do in class and she could see that as a teacher,
815 you know. But she, she worked absolute wonders, absolute wonders. And, I mean, I got
816 my SUQ2, I got my SUQ3. And I am qualified to do the job that I'm doing and still do
817 qualifications now. I did, study at University for dementia, 'living well with dementia' and
818 passed that. So, yeah, I still have trouble with spelling, but you know I've got an iPhone
819 now, it's not the end of the world. You know, I get by. And so no, I didn't have any
820 education. Any education I've got, I've got in my 40s, I didn't get any. (Mm hmm) [ex-
821 husband] on the other hand is a very intelligent person, very, you know. Not that he got
822 any qualifications either but. Um. I think, in a different time, a different place, with
823 different parents [ex-husband] would have gone to university. I think because of his
824 Asperger's he was very frustrating to his mum. And she couldn't wait to get him a job
825 and get him out of the house. But he did do night school and he did English literature at
826 night school and all that sort of stuff. Could do the Telegraph's cryptic crossword in an
827 hour. And now he can't even spell. It's so scary, isn't it? Sorry. Right. You didn't need to
828 know all that, I do tend to ramble. Just tell me to stop.

829 I: It was very interesting. Very inspirational. Thank you for sharing. That really concludes
830 the interview actually. So, thanks again. Going to end now.

831 END