

Interview 6, “Flora”

Date: 28.3.2019; Duration: 115min; Setting: participant’s home

I = Interviewer, P = Participant, O = Participant’s daughter (present by wish of participant)

I: So to start can you maybe tell me a bit about your caring situation, how did that come about, how did you become a carer?

P: Erm, well it’s been what, two, three years now? And my mum’s always had medical problems like osteoporosis and, erm, blood pressure problems and things like that, erm, and then two years ago, my dad was diagnosed with dementia (mhm), erm, vascular dementia he has, and since then, my mum’s physical health has deteriorated as well so I’ve been looking after both of them (mhm), and initially it was just to make sure that they were okay and things but as times gone on, now I make the meals, I do the housework, I take them to their appointments, I do absolutely everything (mhm). Erm and then last Nov-, erm last September, my mum was diagnosed with Alzheimer’s as well (mhm) and she has deteriorated in that respect quite quickly (mm). Erm so there’s various things, we think she’s had it longer than (mhm) just the six months because she had been putting on-, she had been put on antidepressants (mhm) prior to that, to get her mood properly checked, so they couldn’t test her (mhm) until they got her mood proper because the two are quite similar (mhm) in the symptoms, in depression and Alzheimer’s are quite similar so, erm, as I say it was in September, they had got her mood and everything (okay) sorted, and that’s her.

I: Erm so you talked a little bit about the tasks that you’re doing for you parents, could you maybe talk me through that a bit more, what is it that you-

P: There’s-, at this moment in time and if mum had been at home (mhm) erm, the-, I would go over Aldi at the weekends and that would include taking my dad to go for the shopping (mhm), erm, doing the housework, whatever was needed, changing beds, washing, ironing.

O: Top to bottom...

P: Eh? Top to bottom (laughs), cleaning bathrooms and things like that. Erm, what I would do is also my mums personal care (mhm), because she’s incontinent as well and she wasnae very mobile, I would like change her pads, empty the commode(mhm), erm that sort of thing. Empty the buckets that the pads and everything go into. Erm, I would take her for showers (mhm), get her showered and things like that, erm, dry her hair, do her hair (laughs). Erm...

O: Medication...

P: Yeah I would make up my mum’s pill box erm, to erm, make sure that she was taking the right medications at the right time. Erm, I would make their lunch, initially, my dad would see to breakfast (mhm), and he would, at lunchtime make soup (mhm), erm, or heat up a couple of tins of soup, erm, for their lunch and I would just do the main meal (mhm) at night but that’s changed now as well because my dad’s forgetting to have anything(mm). So yeah, erm, whenever they got any sort of financial things in, I have to look at that (mhm), look at their

39 entitlements to things, I've had to find out about that sort of thing. Erm, I go to the bank for
40 my mum, erm, my dad, he often forgets his pin numbers and he's actually forgotten how to
41 use the machine at this moment in time, erm, so I go with him so that he can withdraw money
42 and sort that things out. I also-, erm, their medical appointments, I make appointments for
43 them, I take them to their appointments, erm, so that somebody's there (mm), to know what
44 the doctors are actually saying (mm). So-, and it's a wee bit difficult because they're at
45 different doctor's surgeries (laughs) (hmm). Erm, we have been waiting since last June for a
46 care package for my mum (okay), and we've basically got nothing at this moment in time and
47 it's only because she's been in hospital (mhm) that they're now saying we're gonna get the
48 care package (mhm), er, she's going to be given priority for that.

49 I: How long has she been in hospital now, altogether?

50 P: She's coming up four and a half weeks since she's been in hospital now. And we've still not
51 got any sign of the care package. Initially before she went into hospital, we were-, we had
52 decided that we couldnae wait any longer so we we're going to go down the private route
53 (mhm) but unfortunately she went into hospital just before we could get it started (mhm). So
54 that's all had to be cancelled and erm, things. So it's going to be the council that are going to
55 provide the care package which is better for us but unfortunately she's stuck in hospital until
56 that time.

57 I: Did she have to go into hospital because of hip problems or is there something other...?

58 P: She has quite a lot of falls (mm) and she had had a couple of falls. The first time that, when
59 she fell, erm, just prior to-, she must have had what about a dozen falls over the last sort of-

60 O: She had two in two weeks, two or three...

61 P: Yeah and we didn't know it was actually the falls clinic that first said that she needs a care
62 package and that was back in June but before she went into hospital she had had two falls,
63 the first time we ended up, we sat and waited on an ambulance for about 5 hours.

64 I: No!

65 P: Yeah

66 O: It's not the first time either.

67 P: It's not the first time that we've had to wait that long. The first time that we had to take her
68 in (O: two hours or so of waiting) between, we had to wait for three hours for the doctors to
69 come, and then we had to wait seven hours for the ambulance, and then so it's-, it's pretty
70 bad out there [mm] so we...

71 O: Came in at 10 o'clock at night to come back again in the morning.

72 P: Mhm, that's right that's when she was at the [hospital 07:23], but anyway this last time we
73 had waited five hours for an ambulance, so we actually cancelled the ambulance and the next
74 morning, my sister, my dad and I, it took the three of us to get her out the house (mm). Took
75 her to hospital, she was okay and she was sent home. But this last fall, when they took her in,
76 they did eventually come and when they took her in to the hospital, they actually discovered
77 that she had problems with her kidneys, her kidney's weren't working (mhm) so well, so they
78 needed to keep her for that (mhm), otherwise they would have sent her home (mhm), saying

79 that there's no breaks or anything like that and she would have been sitting 'til now to say
80 that she didn't have a fractured hip. (O: she would have been bed bound) But she would have
81 been bed bound. So yeah, I do that, what else do I do?

82 O: Absolutely everything (laughs).

83 P: Yeah finding out their entitlements to things, that is, that is really difficult (mhm). Erm, [carer
84 organisation] helped me, erm, to get the care allowance (mhm) for my mum but they also
85 helped me to get the care allowance for my dad. This time he's only on the lower (mhm) care
86 allowance and they helped us with powers of attorney, erm, but the DSS or whatever they are
87 called these days, they didn't tell you anything, you've got to find out things by yourself (mm).
88 Erm, we-, I discovered that because my dad had dementia, erm, they were entitled to a
89 reduction (mhm) in their council tax (mhm) and I did put the forms in but the GP said his
90 dementia wasn't bad enough which I thought right, so we didn't do that. Then when mum
91 was diagnosed, there was a psychiatric nurse was coming in and she had said do you know
92 that you can get a reduction in your council tax and I said, "we already tried it", I says, "I got
93 the forms for mum", and I says, "but we already tried it for dad", and she was, she was
94 disgusted (mhm) erm, basically because she says it doesn't matter how bad it is, it is a severe
95 mental problem (mhm), erm, so she says, "you give it to us because for the dementia they are
96 under the same consultant", and she says, "give me the forms and I'll get them signed". So
97 she did, and they've ended up getting-, now they don't pay any council tax at all, erm, and
98 they were given a refund for all the time that they had been entitled to it. So-, but to be honest
99 with you, my mum and dad didn't understand it (mhm). At this moment, every time I say that's
100 the money from the council tax then, and they're like, "what's that for?", erm and you have
101 to explain it to them again. And of course, they've just had the thing in to say that this year
102 their council tax is zero, and mum, she's more concerned about, "but they'll not pick up my
103 buckets", and I go, "no mum, you've worked towards this all your life, this is because of your
104 age". I just tell her it's because of her age that you didn't have to pay it anymore, so there's
105 these things but there's also things for me that I've just stumbled across (mhm) and I've got
106 the forms through there because I had to give up, I had took partial retirement a year past
107 November because things were getting too difficult (mhm) to work full time and look after my
108 parents, and it was having an effect on me so, erm I took partial retirement so that I only work
109 three days a week but I do get a pension (mhm) to make up the money and so I wasn't entitled
110 to carers allowance (mhm) that they have, because I earn too much (mm) but what they didn't
111 say was because I'm only working three days a week my national insurance contributions are
112 less (mhm) and there's things called carers credit (mhm) and you fill in these forms and as
113 long as you're looking after someone for 20 hours a week, they make up your national
114 insurance so that my state pension is not going to be short because I've had to (mhm) [?
115 12:38]. I mean I'm not getting money in my hand but in the long term, now I'd just stumbled
116 on that (mhm) was one day I was looking on the internet and I was like, "what's this?", I'd
117 never even heard of this and I've got people at work that have got parents that are in the
118 same situations and they've been really good at telling me, "you could get this or you could
119 get that", erm, but none of them even knew anything about it (mhm) and that is where your
120 technology side could step in (mhm), to let people know what entitlement they might be able
121 to get (mhm). So yeah, that was...

122 I: Apart from technology, who would you expect to tell you about these kind of things, where
 123 would you expect this information to come from?

124 P: Well, I would kind of expect GP's, the council for a kick-off. I mean they-, everything's a state
 125 secret really (laughs) it really is! (O: it is.) They will give you no advice and they will give you-,
 126 they'll not sort of say to you, "well you're not entitled to this but you might be entitled to
 127 that", they never tell you that, they just tell you you're not entitled to that (mhm) and you've
 128 got to find out things, so I think the council play a big part (mhm), granted they're trying to
 129 save money (yeah) but...

130 O: They're still meant to be supporting you

131 P: Supposed to be sup-, yeah, exactly. Erm, especially in the elderly because they've paid their
 132 taxes all their lives (yeah) so the likes of them. There might even be a sort of dedicated (mhm)
 133 site somewhere but I donae know anything about. I mean even when we we're going to go
 134 down the private route for a care package, it was that the council would pay so much and we
 135 would pay the remainder (mhm) to the company. I had to try and find out that information all
 136 for myself, the council said, oh you can go down this what's called 'secondary care' or
 137 something it's called, you can go down that, erm, that route and I says, "but how do I go down
 138 that route?", and they went, "well you'll have to find someone to care for your parents and
 139 then contact us", (mhm) and that was it. And I was like-, I says, "do you have a, a list of carers
 140 in the area that I can sort of start with?", and they were like, "no, but you can go on this site
 141 that's called 'care sourcer'", and they gave me that and when I went on that, they gave me
 142 two companies that were in [location] (mm) erm, (laughs), you know what I mean it was like,
 143 one was really cheap and I couldnae get into their inspector reports erm, so in the end you
 144 got me a list, was it you that got me..? No it was [sister] my sister, she works up in [location]
 145 and she got a list that they deal with but that as you say it's not necessarily that they work in
 146 this area (mhm) so that was a starting point. And then I phoned [carer organisation] and erm,
 147 [name] she sent me a list of all the ones and she says that it's not an up to date list but it's a
 148 starting point and then ask [name] to have a look down the list because [name] at [location]
 149 as a carer erm, and she was sort of-, she knows some of the companies and she would say,
 150 "no, donae go near them (laughs), they've got a good reputation", and things like that so, I
 151 just basically hard to start working down this list (mm) er, to find carers. As it turned out, they
 152 were expensive but [care facility] were the ones that they said that they had availability
 153 (mhm), erm, they were expensive, and then I had to get in touch with the council and then
 154 the council, they were sort of going, "well they are not one of our carers but now she'll have
 155 to go on the list for us to assess her", so that they would assess my mum and then see how
 156 much they were prepared to pay for her care (mhm). And I was like, "how long does that
 157 take?", and she says, "oh, I can't give you a time", and I says, "well, is it an hour, a month or
 158 is it six months?", and she went, "well, it'll not be six months". And that's what I was left with
 159 and after that I just kept phoning them and pestering them (yeah), erm, which you didn't want
 160 to do because you know that they're struggling, but every time I phoned, I got a different
 161 story, erm, I even said to them, "well how much do you, so that we can work out our finances,
 162 how much do you pay an hour?", and it went from anything from £13 to £16 (mhm). So you
 163 couldnae, you couldnae work (mhm), work out your finances and what we could afford etc.
 164 Erm, eventually what they said was, I says, "look we need this care package and we need it to
 165 start straight away", and the occupational therapists had been out so what they had said was,

166 “well initially what we’ll do, is we’ll base it on what the occupational therapist said and we’ll
167 put in for the funding for that and we’ll let you know when we’ve got the funding for it”. And
168 I was like, “right, how long does that take?” and she was like, “oh I canae tell ya”. She says,
169 “we do have a bit of backlog”, (mhm) so it was like just fighting the wind really. Every time you
170 go a wee step, there was a big gust and it put you back again. It was really frustrating. As it
171 turned out as I said, the [care facility] were coming out to assess her themselves, erm, and she
172 went into hospital so [care facility] couldnae come out, erm, and now they’ve not got the
173 availability that they had before (mm). So, we’re back to square one but the good thing is that
174 I keep phoning erm, social work every week and they’re saying, they keep assuring me that
175 my mum’s getting priority and as soon as the package becomes available, she will get it. Erm,
176 but again it’s how long is a piece of string (yep, yep), and so we just have to just keep coping
177 until that time.

178 I: Sounds incredibly time-consuming having to organise all these things.

179 P: Well that’s it, it’s time that I could be doing other things, because by the time that I come back
180 from my folks, I’m tired (mm) but I still have to try and find out this information (mm) and try
181 and get things sorted (mm). Erm, even to the extent that I have to get their wills changed (mm)
182 and erm, because their wills were completely out of date (mm). Erm, in the end I just did them
183 myself (mm). You know what I mean, it was just like, I thought, “right”, I looked it up so that
184 it was legal and so we drew their (mm), their wills up ourselves and got them signed by
185 neighbours and things so, I mean it does, it takes a lot of time because your searching on
186 websites but everybody keeps telling you different things (mm), then you get things that are
187 only available in England and they’re not for Scotland (mm) and because we’re different sort
188 of governments and things but yeah, I find that the council keep everything a secret (mm)
189 (laughs). And it would be-, they’re the ones that know (mm) so-

190 I: Or should know at least.

191 P: Yeah. So why they didnae give out this information when they know that this is a couple that
192 are in dire straits basically because if it wasnae for me and my sister, they would have been in
193 care homes and it would have been costing them an awful lot more (mm). Erm, but it seems
194 to be the way it is at the moment and I understand that Brexit and sort of government
195 decisions are really pushing them, I do understand that. Erm, but I forgot what I was going to
196 say then (laughs). Yeah it’s just they make the situation worse for people (mm) rather than
197 better for people (yeah). Erm, and to be honest with you, even at this stage, other than the
198 occupational therapist, my mum has not seen, or my dad, neither of them have seen anything
199 a face, given a name of a social worker that is their care worker (mm) erm, or fighting for them
200 (mm), or anything. But to be honest with you, I did actually end up sending a letter to my MP
201 but unfortunately they canae get involved until I get mandates and everything (mhm) so that
202 they can talk to the council but as it turned out, this social worker did phone me back, because
203 at that point they were, everything was still up in the air (mhm). My mum was in hospital, she
204 wanted home, my dad was-, he was having panic attacks and things like that so I just wrote to
205 my MP (laughs). But I’ve since emailed him and said, “look can you put a hold on that because
206 it looks like they’re starting to get their act together now”, (mm) but yeah it seems to be if the
207 family just cope (mm), the council are quite happy for them to do that. It doesnae matter

208 what effect it's having on the carers health, the carers finances, nothing like that, as long as
 209 we're not bothering them (mhm) they're quite happy.

210 I: Do you think that things might be a bit different if there wasn't you and your sister looking
 211 after your parents, if they were alone, do you think that they might...

212 O: They'd be left in the house to deal with it their selves and that's already what's happening,
 213 ken what I mean?

214 P: I actually dread to think because they're the type of people that willnae ask for help (mm) so
 215 really they would probably be these people that go through the cracks (mm). I didnae know
 216 who would actually come out and (O: step in) step in. Because even when she went to the
 217 falls clinic it was because her GP was like, "no, I'm gonna refer you 'cause we want to see
 218 where these falls are coming from", as it turns out, apparently the Alzheimer's, people fall
 219 over (mm). It's part of the, the illness. But it's only because we got in touch with the GP's
 220 (mhm) that this came about erm, my dad would never have been diagnosed with dementia
 221 but I had noticed things so it was me that took him to the GP. Erm, and to this day my dad
 222 doesn't think there's a thing-, single thing wrong with him (laughs). It's just the government
 223 and everything because they're gonna take his driving licence away from him now and er,
 224 that's upsetting him (mm) (laughs), and he keeps like, say, "you're on this dementia
 225 treatment", and he's like, "no, I didnae take any dementia tablets", and he says, "how long
 226 have I been on them", and I'm like, "two years dad" (laughs). He just now, erm, because of his
 227 situation, because he's deteriorated that bit more, I have to make sure that he takes his
 228 medication as well, and make his medication up. He just calls me a sadist (oww), 'cause he's
 229 like, "you're just filling me up with all these drugs!", now when I go in, he just goes, "right"
 230 (laughs), puts his hand out and says, "right".

231 I: So, can you say on average how much time do you spend on all of these tasks that you do for
 232 your parents, so the practical tasks but also all of this organisation, is there-, (oh god) could
 233 you put a number on that?

234 O: Just dinner-wise, you're talking about seven, eight hours, nine hours a week just on dinner,
 235 that's just dinner.

236 P: Then about three or four doing the housework (mhm), (O: running back and forward) running
 237 back and forwards. I would say on the days that I'm off, you're talking about practically all day
 238 (mhm), so I would say at a good nine, ten hours on those days, so that's four days a week, and
 239 then a couple of hours-

240 O: On Saturdays you're there about two or the morning, you go and do your shopping for nine
 241 o'clock in the morning, you're there 'til back six, seven o'clock at night, so that's a full day
 242 (mhm), so you're talking full time like 30-, (P: yep) good 30 (mm) odd hours a week.

243 P: Yeah, I would say anything between 30 and 40 hours a week.

244 O: And that's when days are good. Ye know things have obviously like deteriorated a wee bit, it's
 245 becoming worse, I mean she's not got any time for herself at all and I keep on saying to her
 246 she needs to have time for herself but she'll no dare because she's constantly-

247 P: Basically, between work, I've been off for the last few weeks (mhm), with stress but when I'm
 248 at work, I work three days a week, and by the time I do everything for them, so I've got no

249 social life whatsoever (mm), I've not even got much conversation because it's all based around
 250 my parents (mm).

251 O: She doesn't even want to go to [place] just because she doesn't know what'll happen. We're
 252 only going for the day, we'd be back about eight o'clock at night but she doesnae want to
 253 leave them for that length of time, but she needs to have her own life as well, ken what I
 254 mean? And that's where the council...

255 P: Yeah so, I was dragged to [location] to get a massage (laughs). But even though I was there, I
 256 was phoning my dad, and saying, "right it's time for you to make your soup" (yeah). My
 257 nephew-

258 O: [Name] could see you were starting to get upset about it, ken what I mean? So, it's (yeah)
 259 constantly-

260 P: I do worry when I'm not there (mm), I do worry about them (mm), I've got to admit. Erm, and
 261 they're coming up on Friday, tomorrow (mhm), it's their 61st anniversary (ahh), so I'm sort of
 262 being, running around organising something for that because they've been separate, and this
 263 is the thing is that they're not used to being separated from each other (mm) erm so I've
 264 arranged with the hospital that they're not going to feed my mum (laughs) and we're gonna
 265 taken her a cream tea and get fifties music playing in the background and just leave them
 266 alone, romantic (I: that sounds really lovely). Because they've not a had a meal together or
 267 anything for weeks (mm) and as I say my dad has-

268 O: Visiting time's not really quality time...

269 P: It's not 'cause they've not got a lot of conversation so I'm going to take their wedding album
 270 and leave them with that, because that will give them something to sort of reminisce about
 271 because they can both, both remember that far back, they just canae remember what they
 272 had to eat (laughs). So erm I thought right, I'm taking the photo album and just give them that
 273 wee bit of time for themselves.

274 I: That sounds really nice.

275 P: We shall see. My sister, she's got erm, photos made into these blocks (mhm) and one each of
 276 them so she's gonna give my dad the one of my mum, and vice versa (aww) so that they can
 277 always be beside each other (yeah).

278 O: 'Cause even in the house they dinnae sleep in the same beds either, ken what I mean?
 279 Grandad went in the spare room because...

280 P: He went in the spare room because my mum was getting operations to her legs and things
 281 and he didnae want to hurt her and she was in a lot of pain so, erm, now he just goes through
 282 there, they're just like, ah it's fine. But they leave the doors open (aww), so that they can shout
 283 to each other (laughs) erm, and of course, my dad during the nights and things like that, my
 284 dad is well, but my mum was having falls. My dad was trying to pick her up so he ended up
 285 doing his back in (oh dear) erm, because I mean he's 82 this year so he's not fit for it even
 286 though-, but there's that connection that he cannae see her lying on the floor (yeah yeah).
 287 And she's got the emergency button, but she never presses it. She's only used it a couple of
 288 times but it's like, that what you've got it for, press the button and dad just put a blanket on
 289 her, make her comfortable. Erm, and then they pick her up and they tell me a few hours later,

290 "oh your mum had a fall today", and I'm like, why did you not press the button? (mm). And
 291 they were like, "oh I forgot". It's-

292 O: Makes you worry though 'cause if they even forgot that the fall had happened, you would
 293 hear nothing about it, ken what I mean?

294 P: Exactly, exactly. My dad had a fall a couple of weeks ago. He went to kick-, he went to kick a
 295 wee, a wee paper cup (laughs) and he just went right over. Now anybody else it would have
 296 been funny, but being my dad, I jumped out the car 'cause he was actually waving me
 297 goodbye, erm, (laughs) and I thought-, he was straight up and I'm saying, "have you hurt
 298 yourself?", because he had this sciatica because he's been lifting mum and says, "are you
 299 hurt?", "no, no I'm fine, I'm fine", and he says, "that was just stupid." And off he went. But
 300 the next day, I says to him, "how's your back? Are you ok after your fall?" and he went, "did I
 301 fall?", so if he cannae remember falling (yeah) just in 24 hours (mm), what-, they're gonna
 302 eventually forget that my mum's fallen (mm), so yeah, it's, it's, it's (I: it's difficult) it is difficult.
 303 I'll admit that (laughs).

304 I: So I would like to talk a bit more about your work, so can you maybe take me through a normal
 305 work day for you, what is that like?

306 P: Erm, I go into work at 7 o'clock in the morning (mhm), erm, I try to get there for seven (mhm)
 307 because I'm on flexitime (mhm), and erm, I usually leave around about 3 o'clock. I've got to
 308 work seven hours and 24 minutes in a day, I know 24 minutes but there ya go. That's a full
 309 day, excluding lunch obviously, so really its eight hours and four minutes (laughs), erm,
 310 sometimes I would take a half-day or I would leave early if there was appointments that I
 311 needed to come to (mhm) for mum and dad or if there was somebody coming to the house
 312 or something (mhm) like that. So...

313 I: Do you have control over that, or do you need to ask your line manager whether you can...

314 P: No, as long as we work a minimum of three hours (yeah) erm, then we can, we can please
 315 ourselves, we can please ourselves any time between erm, seven in the morning 'til nine at
 316 night (uh huh) so that's the sort of space (mhm) and in that time we have to work three hours
 317 (ok) but what three hours we do, but obviously we'll lose that time so have to make it up at a
 318 later time (mhm). So, on a Tuesday what I would do is, I would usually be in at seven and work
 319 'til half past seven (mhm) so that made me sort of roughly four hours credit that I can use
 320 when there're appointments and things (mhm) but erm, my present boss, she has been-,
 321 'cause I've been sent to the occupational (mhm) health because I've had sick leave and
 322 whatnot and they basically said that I should be given the time to go to the hospital for my
 323 mum or dad, they will make my time up for that day so that I'm not having to use my leave or
 324 my flexi. And she is really good, she is really good. Unfortunately, I just found out yesterday
 325 that she didnae get the job that she's been doing for four years, she had to apply for it and
 326 she didnae get it so. So, I'm going to get somebody else, who's not necessarily going to be as
 327 understanding as she is (mhm). So yeah, that's what I would do on a, and then a Wednesday
 328 I would be-, just try and do a normal day but night-time so it'd be 10, 'cause I'd have made up
 329 the time before, I would sort of think well I could have a couple hours, so yeah that's the
 330 general... I also have the ability because I'm only working three days, I can phone and say,
 331 could I swap my Monday for a Thursday (mhm), but I can only do that so many times obviously

332 (mhm) but also every fortnight I look after my great niece (laughs) (O: On a Thursday and a
 333 Friday) on a Thursday and Fridays to let her mum and dad get to their work.

334 O: She's too kind, that's her problem (laughs) to be honest that-, she genuinely is.

335 P: She's a wee gem, she's a wee bit of sunshine, that's what I always call her.

336 O: Aye, she is to be fair.

337 P: Erm, so I look after her, she's, she's just turned two (aww), so I look after her (ok) on a
 338 Thursday and Friday but we take her over, I take her over with me to

339 O: Takes her round to gran and grandad when she's got the bairn (laughs), then takes the bairn
 340 home, goes back to granny and grandads, makes their dinner, comes home, doesn't eat
 341 anything herself (laughs), barely has time to even get herself a shower.

342 P: Right, I think (laughs).

343 O: It is absolute true though you've actually not got a minute for yourself, and you don't give
 344 yourself a minute either. And if it's not that, she takes my other cousin's child overnight
 345 sometimes as well and I'm like-

346 P: Oh, that's only, that's only very occasionally...

347 O: That's not the point when you've not got enough time...

348 P: Just to let them have some time (laughs).

349 O: What about you having time?

350 I: Sounds like you're really, really busy (laughs)

351 P: I've got to admit, these last few weeks I've been exhausted, been exhausted. I'm on erm,
 352 antidepressants and I have been for about a year and a half and this wee while, because of
 353 when I got to my bed, I'm just not sleeping, so the doctor gave me some sleeping pills but I'm
 354 trying really hard not to use them (mhm). I'll probably use them more erm, when I'm back to
 355 work, 'cause I'm planning on going back to work on Monday (mhm), so just try and get some
 356 kind of normality going again. And erm, I need to sleep because I was finding that I was awake
 357 until three, four in the morning and things just going round in my head and whatnot so, yeah
 358 (mhm). It is having an effect on my health, I know that, but at the same time, I canny give up
 359 on my parents, you know what I mean? It's not just something that you've got a choice over.
 360 My sister, she's helping a lot more than she used to.

361 O: Aye, now she is definitely but I think that is because she has now seen the effect that it's
 362 having on you, but she never really got to that point anyway, and your brother takes
 363 absolutely nothing to do with her.

364 P: My brother's just a waste of space (laughs). Erm, yeah, he's just, he's been to see them once
 365 since New Year so...

366 O: That was to go and ask for money.

367 P: Mhm (mhm). So no, my brothers not really in the picture (mhm).

368 I: And how is your sister helping with caring?

369 P: She, she'll, she works erm, at [hospital] (mhm) so erm, obviously she works long shifts so when
 370 she's working, she cannae do anything (mhm) erm, but on her days off and things she's going
 371 over, she's doing that and then she's sort of helping with that. She's been in and out (mhm)
 372 as much as she can to the hospital and things.

373 O: She definitely has probably the last three or four months, she's definitely more hands on
 374 because before my [aunt], she does mean well but she's that wrapped up in herself and her
 375 wee life and her grandchildren and her husband and her friends and it's like, you've got your
 376 own parents and your sister, remember?

377 P: But she's doing the right thing as well, is she's doing sort of the opposite of me. She is making
 378 time for other things (mhm) and times for her.

379 O: She used to be a wee bit too selfish, and my mum was a bit too selfless if you ken what I mean.
 380 It was like total chalk and cheese when it came to it.

381 P: But [sister] stepped up (O: much better) much better er, and as you say, she's worrying about
 382 me as well because I think they realise that if I go down, we're all going down (laughs), you
 383 know what I mean? (mm) And that actually worries me a lot (O: me too) and I do worry about
 384 kinda, if anything happens to me, where is that gonna leave my mum and dad? (mm). And
 385 that's why I'm really pushing for this care package because I need it.

386 O: Your daughter, what about your daughter?

387 P: You'd cope, you would come and look after me (laughs).

388 I: So how would that usually work between your sister and you, erm, are you co-ordinating in
 389 any way?

390 P: Well at the moment when [sister] is not working, she'll go into hospital at one point and I'll go
 391 in at night or vice versa depending on the, the sort of routine. When mum was at home, she
 392 would go over on her days off and she would help with the ironing or she would-, 'cause I hate
 393 ironing (laughs), erm, so she goes over and she does the ironing, she's really good at it. Erm,
 394 and she'll, she'll do sort of things-, the only thing is that my dad, my dad disnae, (O: it's her
 395 approach, ay like) it's her approach, is he says, she means well but she's so bossy (mm).

396 O: She comes in and she just takes over and it's their home at the end of the day (P: aye), ken
 397 what I mean, you've got to respect that.

398 P: And they have come to loggerheads a couple of times but at this moment in time because
 399 mum being in the hospital, he's, he's, he will not go in with my sister (mm), 'cause I say,
 400 "[sister] is gonna come and pick you up", "what have I done to you like" (laughs). This is the
 401 thing and it's not that he doesnae love her or (O: nah, nah), it's just that he feels she takes
 402 over too much (yeah, yeah).

403 O: You're more laid back.

404 P: And it's partly her job as well because that's a job that she does, she's a care worker in a
 405 rehabilitation place (mm), erm, so it's hard to sort of-, she comes across too professional
 406 rather than-

407 O: She's a wee major

408 P: She is. Real bossy boots. But as I say, her hearts in the right place and these last few weeks,
 409 she's been phoning me and saying, right you are having a day off (mhm).

410 O: She'll give herself the day off still, she still has to go over and-

411 P: Well, I just nip in and check in the morning to see that he's ok, 'cause he does seem to be-, he
 412 washes in the mornings (mm). To go and find him (laughs). But she, so she goes and she'll say,
 413 "no, I'm going over to make their tea", 'cause I'll say, "well if you take dad to go and see mum
 414 or whatever", I says "I'll be there to make his tea when he comes in", and she's like, "no, just
 415 tell me what's to make". So, I do but I feel very uneasy on those days (mm), especially when I
 416 go in and see my mum, the following day and she went, "oh, you've come to see me have
 417 you?". And she's like said to my sister, "and you're coming back to see me?" (laughs) "no,
 418 she's just having a day off, she needs a day off" (O: aye). And then when I do see her it's like,
 419 "are you back at you work yet? You need to get back to your work", it's like, "yeah mum".

420 O: It's quite funny 'cause last time we went to visit them, granny was saying, "she, your mother
 421 does too much hen", blah, blah, blah but see when she's not there like, on the floor, "are you
 422 coming out to see me?", (laughs).

423 P: That's it (I: tricky) (laughs).

424 I: That's really nice I think, that you have someone to share this with.

425 P: Yeah. As I say, [sister] has taken a more sort of practical role and she's been going over through
 426 the week because on a Saturday I can be over to get mum showered, erm, but she's going
 427 through the week (mm) on her days off, and she's giving her a shower through the week (that's
 428 good). Erm because I find that, it's a shame because my mum had a shower every day of her
 429 life (mm) erm, and the house, she was so house proud, ay? And it's really difficult to-, for her
 430 not to get these things (mm) every single day but she excepts that now, but she was always
 431 like, "am I smelly?" (laughs), and things like that (mm).

432 O: She was always quite self-proud, with like her hair (P: she was) was always done and she had
 433 those scarves.

434 P: That's right. But she got her hair cut and blow dried at the hospital yesterday

435 O: All curly now.

436 P: It's still straight (O: is it?) but it's been done a wee pixie style. It's really nice actually. But her
 437 hair's pure white and she hates it (mm). I says, "do you know how much?", and of course I'm
 438 going the same way 'cause it's a family thing. All the women on my mum's side of the family
 439 (O: pure white) have got pure white hair. And so, mine's on it's way.

440 O: Dodging that bullet.

441 P: So far. My mum was 16 when her hair went white. (I: 16?) Mhm (wow) and mine started when
 442 I was 20, 'cause I kept saying I'll just let it grow like that gracefully, I'll do that. And the first
 443 one I saw, the bottle of dye came out (laughs). And has been ever since (laughs).

444 I: Just to talk a bit more about your work, erm, so the flexi time, is that a general policy or is that
 445 something that you were able to negotiate for your own individual situation.

446 P: No that's, that's the same situation for everybody.

447 I: For everyone, ok. And are you able to work from home in your work?

448 P: No, no.

449 I: No, so it's very office bound?

450 P: Yes. At this point I think they are sort of starting to look towards home working because there
451 are some people, it depends on what job you do (mhm), erm, that can do work from home,
452 but my job, it's plans based so I have to be in (mm) the office.

453 I: Ok. Are you able to take breaks when you are at work, whenever you need to? For example,
454 to make a phone call?

455 P: Oh yeah, yeah, yeah. Erm, funnily enough they took all the phones off us (laughs). Yeah, we're
456 on skype now (ok) hate, it. Hate it! So yeah, we're on skype but we've all got our mobiles so I
457 mean I can go out for a cigarette break as long as I take the time off my flexi time, it's my own
458 time. I can go for a cigarette break, I can have well I get my two tea breaks anyway and your
459 lunchtime. But if you need to make a phone call, yeah.

460 I: That's not a problem (that's not a problem). That's good. That is really good. Is there any way
461 that your caring impacts on your work or vice versa on a day-to-day basis would you say?

462 P: Erm, yes (mhm) very much so.

463 O: For one, you were never have took retirement if you didn't have to. You wouldn't have took
464 that option.

465 P: No, I wouldn't have taken the partial retirement if it wasn't for caring for my folks. I would-, I
466 use up my leave quite quickly shall we say. Even just the sort of, I can be sitting and I'm working
467 away, and then I get a phone call to say "your mum's fallen", or it can be my mum (mhm), and
468 she's like, "oh [name] I've got this", (mm) and I have to leave work. So yeah, it does have a
469 detrimental (mhm) effect on my work (mhm).

470 I: And how often does that happen would you say? Is that a regular thing or...?

471 P: It's over the last few months it's been getting more regular (mhm), there's even the sort of
472 me sitting at work and I know that my mum's not well (mhm) so I'm maybe not concentrating
473 as much (mm) and that has a big effect (mm) so yeah, I mean, just because of appointments
474 or having to take time off, I've missed a lot of meetings, so I'm not up to date. I have to sort
475 of say, I mean my boss, she'll come and say, "right, this is what we discussed", and things like
476 that, but sometimes you want to be there (mhm) and contribute, so that's, that's quite
477 difficult as well, so all these wee things do have an effect on the work.

478 I: How far is it from your workplace to your parents' place, so if something does happen, are
479 you able to get there?

480 P: I'm driving, so about 25 minutes of driving (mhm), yeah. I can usually be there within a half
481 hour.

482 I: Ok and from your home to your parents, how far is that?

483 P: Erm, two minutes (ah) just across that street and at the end of that street (ok), erm, so yeah,
484 they are two streets away (I: that's really close) so, yeah.

485 O: Hence why she's always over there, she can, it's not a long journey (laughs).

486 I: And how is that for your sister, is she close by as well?

487 P: She's, no, she's in [location] so we're talking two miles?

488 O: Two or three.

489 P: Two or three miles, she's away. Erm, so but by car, she can be over in five minutes, but that's
 490 the thing, sometimes she's not got the car available to her as well (mm), because her husband
 491 works (mhm), erm, so it just depends (mm). Erm, and she looks after her wee grandson as well
 492 so...

493 I: How do you feel about your situation as a working carer, would you say?

494 O: What was that sorry?

495 P: I donae quite understand (laughs).

496 I: So, being someone who's combining work and care, how do you feel about that in general?
 497 Would you like to work more, would you like to be able to care more, how supported do you
 498 feel?

499 P: Erm, to be honest with you, from a work point of view, I do feel supported, I do. Erm, if I was
 500 given a choice, I would like to work more (mhm), but through duty, love, whatever, I want to
 501 care more (mhm). You know what I mean, so it's quite a conflict because I mean I've been in
 502 my job coming up for 37 years (mhm), I've been in the same job and I love my work but at the
 503 same time I love my parents more (mm), do you see what I mean? So, I do feel sort of drawn-

504 O: Plus, when you're at work you cannae really concentrate either.

505 P: And it's, it's funny because I think because my boss, my direct boss and the organisation are
 506 supportive (mhm), that if they were nae quite so supportive, I wouldn't feel so guilty (mhm),
 507 if you see what I mean (mhm). Erm, I would've been like, "well bugger you" (laughs), sort of
 508 thing but because they are supportive, erm, when I'm having to take time off like this last few
 509 weeks, I feel as if I'm letting them down (mhm) but, when I'm there, I feel as if I'm letting my
 510 parents down and it's that conflict is there all the time (yeah), whether it's in one way or
 511 another, there's always conflict, guilt, dispirit (laughs), you know. But that's the thing is, I know
 512 that my parents are not gonna be there forever, and that is the thing is that it's not gonna
 513 happen forever but sometimes I sort of think, well, is my job (mm) gonna be there forever?
 514 It's still gonna be there and when I donae have my parents, what am I gonna do? (Yep). I am
 515 going to be so lost. So that does worry me, because I'm on my own as well, I've not got like a
 516 partner or things like, and this one's using her wings.

517 O: [? 54:06-10]

518 P: No, no. No, no. No, you're quite right, you're quite right, that's what you're meant to do that's
 519 the thing, you're meant to go enjoy (laughs), sort of spread your wings. You've got a life that
 520 you have to get on with. Erm, so that's an actual-, and that's the way I want it, but it's like,
 521 when am I gonna-, what am I gonna do when it is only me (mhm), that I've not got these things
 522 to-. I'll probably have about 20 dogs (laughs).

523 O: I tell you that! (laughs).

524 I: At least someone to look after.

525 O: I used to say that to [name] for years, like, what worries me is when-, no when one of them
526 goes, when they're both eventually, the time comes that they've passed, what then are you
527 gonna do because you've halved your working time as well so you're gonna have all this time
528 to fill up which you're not gonna ken what to do with yourself like, even going to the bingo on
529 a Thursday is not gonna fill up the other five, six days a week, ken what I mean? So, I was
530 genuinely and you're already the state that you've already got into and now it does make me
531 wonder what they're gonna be like.

532 P: But then I do have [friend], [name] (O: you do) is my friend, she's been my friend since I was
533 six (mhm). Erm, and out of everybody, she's the one that doesnae give up on me (mm). And
534 she still invites me to-, she knows that I'm gonna say no, or she knows that at the last minute
535 I'm gonna have to call off or things like that but she, she does, she still invites me to things
536 and that sort of thing and she's like, "keep in touch!", and she cares where I am and this sort
537 of thing so I do appreciate her a lot because there's a lot of friends that over the last few years,
538 they would have gone (mm), "well what's the point in asking [name] because, she's not gonna
539 be there. (mm), she's just gonna say no". But [friend] doesn't give up on me.

540 O: Nah, she's actually a proper true friend like (P: aye), there's no disputing that one. She's good,
541 that one (mhm).

542 I: Are you able to talk to your friend about your situation as a carer?

543 P: Well I didn't see her now that (laughs) but yeah, I mean every now and again she'll text or
544 she'll phone me and she'll say, "how are you?", and things like that, but it feels bad because
545 every time you speak to them, "oh my mum's in the hospital, and this is happening and that's
546 happening", and it's all dreary and rubbish (mm). And she's telling me how she's gonna be a
547 granny for the first time and like [talking over each other].

548 O: ...then go through the same motions as what you're going through now, ken what I mean? I
549 don't ken what her parents situation is but (P: well) she's either already been through it or
550 she's gonna go through it, ken what I mean? (P: well) That's the whole point of supporting
551 each other.

552 P: Her mum...

553 O: ...used to live in [name] house.

554 P: No, [friend] lived in [name] house.

555 O: Oh I thought it was her mam.

556 P: No, no, her mum [name] (O: oh aye, aye) lives just up the road from your granny and grandad
557 and they were great friends all their lives (O: really?), aye. But [friend]'s dad died years ago
558 (O: right), erm, but no, her mum's in this similar sort of situation but [friend] got such a big
559 family and they all-

560 O: Aye she has got a massive family like, massive.

561 P: Erm, they all look after each other so yeah.

562 O: That I think, with them having such a big family and then being like you, [name] and [name],
563 you [name] and [sister] ken what I mean? It's a massive difference like, when you've got so
564 many hands to come and but then you've got almost like to no one, it's hard for you.

565 P: Yeah.

566 I: Erm so for the final part of the interview, I would like to talk a bit more about technologies, so
 567 you already mentioned that your mother has a wrist alarm (mhm), where did you get that
 568 from? Did you have to organise it yourself or was that...?

569 P: It was an occupational therapist that got it organised wasn't it? (mhm) And I think it's £50 a
 570 quarter or something for that (mhm) so yeah, they got that. The occupational therapists from
 571 the falls clinic and various places, they erm, well it's not technology but they arranged for a
 572 walker and a trolley and she just recently got one of these electric chairs that stands you up
 573 (mm), erm, she's not had much use of it yet but...

574 O: Couple of days...

575 P: And they were a bit, so equipment-wise, apart from a wheelchair, my dad bought her a
 576 wheelchair (laughs). My dad bought a wheelchair, and an electric bed.

577 O: And he'll not even sit on it his self he needs it too.

578 I: So, your dad does not have a, a wrist alarm or something like that?

579 P: No.

580 I: It's just for your mum?

581 P: Just for my mum (mhm). But there's the button in the house as well that he can press (if she
 582 would fall...), if she were to fall, he can press that (mhm), so I mean we maybe should get
 583 something for my dad now.

584 O: Donae take this the wrong way but I genuinely donae think it'll be worth it because they've
 585 already got one in the house (P: and they donae press it) doesnae get used, ken what I mean?
 586 So when they've got Alzheimer's and dementia they're not gonna remember to use them no
 587 matter how many times you tell them so, even if you give them another, it still just another
 588 bit of jewellery, ken what I mean? So, I wouldnae bother to be honest. Just wouldnae.

589 P: I'm actually gonna get him chipped, that would be good, for old people, is get them chipped
 590 (O: mhm). So that you like you know, like find my phone, it's like find my mum. That's the
 591 thing is because my mum's infirm (mhm), she's not gonna wander anywhere (O: yep), and
 592 she's not gonna leave the house and things like that, so that's ok (laughs) (O: aye), from that
 593 point of view (O: she'll always be on the couch) whereas my dad, my dad goes wandering
 594 (mhm) and it would be quite good to have him chipped, just so that we can just sort of go,
 595 "right, he's down the road so we donae lose him" (mhm), erm, because we do-, he's walked
 596 this area all his life and he's always enjoyed walking and you donae want to take that away
 597 from him (O: yeah) but he canny use a mobile phone so it would be great to have something
 598 that he can say, oh he's just out for a walk, or sometimes you donae see him for four hours
 599 (mhm), and at that point because of his dementia, ye donae ken if he's gotten lost (mhm) or
 600 that sort of thing, erm, but he doesnae tell you where he's going either (mm), because he just
 601 goes and walks (mhm), so that's-

602 I: Has he gotten lost before? What was-, did you have to go look for him?

603 P: Christmas Day. [O: Christmas Day.] Christmas day we had to go look for him. He went-, he
 604 didn't believe it was Christmas Day (uhuh), and he had a row with my mum over, 'cause she

605 was walking him (laughs) she wanted him to open presents and things and he's going, "but
606 it's not Christmas Day", and he was adamant erm, and we were going for a meal at 12 o'clock,
607 our Christmas dinner and er, when I got there, my mum says, "oh he walked out", couldnae
608 find him anywhere I was all over the streets and I'm like, "for god's sake, we're gonna have to
609 call somebody out on Christmas Day (mm)". As it turned out, he sort of wandered back in, he
610 went, "what are you doing here?", (laughs), it was like, "you've got 10 minutes 'til the meal,
611 go and get changed", and he's like, but he just refused point blank (mm). And it's worrying
612 because he doesn't-, when it gets dark he doesnae recognise anywhere (mm), doesnae
613 recognise where he is, in the dark, because things look different (mm), erm, so, if he was to
614 wander out in the dark, he would definitely get lost, which isn't so much a problem coming
615 into the summertime, because it's lighter longer, but in the winter, it's a bit worrying because
616 he could go out for a walk and it get dark while he's out (mhm), and it's gonna completely
617 disorientate him (mm). So yeah, I think, I think we should put that forward. I don't know what
618 human rights people would say-

619 O: I was literally just thinking that, but if they can do it on snapchat hen, they can do it to the
620 elderly.

621 P: -but I think they should get them chipped. Well, they do it on the dogs (laughs) (O: they do).
622 Sorry I know that it's like-, but something like that, even (O: no) you donae have to chip them
623 actually-

624 O: Nah but you're right in what you're saying-

625 P: -even if they had a bit of jewellery or something that you could track them (mm).

626 O: That's also another idea, is if Grandad's gonna continue to go on walks is give him a bit of
627 jewellery that does say where he's been, so that if anything happens (P: yeah) folk can bring
628 him back

629 P: Yeah. But it would be quite good if I could track him (O: track him) and erm-

630 O: Like this morning, where he's all been and if he's still out (P: mhm). Must have got a-

631 P: He keeps coming here and saying, "oh but you weren't in hen", er, yeah, I was. Yes, I was. But
632 I don't think he knocks on the door (ok).

633 O: He's looking for your car and sometimes it's parked in the corner, I think.

634 P: Aye, and I'll say, if I'm not in and the car's outside, I'm out with the dog, so I'm not very far
635 away. But, no. He told me the other day that I-, he had phoned me three times. I don't know
636 who he phoned but it wasnae me (laughs). So, I mean these things are funny but at the same
637 time, they're worrying (O: aye) (I: of course), they're worrying.

638 I: So the, the erm, the wrist alarm that your mother got, erm, when she got it from the
639 occupational therapist, did they have a conversation with you about what kind of technology
640 might be appropriate for your mum or just...?

641 P: They did sort of say, erm that the best one was the alarm (mhm), erm, because I think you can
642 get the ones where if they donae sense any movement (mhm), erm, that would trigger
643 something. But that would be a false reading (mhm), because there's more than one person
644 in the house (mhm), so erm, that was the one that they sort of said... (mm).

645 I: Would you suggest that to someone else who was a working carer, say basically that kind of
646 technology's available (mhm), would you-?

647 P: Yeah (yeah?), yeah.

648 I: How do-, can you think of anything that would make it even better that technology that would
649 make you work better for you? How can it improve basically?

650 P: No but even the alarm, even if there was a-, had a sort of sensor that had a-

651 O: Like a fall sensor.

652 P: Like there was something like that.

653 O: That they can tell by the vibrations or whatever that they've had a fall.

654 P: Yeah, so if there's a thump or something like that (mhm), if it gets jerked really badly (mhm)
655 that it would trigger off that there's something happened but they've not necessarily erm,
656 pressed the button.

657 O: Check the box, find out if they've fallen or not and if they have, they can send out who they
658 need to send out (P: mhm). If not then it's fine, they're alright, ken what I mean? 'Cause they
659 have the sensors that tell you, detect if anybody's moving about, ken what I mean, and getting
660 up off their chairs so surely they should be able to do something with that I would personally
661 think.

662 P: Not that there's anybody with my parents that would be rough with them, but it would also
663 be an indicator if there was somebody (mhm), being rough with somebody (mm), but that
664 would be maybe a deterrent (mm) (O: aye, yep), if they're being burgled or something like
665 that (mm), that would be quite...

666 O: Just a bit more security in general in a way like.

667 P: 'Cause you do get all these folk that are vulnerable and they turn up at doors and things like
668 that. Erm, so aye, it could work as a dual thing.

669 O: There definitely is like a lot more that they could do for the elderly community as far as that
670 goes like, for definite. Rather than just like wee alarms and stuff when it's too late, if you ken
671 what I mean? Sometimes, 'cause especially like there's nae point in giving absolutely anybody
672 the dementia boxes, ken what I mean? So, there should be something in place.

673 P: The thing is, when granny got that box, before she was diagnosed with dementia as well.

674 O: Aye, but grandad already had the news and he's never gonna ken how to use it.

675 P: He does know how to use it, but he thinks that he should be the one that picks your granny
676 up (mm). That's us trying to get through to him and now that he's hurt his back, because it
677 was only a matter of time before he did (mhm), erm, now that he's hurt that'll remind him
678 (mm) (O: aye). Erm, I mean I've put things at the box, if mum falls press this button, I've got
679 my phone numbers but he doesnae really know how to use the phone very well (mm). Erm
680 I've got instructions on it (laughs) (mm). Erm, but there's even things like there's been things
681 in the past where my mum's fallen and my dad wasnae there (mm), and she's-, or he's been
682 in his bed and she's not wanted to wake him up (mm). And she's sat for hours (O: on the floor),
683 on the floor, couldnae get up, she was frozen (mm), and it was like, the phone's right there!

684 The phone was right beside you, (mhm), so why did you not phone me? And I can be there in
685 two minutes (mm), erm, why did you not phone me? “Oh, I never thought” and she says, “Oh
686 I’m frozen, I’m frozen!”, erm, so I was like, “but the duvet is there. You just had to pull it
687 across”, but that way of thinking, that, sort of common sense if you like (O: aye), erm and it’s
688 funny because I watched that program erm, about the ambulance service and they go out
689 and, it’s funny because they get called out to a lot of falls (mhm), and you see the people and
690 they’ve fallen in the bedroom and they’ve maybe been there all night, and not one of them
691 thought to pull the duvet over themselves (mm)-

692 O: Or a cushion. It just sat there.

693 P: -so, aye, that’s a problem, ay? (mm, mm). Maybe they should have them hanging from the
694 ceiling so that when they hit the deck, it just floats down (laughs), covers them up (laughs).

695 O: Best thing is just for them not to fall in general, like. So, we moved granny’s room about a
696 hundred times and she still manages to fall in the same place every time even though you’ve
697 been there to make sure that she doesn’t fall.

698 P: Aye, the last time was erm, (O: it doesn’t matter what you do sometimes), she’s not done the
699 dishes in years (laughs), but because my dad had hurt his back (mm), she wanted to give him
700 a hand, so she went to do the dishes. Now my mum’s (O: can barely reach the...), about four
701 foot seven, four foot eight (O: if you’re lucky), if you’re lucky, erm, because she’s gotten
702 smaller and smaller and she can’t even reach the cupboards to put things away, so why she
703 was, I was like, “why were you doing the dishes?”, and she says, “oh I just wanted to dry
704 them”, and I says, “but they were drying quite happily by themselves”, I says, “mum you’ve
705 not done the dishes in years!”, and she’s like, “ah hen, but your dads hurt his by lifting me”,
706 so she wanted to... I was like, “oh”. I says, “so the moral of this story is, do not do the dishes”,
707 (I: do the dishes)” (laughs). ‘Cause it’s a stone floor (yeah), and it’s a tiled floor (yeah), so that’s
708 how she’s done the, the break.

709 O: But it does make you wonder though, ‘cause she did fall the week before. She did break her
710 hip or like... I would personally think catching-

711 P: Well, the one before she wasn’t in pain (was she not?), nah. That was her knee (aye), which
712 she had hurt rather than her hip (mm), so no it’s definitely through the one, the fall in the
713 kitchen (mm).

714 O: But she has had that many recently too that it’s only a matter of time ‘til she breaks something.

715 P: But it’s a thing, it makes you wonder because, when she was in the hospital, they saw that she
716 was making progress, they took the x-rays, now when you know that somebody’s got
717 osteoporosis, it doesnae take a lot to break a bone (mhm), so you’d think they would have
718 been a wee bit more careful (mm), in x-raying her, and then when she was on the morphine,
719 she could move, and as soon as they took her off the morphine, she couldn’t move. So, you’d
720 think that that would be an indicator and say, “Do another x-ray here” (mm) (O: she should
721 have been observed) but it was three weeks on when she got taken to a different hospital
722 (mm), they were like, “what’s going on here?”. Because the [hospital] had told them to get
723 her over there, the [hospital] had told her that she was independent as well, I mean she’s
724 incontinent, she’s, she canny walk (O: she’s not independent, there’s nothing independent

725 about her) (laughs) there's nothing independent about her (O: in the nicest way possible). But
 726 anyway, sorry, sorry, we've digressed.

727 I: It's fine (laughs). I just have a couple more questions. So, if you had a magic wand, what would
 728 you like technology to do for you? If you could wish for anything.

729 P: If I could wish for anything? I think the obvious one would be that they can, make them better
 730 (mm) (O: aye). Just make them better, make them more like they were 30, 40 years ago (mm).
 731 Running about, doing their jiving and all the rest of it (mm), but apart from that, technology,
 732 what would technology do? Probably something, I don't know.

733 O: It's a tough one.

734 P: It is a tough one.

735 O: It is actually, 'cause you wonder what, when you there as a human being yourself, you wonder
 736 what technology can do for these situations, 'cause there is only so far technology can go for
 737 these situations really,

738 P: Without making it personal, you know what I mean, technology's great (mhm) and your sort
 739 of wildest dreams, I mean if you say that there was a robot in the house and it was doing
 740 everything (mm) that I'd do, so that I could-, but it would be nice for me to be able to do, erm,
 741 what do they call it, what do they call it, instead of doing all the practical stuff (mhm), spend
 742 quality time (mm), with my parents, take them out (mm), that sort of thing, give them a bit
 743 of, a bit of life as well (mm). Erm...Yeah, but then I sort of think, well you're talking about
 744 robots and technology doing everything, which is so impersonal (mm), for them.

745 O: Aye it's not very personal-centred, it's more for you if anything.

746 P: Yeah so at least when I'm out doing the shopping with my dad-, I mean I can-, we could do it
 747 online and then technology would do that for us (mhm), but there's a part that it's the only
 748 time to get my dad out away from my mum (mm). So, and it just lets him interact whether he
 749 meets somebody when we're out shopping and that sort of thing (mm), it just gives him a bit
 750 of fresh air (mm), he never tells me what he wants 'cause he doesnae know what he wants
 751 (O: no), so he'll just say, "just you get me-, you ken what I like".

752 I: It's part of the fun.

753 O: It's stimulation that he's thinking that he's helpful and useful and he's still got I suppose pride
 754 as well.

755 P: It is his pride, it's-, in the couple of weeks when he'd hurt his back that he couldnae come with
 756 me, erm, he did feel completely useless and he's like-

757 O: Wehn you're a man, you are like, the bread winner to a certain degree.

758 P: I mean he does, he pushes the trolley so there's that personal side (mm) so if technology was
 759 doing everything (mm) for them (mm), I mean where would they get their stimulation from
 760 (yeah), and that sort of thing? But I would like to spend quality time but it's maybe not
 761 technology, that's where the care package comes in (yeah). Erm, and takes some of that away
 762 so that I can say, on a Saturday so I can do, right, we have to go do the shopping, I need to do
 763 the Hoovering and your bed needs changing, blah, blah, blah. And doing that, I could be sort
 764 of going, "hmm, why don't we go to the [place], put you in the -, put mum in the wheelchair

765 (O: aye), or just, or even just "let's go out for a walk" (mm), and that sort of thing, but, but,
 766 that would be, that would be lovely.

767 O: It would give you a better quality of life, for them and for you too (mhm), ken what I mean?

768 P: Erm. But technology

769 O: It's a toughy.

770 P: It is a toughy!

771 O: My brains here too and I cannot think for love nor money. Definitely the sensor thing that you
 772 said about the falls and stuff, that is definitely one I would have to say is (P: that would...) be
 773 massively helpful. 'Cause even working in the community, when I was a carer-

774 P: But even something that would, that would erm, even remind me, 'cause it's like sort of like,
 775 some, if the microwave's not been on (mhm), at a particular time (mhm) (O: then you ken),
 776 then I ken he's not made his soup (mhm), so I could phone him (mhm), and say, "dad, it's time
 777 for your soup (mhm), go and make your soup", (mhm), erm...

778 O: Even like the bed sensor, so that you ken he's up in the morning, like that lets you ken that
 779 he's up, he's moving, he's out his bed, ken what I mean? So then hopefully like daily activities
 780 then start to-

781 P: Or even, something that the kettle, the ket-, now the kettle (O: aye that's a definite one),
 782 because the kettle (O: determines if-), determines if he's had his breakfast, if he's had his
 783 lunch because their tea's over there and I've found that since mum went in, I'm going in later
 784 on and the teapot is cold (stone cold), yeah. Erm, that sort of thing. Just something that would
 785 (O: sensors) so that if I'm not there, I still know...

786 I: So you have the reassurance.

787 P: The reassurance that's right, the kettle's not been on for the past three hours, it's time that
 788 (mm) I phone them or something (mm), just to remind them (mm) and make sure that they've
 789 had (mm) that sort of thing. That would be quite good, ay? (O: mhm) Erm...

790 O: Could also get a kind of reminding thing for them, especially if grandad's gonna be in the house
 791 for a while by hisself, just to remind him to go have his soup, to have his breakfast. When it
 792 gets to certain times 'cause his wee mind will just be getting carried away with everything
 793 that's going on.

794 P: Well, there's a couple of times that he thinks he's had something (O: aye, that's what I mean),
 795 and he's actually not.

796 O: So, if something goes off, then he can go, "right I've not had that today", or, "I need to go and
 797 get that, it's that time of day, I better go and get my soup".

798 P: Aye, see I did think about an alarm for them (mhm), but they wouldnae know what the alarm
 799 was for (mm), you see what I mean?

800 O: Would have to be that actually tells them, like on a screen, like says like, right it's soup time,
 801 or like (mm) roughly or even medication times so they open their medication (mhm). Ken what
 802 I mean? Just like something like that, like a wee clock thing that tells you, like a reminder, that
 803 tells them. And then that keeps them right as well, it's a wee bit more piece of mind for

804 yourself and then if you go in that night and they've not taken their medication and they've
805 not had their soup, we can get our own. (laughs) Like that way I, it's as simple as that.

806 P: 'cause they donae do it on purpose.

807 O: Nah but, but you ken what I mean, give 'em a wee telling off (laughs). Get your soup. Have
808 your soup or else. Just saying, like that would be quite handy.

809 P: It would be that you could sort of keep track on them without being like cameras on them all
810 the time (O: aye), but-

811 O: It's not a bad idea about us getting cameras.

812 P: But, aye. Sort of something that just reassures you that they have-, that they are doing what
813 they need to (yeah, yeah), erm, yeah.

814 O: And that keeps the routine, and the more routine that they've got, the better it is for dementia
815 and Alzheimer's as well (mhm), ken what I mean, so...

816 P: And that's why grandad at this stage is all over the place (O: aye), because his routine has
817 been turned upside down (yeah) and then when I go to work, back to work next week (mm),
818 his routines gonna be even more, because I'm not gonna be there through the day (no), to
819 actually, erm, check on him and that sort of thing, so yeah, he'll have to learn how to use the
820 phone so that I can phone him and say, "hiya". But he does, he knows how to answer it now,
821 erm, he's just not very good at pressing the numbers.

822 I: Is it, is it a mobile phone or a landline?

823 P: It's a landline (mm), and nah he's had mobiles in the past and he doesnae know how to use
824 them (O: nah).

825 O: I remember showing him when he was like 70 odd, how to use a phone, and he didn't even
826 ken then! He couldnae use it.

827 P: My mum, she's got a mobile and she turns it off (O: aye, aye). So, she'll phone you and she'll
828 go, "phone me back", and she turns her phone off, so you canny phone her back. But she's,
829 again, she's not used that for ages.

830 O: It's just another thing in the drawer.

831 P: See that's the thing with technology, is we can sort of think of the things that would be useful,
832 but a lot the things wouldnae really be useful for dementia patients because they wouldnae
833 know how to use it (yeah). So, you're trying to think of something...

834 I: That's the extra challenge.

835 P: It is, it is. We know how to work it, but they don't and they're probably never gonna learn
836 (mm) these sort of things (yeah, yeah). Erm because they're losing the ability to use
837 technology of any sort, I mean even the TV. Erm, you go and put the TV on for my dad and he
838 sits and watches the same station because he doesn't know how to turn the TV over (mm).
839 And it doesn't matter how many times I try to show him, it's like, "you press this button".
840 Erm...

841 O: But granny's always been the wee governor. Always in control.

842 P: She's been the governor, aye (laughs).

843 O: Anything like that, my granny is taking charge, for years. So, the poor man's never even had
844 the chance to learn (laughs), ken what I mean? Never, now, he's never gonna learn now
845 (laughs). There's no chance (laughs), not a chance.

846 I: The things you never think about.

847 O: Train your man when you can (laughs). That is the story. Yeah, it's hard to do, very hard to do.

848 I: Okay, erm, so if you met someone else who's combining working and caring for someone
849 who's living with dementia, what sort of advice would you give them?

850 O: Give yourself a break.

851 P: Yeah. I would, I would, I would really-

852 O: Don't put too much pressure on yourself.

853 P: Donae put too much pressure on yourself, and just, know that you're doing the best that you
854 can (mhm) for other people. I would also say, this is what you're entitled to (laughs). I would
855 give them to sort of-

856 O: Guidelines?

857 P: Mhm. But also, probably if they were sort of just coming into it, I would be sort of giving them,
858 passing them on ideas on how to make things easier (mhm), for the parents (mhm). Erm, and
859 to remember that they're human (mm)

860 O: Aye, even though the tables have turned, they're still...

861 P: It's-, they're your parents (mhm), they're still your mum and dad, and the...

862 O: Donae start seeing them as a burden ay.

863 P: Sort of, the emotional side is sort of, turned upside down (mm), because my parents, my
864 parents were great parents, erm, you could go and speak to them about anything (mm),
865 absolutely anything, they would support you, they would tell you when you were wrong like
866 but, but, it's like now I donae have that? (mm). So that takes quite an emotional thing is that
867 you're literally changing roles (mhm), that erm, and I miss being able to go and say to my mum
868 and dad, "oh god this happened".

869 O: And they'll ken what you're on about.

870 P: They'll understand, and they'll remember it five minutes later (mm), erm, and to just know to
871 expect and I would also recommend to them a book that I've got upstairs.

872 O: I was gonna say that funnily enough.

873 P: And actually it's a book that's written by a woman that was a, she was a nurse I think, erm,
874 and she got dementia when she was-, and it's all from her perspective (mhm), and I found it
875 really, really upsetting (O: aye), but at the same time because you're hearing what her thought
876 process because it's easy for us to say, "oh they've got dementia, they donae understand this
877 and donae understand that", but it gives you a sort of insight into how they might be thinking
878 (mm), that's what's going on in their head but they canny actually articulate it (mm), it's really
879 quite a poignant book and it's taken me ages to read it and it's not that big-

880 O: Only 'cause she's not got the time to read it anyway (yeah).

881 P: But it does, it does hit but at the same time, that's full of ideas (mm). Because the woman,
882 she actually started doing things for herself. She started putting post-it notes (mhm) on things.
883 Erm, so I even did this thing in my mum's bedroom, and I put post-it notes really low on the
884 wall, erm, at the side of her bed and I put, 'mum, if you can read this, press your button'
885 (laughs) It was just a (laughs).

886 O: It's right in what you're saying.

887 P: But it's right because she would be down there, erm, and that's what I put, this post-it note
888 and stuck it (I: that's really clever), stuck it to the wall, and I'm like, "mum if you can read this,
889 press your button". Erm, and it's quite funny 'cause she never-, she didnae, but (laughs)

890 O: I think it's been used twice the whole time it's been in there, if you're lucky.

891 P: And it's just, I don't think I would sort of say, "this is what to expect".

892 O: Everybody's different.

893 P: Because everybody's different (mm), but also, it's quite frightening (mm) for the person
894 because, I've had, like I said, like colleagues at work and we've sat and had blithers about this
895 is what my parents-, and I was at the beginning of that (mhm), whereas they were sort of in
896 the middle, to the end (mhm), and they're like, "oh this'll happen, and that'll happen", and it
897 terrified me (O: aye). Erm, the sort of thing, and some of the things have happened and some
898 of the things havnae happened. Erm...

899 O: They've got different-, they've got completely different illnesses, every person is individual in
900 general, ken what I mean? So, everybody is literally gonna be different.

901 P: It's just a matter of patience (mhm) and-, but as I say, I would sort of advise them on the
902 practical things and say, "go to this website, this website's a really good website to tell you
903 the-, what you're entitled to" (mm), or, "these are things that I've discovered that it would
904 have been really nice to have known at the very beginning" (mm), so that you could work it
905 out. I would certainly be telling them about [carer organisation] (mhm), because I think they're
906 invaluable, I really would.

907 O: I think these are actually underrated to be honest, and I wouldn't have thought they'd even
908 [? 01:30:23] that youse are about either, ken what I mean?

909 P: That's what I'm saying.

910 O: That is a problem like, folk donae ken there is this support elsewhere (mhm), ken what I mean?

911 P: But you didnae have to go through social services, you didn't have to sit on a waiting list (mm),
912 erm, sort of thing, that you can phone and have a wee chat if you, if you wanted to, they sort
913 of-, I would definitely tell them about [carer organisation], erm, if they were in a [carer
914 organisation] area, but I think [carer organisation]'s more or less everywhere now isn't it?
915 Erm, and yeah, I would even tell them if they were waiting on care packages and things like
916 that, keep on at them (mm), because if you just sit back and do the things that, and wait for
917 them, you're never gonna get anywhere. Never get, gonna get anywhere. So, these sort of
918 things, yeah.

919 I: That's really good advice, thank-you, thank-you. So, my final question really would be, what
920 are the wishes for yourself, what do you wish for your own future?

921 P: Happiness. I didnae know that I wish for anything to be honest for me. And for me...

922 O: This is your problem, when it comes to yourself.

923 P: Perhaps winning the lottery (O: aye) (laughs), apart from that, erm, there's not really anything
924 that I wish for myself. I wish for other folk (mhm), like I wish for this one [points to O], I wish
925 for my parents, I even wish for my brother (laughs). That he would, like he would grow a heart
926 or something (aw), but (O: a pulse?) (laughs), but (O: for yourself though), for myself I would
927 really like to spend some time with my parents doing quality things, but if I could have
928 anything in this world, I would want to spend that time how they were (mm), years ago. How
929 they were years ago, just to have those conversations and sort of know they were there for
930 me (mm).

931 O: 'Cause you donae who to look for like support for anybody else, you donae look at from me
932 or [sister] when it comes to like, just the way you're generally feeling, you would always go to
933 your mum and dad (mhm), ken what I mean? So not having them there, you probably feel like
934 you're a bit stuck.

935 P: Well I mean, they saw me through two divorces (O: aye), bringing up a child by myself, all
936 these thing-, that emotional and practical help that they gave me, I can't-, I sort of think (O:
937 where would you go) where would I have been (mm), erm, so yeah. So, I want to give them
938 that back (mm), and as I say, they gave me a good childhood, if they had been rotten parents
939 or-, I would maybe feel differently but.

940 O: I don't think you would though because I ken what you're like, I donae think you would
941 (laughs), you genuinely wouldnae like, even if they were rotten parents, I donae think you
942 would be any different, ken what I mean? Because you canny deal with that conscience or
943 guilt or anything.

944 P: That's what I would actually say to anybody else, is you need to be a wee bit selfish (mm).

945 I: You need to be hard.

946 P: You have to have that wee bit of selfish that you can have, you can do things without feeling
947 guilty about them (mm), because that's advice that I would give somebody else that I wished
948 I had (laughs) (mm). You know what I mean? (yeah). And they probably wouldnae because to
949 be honest with you, I donae think anybody takes on the carer role that doesnae feel the same
950 way like me. You donae do it out of duty, you donae do it, it's what's in you (mhm) erm, and
951 that's why I didnae sort of go down on my brother so much because it's just not in him (mm).

952 O: It's the way he deals with it too like (mhm).

953 P: It's his way of coping I suppose so I'm not gonna condemn him for it, but-

954 O: But there's nae harm in asking for help either.

955 P: I just donae understand him! If you see what I mean (mhm), erm, I'm not gonna condemn
956 him, but I don't understand him (mm), because he had the exact same parents as I did. He
957 turned to them for help through his life as well, the same as anybody with sort of a close family
958 does. And we help each other. But for now, for him to just cut himself off so much.

959 O: Since he got married really.

960 P: I donae, I donae understand it (mm). Erm, but I just sort of give him the benefit of the doubt,
 961 that it's his way of coping (mm), rather than being a total selfish ass (laughs) (O: aye), ken
 962 what I mean? It's like heartless and thing a bit. There has to be a wee bit of selfishness in your
 963 persona because that's the wee bit, mhm. And it has, it's all and consumed me (mm), so-, and
 964 I donae resent it, I donae feel I'm missing out on anything, erm-

965 O: Never once have I heard you like getting fed up at them (P: no), like I've done care in the
 966 community and I've seen families and they're like, "oh for Christ-", about their parents and
 967 it's like, never once has she went, "nah", ken what I mean? Like, you've never, it's never been
 968 too much hassle, ken what I mean? (mhm) No matter how much else you've got going on, it's
 969 never been too much hassle, it's never been a burden to you either, you've never made it
 970 perceive like that (P: no), ken what I mean? And you've never perceived it like that either.

971 P: Well there's times that in my head I'm like, "oh for God's sake" (mm), erm, but then I just get
 972 on with it, just get on with it. And try and keep their life as much as possible how it used to be
 973 (mhm) (O: aye) and keeping them, their house nice, keep them personally clean and tidy an
 974 things like that, erm, I tell Grandad what was he wearing, that's the thing, when you saw him.

975 O: He had his shirt and navy-blue trousers on.

976 P: 'cause I says to him last night, I says, "I want all these clothes for washing".

977 O: I couldnae recognise him to be honest with you.

978 P: And he's like, he says, "there's nowt wrong with them!", and I says, "Dad, you've got stains on
 979 your trousers", I says, "you've spilt your soup down your jumper", I says, "it's there, there,
 980 and there", and I says, "so I want that jumper and I want that-, those trousers", and I says,
 981 "well actually, just when you get ready for your bed, put everything in the washing basket,
 982 and he's 'no'".

983 O: Even at that though, Grandad was always quite proud of the way he carried hisself as well,
 984 ken what I mean? Like he would never have let that happen, with hisself, ken what I mean (P:
 985 No. I mean) straight through to get him changed (laughs).

986 P: He went for a shave, and he took his tops off and left them in the living room. And he went
 987 for a shave, and I was like, "yes!" (laughs). They were straight in the washing machine. And he
 988 comes out and he goes, (laughs), when I change his bed I steal his pyjamas as well, and he's
 989 like, he's like "you're stealing my clothes again?", but he doesnae realise he's been wearing
 990 them for a week! (O: aye). You know what I mean, and he's sort of-, so I'll be having words
 991 with him. Obviously, we get through that change.

992 O: They're funny though, they are.

993 I: Thank-you so much for sharing your story with me.

994 P: You're welcome, you're welcome.

995 O: I think it's actually been good for you too hen, personally.

996 P: Aye, aye, it's, what's the word, cathartic? Is it cathartic? I don't know.

997 O: Donae ask me hen (laughs).

998 P: I don't know but there is a word for it.

999 I: I just have, very briefly, a couple more questions that are for the context of your story, so how
1000 old are your parents?

1001 P: My mum's coming up for 81, my dad'll be 82 this year.

1002 I: 82, okay. How old are you yourself?

1003 P: I'm 54.

1004 I: 54 okay. And, erm, what would you, er, so what would you-, what's your job description
1005 basically, or your occupation?

1006 P: I'm an executive officer, in the plans department in the civil service.

1007 I: Executive officer. Okay. And the final question would be the highest level of education that
1008 you have achieved?

1009 P: I have an HND.

1010 I: HND.

1011 P: Which believe it or not, I only got about four or five years ago (laughs).

1012 I: Well, congratulations!

1013 P: Got my diploma.

1014 I: Congrats. Well, that concludes the interview.

1015 END

1016 Postnote after member checking via email, Sept. 2019: "An update on the care is that we did get a
1017 care package for mum and all was going well until 6 weeks later when she had another fall and
1018 snapped her thigh bone in two. This resulted in a big operation to put a rod in her leg. Unfortunately,
1019 she will now be in a wheelchair her mobility has been greatly reduced. She is currently in hospital
1020 again awaiting another care plan. When she does get out we have been allowed to get a stair climber
1021 to get her in and out of the house. This device attaches to her wheelchair and basically climbs the
1022 stairs with the help of a trained user (me) with very little effort for me. It means we don't need a
1023 cumbersome ramp taking up all the garden. We also need to convert the bathroom to a wet room and
1024 have been offered an 80% grant for this."