

Interview 1, “Maggie”

Date: 11.3.2019; Duration: 112min, Setting: participant’s workplace

I = Interviewer, P = Participant

I: So I will just test it, can you say something?

P: Erm I’m [name 0:04]

I: Thank you I will start the interview, [ok] ok so erm can you tell me a bit about your role providing care, so how did this come about?

P: Erm my father died in 2015, prior to that I had actually been helping to look after both he and my mother, my mother was diagnosed with dementia in 2012, erm she immediately erm developed other illnesses so she fell and hit her head and had a subdural hematoma which she had surgery for which was successful erm she immediately, when she got out of hospital, fell and broke her hip, more surgery, more general anaesthetic which obviously exasperates dementia, erm being in hospital gave her, delirium immediately [mm] so that exasperated everything, erm and then so that was about a year, it took her to recover from all of that and there was a significant down turn in her health as a result of that, but I’ve been finding over the past period erm things that she’s written, her diary and all sort so things throughout the house and I realise that actually the dementia was developing for a really long time, [mm] and we didn’t understand it, she herself had asked for tests for three consecutive years, before she was diagnosed, [mm] and they kept saying ‘you’re fine, you’re ok’ but they asked her stupid questions, like ‘who’s the Prime Minister?’ and ‘what day is it?’ [mm] and it was obvious that she was not as bad as that, so in the fourth year, which was the year that she was diagnosed, she had a more advanced test and they said ‘yes, ok you have early onset, not early onset but you are in the early stages of dementia’ [mm] erm but then almost as soon as that happened, as I say, she had all these other things and that really exasperated things erm so my father was unwell and he was in hospital, he was at home for a year, during that time I was looking after both of them, [mm] and I was employed at that point, so I was working in the time [mm] and having to do a lot of grocery shopping, dealing with all the medical stuff erm when my dad, he had a pulmonary embolism so he was taken into hospital and he had a stent which was fine, but erm he couldn’t get out because we had no care package [mm] and that sort of situation delayed discharge, [yes] that lasted for 10 weeks, [10 weeks?] 10 weeks even although he had been ready to leave within a week or two maybe, [wow] so eventually when we got him home he lived in this room really, I mean for the first 6 months he did go to bed at night but the last six months, he was just in here in that big chair, erm he had oxygen and so he couldn’t really move and so I did a lot of caring for both of them, mum was deteriorating a lot, her behaviour was changing, so we started to notice that she was becoming argumentative, and aggressive which wasn’t like her erm and at the time, initially I

38 didn't recognise that and wondered what was wrong with her and she and my dad started to
39 have fights and they were never ever like that, they were so in love, for [mm] you know 50,
40 60 years of their lives, they were just amazing couple and then, anyway he didn't have any
41 dementia, he was 94, when he died and he was absolutely fine, I mean old obviously and a bit
42 forgetful, but he was fine, erm mum's 10 years younger than him, [mm] so err anyway when
43 he died I erm the care package continued so we'd had a care package for both of them, still
44 continued for mum and that sort of was ok for a while, I was still working, I was still employed
45 and that was, when did I finish that, 2016, so April '16 I was made redundant and actually it
46 was a really good thing because what was happening was, she would, she was still sort of
47 moving around and doing things in the house, and she would phone me at work and she would
48 say 'I can't turn the kitchen tap off' cos she had forgotten how to turn it, [mm] and so I would
49 have to ask my boss, get leave to come you know drive, get the bus home, pick up my car,
50 drive here, discover that she had managed to turn the tap off, [oh] and then have to, you know
51 and that was massive disruption of work and that used to happen a lot, that sort of thing,
52 different sorts of things, as well as organising everything and doing all the grocery shopping
53 and everything, so then I was made redundant and the solution was, it was great because it
54 meant that I could do the same job as I had been doing subcontracting to the company that
55 I'd been employed by, but able to work for other people, and working from here, so myself
56 and both my parents were painters so my dad had a studio here, [mm] which I can work in,
57 and it's next door to my mum's bedroom, so that is a really good solution, the reality though,
58 is that when I come in, in the morning for work, I've got lots of practical stuff to do before I
59 can even start, so, so you are working day erm you can't just come in and get on with what
60 you are supposed to be doing, and what I find is that we've got four care visits a day, two
61 during the day and two at night, and the ones in the morning, I think they come in about
62 between half 10 and half 11, in the morning and then, mum gets breakfast and medication
63 then, erm and quite often I have to help them, [mm] because she's, she's on medication for
64 Alzheimer's disease but she has erm, she has behavioural issues, so she is quite aggressive
65 sometimes, and the carers can't cope, so I have to help them to change her, and do a little
66 personal care, erm I have to be there to you know sometimes there's new carers, we generally
67 have two that we are used to but sometimes there is new people so I have got to be there, to
68 tell them where everything is and how to do everything and sometimes I get really frustrated
69 and I think I might as well do this myself and why on earth you know what on earth are these
70 people supposed to do when there is nobody like me around, in lots of different situations
71 there can't be anybody there, and, and why, how do they managed erm and they rely on me
72 a lot, so although it seems that we get lots of help and we do, there is an awful lot of time
73 input still, so then, I, I get to go back to work, sometimes I don't get started till one or two in
74 the afternoon, and then at 4 o'clock they arrive again 4-5 to do supper, so I have to stop and
75 help them then, erm and then I work on till 8 or 9 at night, so I try and get 8 hours a day in,
76 erm and it's good because you know before, before mum was bed ridden, she was here, she
77 used to sit in here all the time, and she was up and wondering around and she could sort of
78 watch television and she could look at books and so on and photographs and she can't do that
79 anymore, erm and but that in a way was more difficult because she was always wondering
80 around and she was almost trying to get into my studio and see what I was doing and wanted
81 attention and kept bringing me things as presents and you know [mm] it was really quite
82 emotionally difficult, [mm] erm so at Christmas time, past she fell again and it didn't seem to

83 be anything particular, she didn't all that often but she did occasionally, so she fell, they said
84 she was fine erm but she kind of deteriorated we took her into hospital, she hadn't broken
85 anything, she was perfectly ok, but it affected her confidence, and ever since then, she's just
86 basically taken to her bed, so we got a hospital bed in erm and she just sleeps now all day, she
87 can walk around but she doesn't really, erm but at night she gets up and starts to walk round
88 the house, so in the morning when I come in before I can start work I have to clear the house
89 because it's covered in, I mean I've just got a lock for the fridge, [mm] last, a couple of weeks
90 ago which has made a massive difference, because I used to come in, in the morning and find
91 food all over the house, and, and you know things covered with chocolate pudding and yogurt
92 and you know you would lift up a, a bed sheet and there would be spring onions hidden
93 underneath it, or you know something like that and then the consequence of that, was not
94 only did you have lots of clearing up to do but also you had to go then and buy loads more
95 food, [mm] cos it was all spoiled, so you thought you had a fridge full of food and you didn't
96 have to go to the shops and then you turn out you had to stop what you were doing and go
97 to the shops and buy more food, [mm] so then I put the fridge lock on, and that does help,
98 erm so you could say that to some small degree that's technology helping, [yes] a situation,
99 [yes] erm and I didn't want to do that because I felt, I was worried about two things, one was
100 that erm she would be deprived of food and that cos obviously she was hungry, she was
101 looking for food, erm but she couldn't, she didn't have the capacity to do anything with that
102 food once she found that she couldn't feed herself really [mm] erm so she just kind of spread
103 it around everywhere, and she eats a lot or sort of puddings and like chocolate mousse and
104 yogurt and I would find a chocolate mousse in her pocket every coat or jacket that she had or
105 handbag I would open it and there would be a chocolate mousse in it and I didn't know long
106 it had been there, [mm] and it would be rotting or it would be quite fresh but I'd think well
107 it's been here and the warm so I will have to throw it out anyway even though it looks fine
108 erm so and then I was worried also that she would try, cos she is quite strong, she's tiny, she's
109 about 6 stone, and really tiny but she's very strong, and erm I thought she will pull the fridge
110 down on top of her, by pulling, pulling to try and get the door open, so I was really worried
111 about that but anyway we decided that fridge was really quite heavy and that it wouldn't
112 happen, and so that does seem to have been a solution, to that, erm so now err what I worry
113 about is that she's quiet during the day and mainly sleeping which is really good for me, cos I
114 can get on, but then at night when I, about 6.30 and I think it's to do with the, the light, erm
115 when it starts to get dark, she gets up, and it's like her night and day is completely reversed
116 which erm I've been told by lots of people who work with demented err people that that's
117 normal and there is nothing you can do to change it, erm and so she gets up at night and she
118 starts wondering throughout the house but there is nobody there then, [mm] so if she
119 wondered around during the day when I was there, I would be able to look out for her, but I
120 don't live here so and I couldn't live here, cos frankly I would go mad, erm so I, so I then have
121 to leave her wondering around the house, which I find quite worrying, so I think you know one
122 of the, the main impacts I suppose on my life, the major impact is this low level anxiety [mm]
123 that I just have 24 hours a day, I'm always worried about her it doesn't matter where I am or
124 what I'm doing, I'm thinking is she ok, what's happening, and what am I going to come in to,
125 when I come next time, to the house, I take the weekends off so I use, my partner lives in
126 [town 12:00] so every second weekend we see each other so I'm either down there once a
127 month, he's up here once a month, so, but the other weekends I was always here working,

128 but I've now taken on a part time degree course, and so those intervening weekends I have
129 to study so now erm I'm not here at the weekends and I really worry, every you know, two
130 whole days I'm not here sometimes three days if I'm away on the Friday, so but we definitely
131 don't want to put her in a care home, she didn't want to be in a care home, my dad didn't
132 want to be, he died here in the house, and that's what he wanted and what we wanted, and
133 everybody that I speak to, all the medical people and all the carers, say that's the right thing
134 to do, [mm] so I it suits them because it costs the government less but it suits us too because
135 it's what we want, and it keeps her safe, and also it means that I can spend more time with
136 her because if she was in a care home I would have to go and visit her, as well as doing all of
137 this, [yes] so actually it's better cos I can be with her, erm and also if I went into a care home
138 to visit her, I wouldn't be able to communicate with her because she doesn't really talk [mm]
139 so I would go there, and I would sit beside her bed for an hour and she would probably be
140 sleeping or she would not be able to say anything whereas now I can just go in and out of her
141 bedroom every now and again, check that she's ok and give her a glass of water, erm give her
142 a cuddle you know that's enough to keep the contact going so I think it's much, much better,
143 that we do it this way, but it definitely has it's challenges [yes] for somebody trying to live a
144 life at all of any kind, because what I'm also astonished by erm the carers are very good, they
145 are brilliant but I am astonished by the lack of organisation in the national health service, and
146 the council, they are unbelievably disorganised, they can't coordinate anything they can't
147 communicate with each other, and so much of my time is spent on the phone trying to get
148 people to do the things that are they jobs, [mm] that they should be doing seamlessly without
149 any reference to me at all, and what I think a lot about is, what happens to people who don't
150 have a, a person to look after them, a family member, [mm] who is you know , if they are just
151 elderly people on their own, I don't how they stay alive, really I don't,

152 I: Can you give me an example of these things that you have to repeatedly organise?

153 P: Gosh well, things like, erm instructions are left for the carers to do certain things and they
154 don't do them, [mm] so there is a log book that they fill in [mm] so erm I read the log book
155 when I come in and see what's been happening erm especially if it's a carer I mean for example
156 just this morning, and this is a girl that has been working with us for years and really is fantastic
157 and is the best carer we've ever had, erm she was really chuffed about the fridge lock, and I
158 said, and she was saying what a difference that makes, I said 'but yes you have to remember
159 to put it back on again' [mm, oh dear] I come in this morning and she's left it, I came out, I
160 rang this morning, she was leaving, she stopped her car, we had a chat, she gave me a
161 handover, came into the house, she'd left the fridge lock off, [oh dear] and that is such a
162 simple thing but it means that I've got to email her boss, I mean I will tell her, but I also have
163 to say, you know her boss and say 'please can you remind all carers to put the fridge lock on'
164 that only takes me 5 minutes or 10 minutes but it's out of my day, [mm] you know and I
165 shouldn't have to do that, [mm] and so another massive difficulty that we have, which could
166 possibly a thing for technology, is the falls alarm and the bed occupancy alarms that we have,
167 which are hopeless, [oh dear] absolutely hopeless, and I mean it would take me a whole
168 interview just to tell you about that and I sometimes think my blood pressure goes up and I
169 just think oh I don't know where to start with this, so she's got a falls alarm on her wrist, she's
170 got a bed occupancy alarm in the bed, and I say 'why don't they work, because lots of people
171 have them and lots of people it works for them, my dad had one round his neck, but he was

172 able to press it, so he had capacity' [mm] but my mum doesn't so the one on the wrist arm
173 goes off when it's not supposed to, it doesn't go off when it is supposed to, so that when she
174 fell, erm I came in one morning and found her lying on the floor there and the alarm hadn't
175 gone off, [oh dear] and it's partly I think cos she's really light and so she doesn't fall with any
176 weight so when they are testing this alarm, they kind of throw it on the floor really hard and
177 so unless it you know it's not sensitive enough, [mm] but then it can be too sensitive and it
178 goes off too much, and I know it's really difficult to get that technology right and then the bed
179 occupancy alarm is supposed to go off when she's out of bed for any length of time, but it
180 goes off all the time when she's sound asleep and not moving a muscle, and then when she
181 got out of bed one day a few weeks ago erm the hospital bed you know how they move up
182 and down [mm] and somebody had moved the bottom of it up, into that shape [mm] and
183 she's got out of bed and she got her leg trapped in the side of the mechanism and so when
184 the carer arrived she was sitting on the edge of the bed and her leg was stuck down this [oh
185 dear] and it was really quite damaged and bruised and you know like the skin wasn't broken
186 amazingly but it was you know erm and but she was not sitting on the pad so it should have
187 gone off but it didn't so she was sitting there I don't know how long, so then the carer arrived
188 she got the GP, I arrived everything was fine, but, so we had to say please don't put the bed
189 up, put it down, erm and it's just the communications constant you know the guy who runs
190 the team [name 18:22] I'm in contact with him so frequently, phoning in, emailing him, can
191 we sort this out, can we sort that out, I phone the night team, can you come in for another
192 visit in the night because really can you give her a banana when you come, because she is
193 obviously hungry, and she is trying to get into the fridge, erm can you, erm can you not do
194 this, can you please do that, err and then we've had a PIR system to try and work out where
195 she's moving around during the night [mm] erm so a guy came to set it up, he was really nice
196 and helpful but he wasn't responsible for monitoring it, the guy who is responsible for
197 monitoring it works at the council, he wasn't doing it, after it had been there for a month, I
198 phoned them up and I said 'can you tell me what the data is from this device' 'oh no well, she
199 moved around a bit in the last month' and so then, the guy came back who'd fitted it, had
200 another chat with him, he said I'm going to speak to the other chap and erm get him to contact
201 you, I never heard from him, that was weeks ago, and so they just don't talk to each other,

202 I: So was it the counsellor that had set that up?

203 P: Well, in theory yes because what you, because nothing is integrated so I've asked them why
204 don't you talk to each other and they say 'it's politics' and I said why does politics interfere
205 with the health and safety of vulnerable people [yes] why is politics more important than your
206 job, they haven't got an answer for that, so you have the council they run the system but they
207 out-source the maintenance to a company called [name], they out-source the supply of the
208 hardware to a different company called [name], so these three people they are all trying to
209 maintain the same system and they don't talk to each other, and so one day eventually when
210 I was trying to sort out the bed alarm, the guy from [name] came and also what they do, sorry
211 I jump around a lot, what they do erm is you phone the council and say the bed alarm isn't
212 working, you tell them in great detail what's happening and why it's not working, they then
213 phone the many from [name], and get him to come out, but when he comes he doesn't have
214 a record, he's got no report, he doesn't know anything about it, he comes and says 'I'm here
215 to fix the alarm, what's wrong with it?' so I have to spend another 15 minutes telling him all

216 the things that are wrong, so then he tried to fix this particular alarm, it didn't work and I said
217 and he was, he didn't have any information about it, about all the technical settings, how long
218 it was before it went off after mum got up, for example and so on and what times of day it
219 was set to, so I said 'well the guy [name] from [name] set it up, he was here last week' he said
220 'I can't do anything with this I need a laptop and a programme' and I said 'yes well [name] got
221 that, he was here last week, he set it all up already, why haven't you spoken to him' 'oh I can't
222 speak to him' so I said 'well I've got him number, I will speak to him' so I'm phoning [name]
223 and I recalibrated the system while the guy from Spe was standing beside me and I did it over
224 the phone and I thought well you might as well go away, and so that happens, that's not once,
225 that happens every two or three weeks or months or you know I mean that happens all the
226 time, so that might take, you could say that totally wasted inefficiency waste my time, about
227 an hour every day, maybe more, things that don't need to be,

228 I: So in between that are there times where the technology is actually working and do you think
229 it's useful,

230 P: I don't know that it ever really properly does work I mean when I'm here a lot of the time, so
231 on the hall table there a speaker, [mm] so the team comes through, you hear it, you hear it
232 bleep and I just think here we go again, right it's bleeping, so you wait a few, so you can't do
233 anything you have to stop what you are doing, wait for them to come in and say, (sighing)
234 'Mrs [name] are you ok?' so I go over and I say 'yes she's fine, she is actually sound asleep' it's
235 not, she hasn't moved at all, [mm] and I go and I look in the room, she is spark out, so I say
236 'right no it's fine' erm 'ok, fine I will close it down' and that might happen four or five, six times
237 a day maybe more, [really] yes at least and sometimes it goes off every five minutes, and we
238 call them out, they come and fix it, they go away, it doesn't work, it just happens you know
239 and then they come, so about two or three weeks ago, we had a woman from the council,
240 who's head of that team, CAS team erm community alarm systems, err we had the
241 physiotherapists and the occupational therapists and they were all in the room at the same
242 time, we were all discussing all the options, and [name] from the council said 'maybe this isn't
243 the right system for your mum' erm 'I'm going to investigate infrared sensors on the door
244 frames to see when she's moving [mm] around the house' but said 'that won't tell us if she
245 falls, that will only tell us if she is moving from room to room' so I said 'fine ok' erm then in
246 the meantime can you do something with the bed alarm and she said 'yes' and I've not heard
247 back from her, not for weeks and then the other day when the alarm went off, erm last week
248 maybe Wednesday or Thursday erm the alarm went off and I spoke to the woman on the end
249 and I said 'erm listen [name] said she was going to get back to me, about this have you heard
250 anything about it?' she said 'I'll go and check with her' I've still not heard anything,

251 I: That's not good [it's just] that is really not good,

252 P: And that is that causes me more stress than anything else almost, the time it takes to sort that
253 out, the relentless repetitiveness of the fact that I had to keep doing it, and keep doing it, and
254 keep doing it, and nothing ever changes, the fact that they can't get the technology to work
255 but then they say it works everybody else, why doesn't it work for us, I can't think why, I don't
256 think that can be true erm they keep saying and another thing that happened, I mean this is,
257 I've been going on for years, and another thing that used to drive me absolutely insane was

258 that, it would stop working the occupancy thing, I would call somebody, so I would call the
259 council, the would call out [company], [company] would come, every time they came, there
260 was a different person, the person would say to me 'why have you got this kind of alarm, this
261 isn't the right kind of alarm for you, what you need is this alarm' fine do whatever you thinks
262 right, change the alarm, if it stops working you phone, they send out a guy from [company] a
263 different guy, guy comes in 'why you've got this kind of alarm, it's not the right kind of alarm
264 for you' I said 'well your colleague put it in about a month ago, he said it was the right thing'
265 'erm well it isn't, no you actually need this' 'fine ok change it, do whatever you like' changes
266 it, and repeats, and repeats every time somebody comes, 'this isn't right, it's not set up the
267 right way, it's not set for the right numbers of hours in the day, it's not set for the right delay
268 time, it's not the right equipment' well change it do whatever you want, and so on , and that's
269 gone on for four years, five years, just I mean it's incredible, the inefficiency of it, so yes if you
270 can sort that, you will be brilliant, (laughing)

271 I: I will definitely do my best, to try to solve that, that is really unbelievable,

272 P: And they just don't talk to each other so, so all these people come from the same organisation
273 and they don't have a record, of what happened the last time, who came, what they said, why
274 they made the decision they made, why they changed the equipment you know they come
275 and it's like a fresh piece of paper every time they walk in the door, they go 'hello I'm from
276 [company] what can I do for you?' [Oh dear] I think (laughing) so that takes a load of time,

277 I: It makes me wonder erm do you still want the technology?

278 P: Well that's another thing erm I'm a bit concerned, to get rid of it I think if I get rid of it, then
279 there's nothing, [yes] looking after mum there's not, and I suppose what I've feel is that, to
280 have it there, there is the off chance that it might work properly, when she needs it [mm] you
281 know if she falls, the falls alarm might actually go off [mm] and they might come and pick her
282 up, erm also I think it's massively inefficient for them and expenses for them because there
283 are so many false alarms that they have to come out because they go over the loud speaker
284 and they say erm 'are you ok?' if they can hear her moving around or she comes to the phone
285 and makes a bit of a noise then the know she's ok, but if they don't get anything from her,
286 which is possibly because she is sound asleep, erm they have to come out, so they have to
287 come out and they might have to come out four or five, six times a night, for nothing,

288 I: Does that happen?

289 P: Yes it does happen, and for nothing cos she's fine and she's sound asleep because their system
290 has malfunctioned and it's given them a false alarm, so they are not only wasting resources
291 and time they are taking people away from somebody who might genuinely need them [yes]
292 who has actually fallen and, and they are waking mum up because they have to wake her up
293 to make sure she's ok [mm] that she's not unconscious [mm] so she's having a nice sleep, and
294 these big blokes come into the house in the middle of the night and wake her up and say 'are
295 you ok?'

296 I: That must be really scary, as well,

297 P: I know and that's when lashes out, you see that's when she get angry and I keep saying to
298 them, so they write it down and they say '[name] lashed out' and 'kicked this person or pulled
299 this person's hair' and I said listen mum is really small she's demented in the middle of the
300 night two enormous people, cos they are big I mean they have to be they have got to be able
301 to pick people up [of course yes] you know they have got to be strong and they've got to be
302 healthy and so these enormous bit blokes come into the house in the middle of the night and
303 wake her up and she's terrified

304 I: Who wouldn't be?

305 P: So she sort of goes oh my god, and one of the things about dementia she also has macular
306 degeneration [mm] which she used to be treated for with injections, erm and one of the you
307 may know the side effects, of that is hallucinations [mm] and she long before she was
308 diagnosed with dementia she used to have these horrendous hallucinations which were
309 caused by the eyes problem but then also possibly caused by the dementia, we couldn't really
310 sort it out, but the way, it was interesting, I heard a programme on the radio about macular
311 degeneration and there is a condition which I've forgotten the name of, but it describes this
312 and it's a really strange manifestation because what people with erm AMD experience is
313 visions of people in period costume, very specifically, Victorian, Edwardian erm sometimes
314 Medieval but in costume, but that is what mum had she said that people used to stand by her
315 bed dressed in Edwardian clothes with big, and big crinolines and sort of lace collars and it
316 was just extraordinary in massive detail, and the story is that it's the brain, because the eyes
317 are failing the brain is creating these pictures, it's really interesting [mm] and so she already
318 has hallucinations and she used to wake up and there would be people standing beside her
319 bed and she would have these horrendous nightmares and she was at the point able to talk
320 about it and she said it was really terrifying, so now it is happening to her in real life, [mm] err
321 you know no wonder she's really scared and now she's of course much more advanced in her
322 dementia so she can't articulate that fear, erm but she can react so another big problem that
323 I have was the staff, is trying to get them to understand that she is ill, because they don't and
324 I keep saying to them do you have dementia training, and sometimes they say 'yes we do' and
325 sometimes they say 'we don't have time or money' erm but whenever my mum lashes out
326 they report it to me and in the book, from the basis of a blame culture [mm] so it's her fault,
327 she's an aggressive person, she attacked our staff, and I say 'can you please not use such
328 emotive language, can you please understand that mum would never ever have done that,
329 she would never behave like that she is a very calm person and she's ill and she can't help it
330 and please don't blame her and please don't you know, I know that nobody should go work
331 expecting to be attacked that's not what you know it's not right obviously but at the same
332 time and they have to be protective and they are you know the council has to protect its
333 workers, but at the same time they (P's phone ringing here) this is the carer, can I take it?

334 I: Yes I will pause it-[paused]

335 P: [resumed] That's the carer saying 'have you phoned the GP, to get the medication changed'
336 the GP has to get that to the chemists but I've got to phone the chemist and make sure that
337 they've got it so that [name] can pick it up tomorrow morning before she comes in, so mum's
338 got her new medication and that's me organising all that, [mm] erm which is fine it doesn't

339 take any length of time, I mean of today that might take me 20 minutes, to do that all together
340 so I phoned the doctor, explain everything, then the phone me back, have a conversation with
341 the GP, that's another 10 minutes, [name] phone her, phone the chemists, you know but it's
342 c [yes] constant, [yes] and when you add those up, the amount of time it takes when you are
343 trying to do a fulltime job, is quite stressful and I think all of that needs to be done so what
344 happens to people who don't have somebody to do that, [exactly] how does that work, I don't
345 know,

346 I: Yes, so you've talked a lot about erm getting help from the council, [mm] do you receive any
347 support or any help from anyone else, for example family, do you have anyone that helps with
348 caring?

349 P: No, erm I have a brother [mm] who lives in [place] [ok] he's lived there since he was 24, so
350 mum and dad lived in [place] but he, they say that you will never know how people react in
351 situations and that is so true, and I never would have really understood that until now, so we
352 were, there are four of us, me, my brother, parents, and my son, and that's all there is in our
353 family, [mm] now living and mum had two brothers, both dead, erm my dad's family is all
354 dead, erm we were so close, such a close family, absolutely (P very quiet here and upset) [I'm
355 sorry] and my brother has just vanished, he just has completely abdicated all his responsibility,
356 he is younger than me, that is no excuse, he is an intelligent, empathetic man, he has no
357 partner, well actually he has found a girlfriend recently, so maybe he has, but hither to until
358 Christmas time, no partner for years, no kids, never been married, has a cat, has a fantastic
359 social life, is retired you know took early retirement, has plenty of money, erm could easily
360 come here, regularly, I mean I can go down, he lives in [place] my partner lives in [place] they
361 are quite close together, I go to [place] one a month, I'm saying it's easy, get on the train three
362 hours no problem, how come he can't come up here and look after his mum, why can't he
363 come and visit her once a month, and years ago I asked him when dad was still alive, I said
364 [phone ringing here], it will be a cold caller, the only reason I go is because it wakes mum up.
365 [ok] So he, so about, gosh it must have been, dad died in 2015, so it must have been, maybe
366 the winter January, 2014, I said to [name] erm my brother, I said 'how about if you came up
367 once a month, it would be really nice if we just picked a weekend like the last weekend of
368 every month and I knew that you would be coming and you just did you know did that on a
369 regular basis' and he said 'I've got a life' he said 'I've got a life to live' and I thought 'what' who
370 do you think is up here doing this, and so every time now, I've stopped asking him, but for a
371 few years I got very, very angry and upset and then I thought this is absolutely hopeless it's
372 just doing loads of damage and it's not helping the situation at all, so err we had, we never
373 ever fight, never, nobody ever fought in the family really, hardly ever, I mean there would be
374 some normal altercations but you know we were always so close we visited each other all the
375 time, he would come up several times a year, and he never phones, never, ever phones, never
376 phones me and says 'how is mum' never phones and says 'how are you, are you coping ok? Is
377 there anything I can do?' erm and he could do loads remotely you know, from emailing all
378 sorts of stuff, even you know even if he didn't come up, I would say, if he phoned me and said
379 'how are you, I'm thinking of you, is there anything I can do?' that would be enough, just to
380 think that he was there and he was helping in his head would be enough but no and actually
381 you know I phoned him must have been four or five weeks ago now, I phoned him on a
382 Saturday afternoon, Sunday afternoon, he didn't pick up cos he never does, he's one of these

people, the phone is in his hand all the time but he never picked up, never, ever, he'll wait and then he will screen he call and then he'll phone me later or he will text me later so he text me about half eleven at night and say I'll phone you tomorrow sorry I was busy, and I haven't heard from him, he's never phoned back, and I think what does he think is happening every day with his mum, was does he think I'm doing, what does he think you know if he's not, if he doesn't care about me, fair enough, but what about mum, he doesn't want to know about her, he doesn't want to ask how she is, I don't know so I feel, it's worse than being a single child, if I was a single child I would know it was just me and I would be able to get on with everything but he and I both have power of attorney together, which means I've got to consult him and that was a mistake that I made actually years ago because when mum was not, she was worried about her dementia but she hadn't told anybody and she hadn't been properly diagnosed I don't think at that point so it was maybe, maybe it was 2013, she asked me one day if I would do that for her, and I was kind of shocked, I didn't understand it and I said 'oh mum goodness I don't want to be taking over your life at this point, I don't you know, you are not at that stage, and I kind of said 'no' and I didn't understand that you could do it and not register it, not activate it you know and actually I should have done cos she asked me and that would have been much more straight forward but in the end when we eventually did do it, I said '[name] needs to be part of it too' so I involved him so now I'm stuck with him having to make decisions as well, and every time I ask him about a decision, he sort of asks me all these questions really picks it apart and 'why are you doing this and why are you doing that?' and I think well if you paid any attention to this you would know and also why don't you trust me, I've already worked all this out and why don't you just say yes that sounds fine, instead of making me justify every decision that I'm making, so when I ask him, say when I go away on holiday, I ask him to come or if I go away for the weekend, I might say 'can you please come up this weekend cos I'm going away' and instead of saying 'sure yes ok, I will do my best, I'll see, I've got some stuff on but I will see what I can do and I'll let you know, I'll juggle some things around' what he says is 'I'm awfully busy, I've got a wedding this weekend, I've got somebodies birthday, and there's a party on next Saturday, I can't come cos there is a part, can't come cos there's this and that and then so everything and his attitude is negative, it's like I will do what I can to help, it's I can't cos I'm busy and then I say listen I really, really need you to come, please can you come, 'oh alright then, well for gods sake, ok I'll come [mm] so he comes and then cos I say look I don't want to leave mum cos you know she's not great at the moment, so he comes and then he says, his attitude, although he never actually says it I don't think, or maybe he does say it is erm I don't know why I had to come because she was fine, you know why did you have me come because really you know nothings gone wrong, 'yes ok' and err and then when I say 'look why don't you even just phone up and say how is mum' and said 'because every time I phone up, you make such a big fuss and you are such a drama queen, about it and therefore I always feel I don't want to hear it because it's too difficult and I'm in denial' fine, so (laughing) so yes, so I've got all that to, I mean, the way I'm talking now it's erm, it's you know it's makes it sounds like I am quite a drama queen really,

I: Not at all, not at all,

P: Erm but you know there's seems to be lots of different strands to this, he is one strand in itself it is an emotional thing to deal with, I, my partner is totally fantastic, and he is so supportive I get such a lot from him, he's really good, I wouldn't really managed without him,

427 I: So, he gives a lot of emotional support?

428 P: The practical stuff yes, I mean he is all practical, he'll just come up here and he often says
 429 actually and it's me, you know on a weekend when he's here, he might say let's go and see
 430 your mum and let's go and sort out the spare room or go and you know do some practical
 431 stuff in the house and I tend to be the one who says no because I say, I'm there every day, I
 432 want a break, I want a weekend with you not doing anything to do with mum actually erm and
 433 if he was here more often obviously that would be different erm and I know he's right, but I
 434 just think oh god I get PTSD just coming through the front door, (laughing)

435 I: I can imagine,

436 P: So, so erm yes and there's the incontinence thing and that's a real challenge [oh dear] it is so
 437 difficult, erm it's not frequent, luckily it's not frequent but it has happened quite a few times
 438 and, and I've had you know I've had obviously because of my age I've got loads of friends who
 439 are in the same position as me and we do exchange stories and I know that there's a friend of
 440 mine who had both parents at home, both incontinent, and she dealt with that, she used to
 441 take her dad into the shower and I was saying to her I don't know how you can do that, I just
 442 couldn't do that you know, erm but I find that I had to do it and it is really challenging because
 443 it's your own parent, I mean it's bad enough doing that for anybody at all that you are not
 444 connected with but to do it for your own parents, it's such a very difficult and emotional thing,
 445 erm anyway yes, that's just how it is cos you sort of think, she looked after me, so I have to
 446 look after her (P very emotional here, crying) sorry,

447 I: It's ok,

448 P: Actually, unless well, nobody tells you about this, nobody says you don't think about it and my
 449 parents were both so youthful, my mum looks totally different from me, I look like my dad,
 450 she is blonde and skinny, and gorgeous, and she always looked beautiful and everybody
 451 thought she was my sister, so always looked about 20 years younger than she was and so
 452 sharp and so articulate and so intelligent and amazing and my dad was the same and, and you
 453 think you sort of have this notion of immortality you know you never think that they are going
 454 to die, and you think well even if they do die, you don't think about it, and you think well it
 455 will be a heart attack or a stroke or whatever, you don't dementia is quite newly understood,
 456 [mm] or not really understood actually but newly kind of, such a big thing in our society, that
 457 we are having to deal with and even although my mum's mother had dementia, so I had some
 458 experience of it, and of course I'm terrified, because I think it's genetic and that's two women
 459 in the family but then I am much more like my dad, so I do hope I've inherited his lack of
 460 dementia, erm but you don't sort of realise, you want a long life, you know everybody is talking
 461 about health and long life and longevity and that's absolutely useless unless you're healthy
 462 and it's an interesting thing, it's made, made me realise my lifestyle in the sense that, because
 463 we are all artists in the family, we are definitely not sports people, nobody did sport in our
 464 family, you know my dad used to be, we used to laugh that he always drove everywhere, and
 465 he would quote G K Chesterton, who said, 'if ever I feel the urge to exercise come upon me, I
 466 lie down to look pass it' (both laughing) and he very proudly said that his whole life, he would
 467 never walk anywhere and I, and of course he ended up with terrible back skeletal problems
 468 [mm] muscular skeletal problems, back pain, all the rest of it, died eventually of vascular

469 disease because he didn't move enough and he did smoke, when he was younger and he you
470 know erm and I think well he was 94 and he still managed to get to 94 with not doing any
471 exercise, but he was pretty crippled for the past 10 years of his life or more, and I think well if
472 I get some exercise you know if I do some exercise and we always ate healthily but we never
473 did any exercise, so now I go to yoga every morning, and erm go to the gym and think if I'm
474 going to live, cos we have, touch wood in our family, we have longevity, everybody lives past
475 90, [oh wow] both, I mean my mum is 89 erm both grandparents maternal, paternal
476 grandmother's where in their middle nineties when they died, so we do have, and we don't
477 have cancer in the family and we don't have heart disease, erm so you know generally pretty
478 healthy and I think well that's fine if that's going to happen, but I want to be healthy, I want
479 to be able to make the most of that, there's no point in being mad or crippled [mm] so you
480 know you don't realise that dementia's such a long disease, it's already 7 years with mum,
481 erm she's really healthy physically she has, on no medication, she doesn't have heart disease,
482 she don't have high blood pressure, she doesn't have anything wrong with her, she takes
483 medication for dementia, she takes an antidepressant for mood, that's it, you know so if she
484 didn't have this and she created that garden from scratch,

485 I: Did she?

486 P: yes, [gosh] I mean that garden was grass, when we moved into this house 25 years ago; there
487 was just grass nothing else,

488 I: I admired it before, it's really lovely,

489 P: Everything in that garden my mum grew, and erm she did that with the garden with the house
490 that we had before erm so you know she was in the garden every morning at 5 o'clock, she
491 was doing physical work, she was healthy, she ate, you know they took vitamin pills every day,
492 she did you know from right back to the sixties and seventies she was making her own muesli
493 before anybody ever heard of it, she was juicing fresh juices every morning, vegetables one
494 morning, fruit juice the next morning right through my childhood, and all through our lives
495 she has been healthy, we live you know we lived on fish and vegetables and she gets dementia,
496 where does that come from, you know it's, it's I just wish I understood it more really because
497 you know they have these list of things that you must do, if you want to avoid dementia so
498 you don't smoke, you don't drink you, you know eat healthily you take exercise, you get good
499 sleep all of those things my mum never smoked, she never drank, she did loads of exercise,
500 she ate really healthily she is as mad as a box of frogs, (both laughing) my dad drank red wine
501 every day, smoked most of his life, never did any exercise, never got dementia,

502 I: There are so many stories around it makes you think does it really make a difference,

503 P: It doesn't make any difference, I don't think there is anything you can do and what, and I don't
504 know what it is,

505 I: Yes, probably enjoy life make the most of it; in the end you probably can't control it,

506 P: No, but they are talking about bacterial infections now you know mum had herpes simplex all
507 her life, [mm] and they talk about the virus in the brain, they talk about bacteria from the
508 gums, cos she had gum disease, [mm] and they say that's, they found bacteria from gum

509 disease in the brain of demented people, so who knows what the causes are, anyway, there
510 you go, there's my life,

511 I: Thank you so much, for sharing, I just have a few more questions regarding technology [ok]
512 erm apart from the technology that you have already mentioned, so the bed alarm, the wrist
513 alarm, the falls alarm, erm are you using any kind of technology in your caring or in your work
514 in trying to reconcile the both?

515 P: erm I can't really think what that would be, what do you mean have you got an example?

516 I: So, your phone for example do you use your phone to coordinate [yes, all the time] yes,

517 P: Yes, I mean that is absolutely essential [yes] email and phone to communicate with erm the
518 care team, I email them quite a lot cos you can never get them on the phone, [mm] the phone,
519 I'm always phoning the doctor always phoning all you know there's so many strands, of
520 different people who are involved so you've got the physiotherapist the occupational
521 therapists the hospital, the GP, erm the council, you know all the falls alarm people erm the
522 chemists you know all of these people and you've got to kind of coordinate them all [yes] and
523 so yes phone, is essential,

524 I: Mm, do you think that, can you think of any example how you might want to improve this kind
525 of technology?

526 P: (pausing) I don't know how that, well I don't know I mean I suppose what I would say is, this
527 is not really answering the question, is I would like them to talk to each other without me
528 having to do it, [yes] I would like them to be much more aware of the need to integrate their
529 care systems and stop outsourcing things and stop you know privatising everything [mm]
530 because when you privatise things you lose control over them,

531 I: It's even more fragmented

532 P: and it gets really fragmented and, and everybody is busy you know they are absolutely run off
533 their feet in all of these organisations and they, they're just doing their own thing and they
534 are not really thinking that they have to talk to everybody else and they also don't seem to
535 think that not only would it be efficient but actually in terms of time and a streamline service
536 but it would also be cheaper so you know a lot of what they are doing is trying to save money
537 and they're cutting costs everywhere but if they were more efficient they wouldn't have to do
538 that so that's really frustrating, but that's a really overarching thing, you know you'd have to,
539 err you'd have to erm nationalise everything again you know and get everybody under the
540 same roof, and (Get them talking) get them talking to each other, yes why don't they do that,
541 I don't really know, I mean even the other day, when I phoned the night staff, so I know the
542 girl who runs the night team and I phoned her and I said 'please can we have another visit cos
543 we had one at 11 o'clock at night and then mum would be on her own till 11 the next morning,
544 it's a long time, so I said can we have one about 4 o'clock' she said, 'I can't authorise the
545 funding for that, you need to speak to the social worker, [oh dear] fine so I've got to phone
546 the social worker, so I have to find out which social worker to phone that takes ages to get the
547 right number, phone the social worker erm social worker says, 'oh they don't do two visits a
548 night, they only do one, you can't have two visits' I said 'yes they do, do two visits I know they

549 do because I know that other people get two visits,' you've got to authorise the funding erm
550 so right she says, so then I phoned the first woman back and told her this, and then, the next
551 thing I knew was, I phoned up to say how we got any progress with this and she 'oh they have
552 started already, they've been sending two people for the last two days, it's already started'
553 and I said 'oh, ok, so you haven't even told me,' it's working fine the social worker was wrong,
554 you were clearly wrong, they don't even know their own jobs, and what I find and this sounds
555 ridiculous cos it makes me sound like I'm the only one that knows what I'm doing but because
556 I'm talking to all these different people all the time, I find I end up knowing more about their
557 jobs, than they do, because I'm talking to them and I'm having to tell somebody else erm I'm
558 talking to so many different people that I'm the one who knows what everybody needs to do,
559 but they don't, so I end up telling them, but you can't do this and you can't do that, and this
560 is how you do such and such, a thing, which is all fine but it takes loads of time, [it must do]
561 and I don't and then I might have an eight hour working day and I might get two hour's work
562 done, in that time, but I have to live on the money that I make, in my job and if I'm only
563 working two hours a day, I can't live on that so that's where it is really difficult I think, if I only
564 had to look after mum that would be one thing, and I could probably manage to look after
565 mum and do my job but when I have to do all this other stuff as well then that makes is really
566 hard, and I don't make enough money, so I end up part, being supported by my partner, which
567 I hate, I absolutely hate but I have no choice cos I can't make enough, so

568 I: Can I just ask very quickly how does that work, with your job do; are you getting paid per hour
569 or per work?

570 P: Err generally speaking it varies but I have a nominal hourly rate so in my mind, so I get a job
571 and I look at it and say this is going to take me roughly eight or ten hours to do this, so then I
572 work out how much is that per hour and I say, is that enough money, do you know, cos I sort
573 of do it both ways at once, I sort of look at it and say right that job is a £200 job and then I say
574 right £200 how many hours does that give me, that might give me eight hours, ok that's
575 enough, so that's sort of how I do it, [mm] erm so then I might raise an invoice for several you
576 know, I work for galleries in the town who give me relatively regular work, one of whom I used
577 to work for, and then I have private clients, but not that many, and one of the reasons for that,
578 which is a bit difficult in a way, as that because, because this is a, a very tenuous situation, the
579 reality is I, mum could die any day, I just don't know, I mean I've been told by the GP whenever
580 I say to her, how long you know, what's the prognosis she says 'I've no idea and it could be
581 really sudden, your mum could get an infection whatever' so the problem is that we own this
582 house, but it's mortgaged because my parents took out an equity release thing, after they
583 bought it about 5 years after, but they bought it outright and then they got some money back
584 out of it, and the problem with that is that we have to sell the house when my mum dies [mm]
585 which means I can't work here, and I don't make enough money to rent a place, so when I, I
586 can't make the business big I can't grow it because I don't know when I'm going to just give it
587 up, or change it really dramatically so I can't sort of, so I'm just sort of living on what I get from
588 this, these two organisations and you know I was looking, I raised an invoice this morning,
589 that's only the third invoice I've raised since January it's only the third one in this year, and I
590 think I can't live on that, you know that's just ridiculous because it's more and more that I'm
591 required to do every day now, it's you know more challenging [mm] but I couldn't possibly be
592 employed by an employer and do this job, I mean I have to be self-employed that's the only

593 way that it can work, erm which is fine cos that suits me, but even that's really hard, so I don't
594 know what the answer is because the other problems of course is I keep saying to myself am
595 I doing the right thing, should mum be in a care home would that be better for her, would she
596 get more round the clock care, she would have more people round about her, and she'd have
597 more stimulus, I think she would hate it because she isn't a particularly sociable person and I
598 see how easy it, how much she loves this house cos this is her space, and you know how
599 demented people really hate to be moved, erm and they tend on average to live in a care
600 home four months and then they die, so I don't want that, but erm the other difficulty is we
601 can't afford to pay for it because the house is mortgaged so we'd have to sell the house but
602 then we'd have to pay the bank back, and then if we sell the house, I have to move out and
603 I've nowhere to work and I'd have to sort all this out which I don't have time to do cos I'm
604 working so I think I can't put her in a care home cos I'm in a catch 22 I'm completely stuck,
605 you know I can't move one way or the other, I just have to kind of wait and see how it all plays
606 out really

607 I: Mm it's a really difficult situation; it's hard to imagine what technology can do in your
608 situation,

609 P: I don't really think, I can't really think, I mean it could fix the, the alarm systems [yes] that
610 would be good, it could you know, it could come up with something like that, [mm] but
611 everything that I need in technological terms I already use like the phone and the internet,
612 [mm] you know I mean I do a lot of research into dementia on-line for example I you know
613 erm especially not so much now but at the beginning I used to do and I used to find out about
614 you know advice lines and people who worked, nurses and all that kind of thing, I was always
615 phoning people up, I've kind of stopped doing that as it's become more and more advanced
616 but erm yes I can't really see, I mean I can't imagine what kind of technology you mean what
617 do you, what are you envisaging?

618 I: I really can't say because this is really trying to find out what it is that you would need and
619 building on that, so I was also thinking erm when you were talking about advice, hotlines [mm]
620 are you, have you been using them for yourself as well and how do you get support for you
621 personally?

622 P: Erm, well I use [carer organisation], which is how you came to know about me so erm they
623 are very helpful in some respects erm I've been to a dementia seminar, a training day with
624 them a few years ago, erm I have been to counselling [mm] with them erm and I've also had
625 a grant for a reflexology treatment, six sessions which is really relaxing [mm] and I really enjoy
626 that so and I'm applying for another one through them so that's, that's really good they are
627 very helpful erm I go to yoga, I you know, although the things are, so I sort of look at my life
628 at the moment as in the respect that there are four different things that I do every day, so I
629 go to the gym in the morning, I look after mum, I do my own job, and I do my study, my degree,
630 erm and I think well three of these are compulsory the only one that I could actually drop is
631 the gym, the yoga, but I can't drop that cos that's the thing that keeps me able to do all the
632 other things, [yes] so then, but I have to, I've had to cut it down I used to do it every morning
633 and now I do it maybe two or three times a week cos I just don't have, because now what's
634 happening with the reflexology training is that I'm seeing case studies at night and I'm studying

635 at night so whereas normally I would go to yoga and then come in at about 11, so the classes
636 are generally about 9 or 10 in the morning for an hour, so I'd come in after that, do some work
637 with the carer, start work and then stay till nine at night, but now because I've got to go home
638 early I can't, that mean that I've only got an afternoon to study, to work so actually I have to
639 ditch the yoga so I can come in earlier and get more work done, [mm] so it does, it does get
640 sacrificed anyway [mm] but I really strongly believe that you can't do this job unless you get a
641 lot of self-care erm if I didn't have my partner and the yoga I would really, really struggle I
642 think because there is a limit, I mean you, very unfortunately for you, you've ended up being
643 a kind of counsellor yet again, (P laughing) and you know it's

644 I: It's absolutely fine,

645 P: You get the off load of that kind of sort of sense of you know all this stuff, erm partly because
646 you think you don't want to tell your friends you know, you don't want to, when they say how
647 are you doing you say fine because what can you say, and they don't want to be spending time
648 listening to you off loading to them, and you don't want to affect your friendships with that
649 and so you just, but you have to talk about it because otherwise it drives you mad [absolutely]
650 and you I suppose for me, and this sounds really selfish but I, a bit like my brother I kind of
651 want my life back and that sounds really bad, I can't even think about that you know but, but
652 my partner and I we've been together for 17 years, we've never lived together, we, when we
653 met we'd both been married and we both had kids and we decided not to live together
654 because of the children, so the children were in schools in separate countries and their ex-
655 spouses were living you know different places and we needed the kids to be near them so we
656 right then when the kids go to university we will get together, so the kids are all now, not even
657 at university, they are all finished except for the youngest one who's in their final year and we
658 are still not together and then I think well my son left home when he was 17 so he is now 23,
659 so he's been away, he lives in [place] but he's been away and what you don't realise when you
660 have kids, I don't know if you have got kids but erm you think that they grow up and leave
661 home at 17, 18 and that's it but it isn't that at all, they need more and more help you know,
662 so I'm looking after the three of them, remotely you know almost every day there is something
663 to sort out for them, and so that's also an added thing, which I love doing, I'm not complaining
664 about it, but it's an extra thing to do and then erm I think ok so [name] left home at 17, and I
665 thought maybe I could get some time with my partner at that point and then it never ever
666 occurred to me that my mother would just slide into that space that he left and be much more
667 difficult to look after because, it's like looking after a toddler, but when you are looking after
668 a toddler they are always learning and growing and it's also a positive beautiful thing, and
669 when you are looking after a toddler like this, they are deteriorating all the time and they are
670 becoming less and less capable and it's, and to see that happening to your parent, [sighs] is,
671 yes and you just think, how long is this going to go on, cos I've already, [name] we've already
672 put our lives on hold so to speak, we have been living separately for all these years while we
673 have waited for the kids to get stabilised and sorted and then I think ok so that's at least 10
674 years we've been doing that more, and then I think is it going to be another 10 years, before
675 we can get together, because of my mum and I'm beginning to really resent it, [mm] but I
676 can't, I can't resent it, it's, you can't you have to accept it, and I suppose that's where I feel
677 bad about my brother because he's just getting on with his life and he's just saying fine I don't
678 care, I've just got a life to live and I think, but you've not got kids, you've not got a partner,

679 you've not got anything, you could easily come up to [place] but no, so yes I kind of, but you
680 can't resent it and you can't want it to stop because wanting it to stop means that person dies
681 and you don't want that, and yet I look at her and I think, mum this is terrible, she will, if she
682 knows anything about what's happening to her she will hate it and she has often said to me
683 actually, especially during the moments of incontinence, she says 'I just want to die' and it's
684 awful it's really sad and I just think I would also want to die at this point, you know and that's
685 a whole different ethical question, [completely] but yes, if it was a cat you know you would
686 put it out of its misery,

687 I: Yes, I think these questions sooner or later we have to ask ourselves [we have to] these
688 questions as a society,

689 P: We have to answer you know find out what do we do in these situations and [name] and I
690 have both said to each other we're definitely going to Switzerland I said 'do not keep me alive,
691 when I'm like that, if I get like that, I don't want to stay alive' erm you know and I've got a
692 living will now and I've got power of attorney already established, because I realise how
693 important it is, for people to look after things, and technology advances so quickly that who
694 knows,

695 I: Yes, who knows, hopefully we will find some good solutions,

696 P: Yes, and maybe, maybe the technology is also about finding cures for things?

697 I: There is a lot of work being done, so [mm] who knows, erm would you recommend technology
698 to someone else, in your position at all, particularly in regards that it doesn't really work for
699 you?

700 P: Pff, I don't know, I mean technology that works is good, technology that doesn't work is just
701 frustrating and time consuming so I suppose if you are going to be erm researching into
702 developing technology, I would, I would say find alarm systems that work effectively and
703 efficiently and yes that would be a real area, you know I would, if I were new and maybe this
704 wasn't within the remit of your project but I'd go to the council, and speak to them about their
705 systems and how they can, how they can get the systems to work better and erm how they
706 can also, and maybe technology would help them but I suspect it's a human problem, erm
707 talk to each other,

708 I: Yes, it's definitely going to be on the list, definitely

709 P: so even if they had a computer programme that connected all of their systems [yes] together
710 and everybody could tap into it, because at the moment they don't have access to each other's
711 system [yes] but there should be you know for example, my partner works in construction and
712 they have a programme called [name], [mm] which is erm a platform that everybody has
713 access to, password protected, anybody can log into [project], and all the drives for the
714 buildings that they build are on there, and all the comments that everybody makes go into a
715 central place and everybody can see it, at any time and that's what they need [yes] and it
716 already exists, they just need to buy it, and use it,

717 I: Absolutely, erm I've got a bit of a weird question, if you had a magic wand, and you could wish
718 for anything what would you like technology to do for you?

719 P: (pause here 10 seconds) mmm I don't know actually erm pff, I can't think of anything I mean
720 apart from making my life easier by automating a lot of the processes that I spend my time
721 doing, I don't know how that would work but, it would again be about integrating all the
722 services so for example you here about the NHS investing in a new computer system erm and
723 that seems to be a very, very difficult thing to do, it's very complicated, it crashes all the time,
724 nobody can use it, erm it costs millions and millions of pounds, and bankrupts everybody, that,
725 that sort of thing I think shouldn't be the case, I think that it should be possible to create a
726 stable system that works erm that doesn't give you the wrong information all the time err that
727 doesn't cost the earth that maybe you know that's the magic wand bit cos obviously all those
728 things are not possible, but yes I would, I would integrate everybody, I mean I remember when
729 I was in my twenties so long, long before mobile phones ever emerged my mum and I used to
730 regularly go down town to [place] to go shopping for clothes cos we both loved clothes and
731 we'd go to shops and she would erm we'd get lost, we would miss each other and I remember
732 walking along [place] and mum saying what we need is a thing that we can have in our hands
733 like or you know in our brains or something that we can talk to each other, it was kind of like
734 inventing the mobile phone before, 20 years before it happened and I think, I'm for the days
735 when people are embedded with a chip, you know really, I think that we can communicate
736 telepathically, that we can, you know we can do without all that cumbersome interface and
737 we can just talk to each other [mm] I think that would be really good erm I think that there is
738 a lot of investigation and development at the moment into robots for caring for people,
739 [absolutely] I don't know how that would work, I mean it sounds like a great plan, I think it
740 would scare everybody to death,

741 I: Can you think of anything that you would want a robot to do?

742 P: Well, I mean, it quite, that's quite a difficult thing especially for me, I don't know if you ever
743 watch Doctor Who?

744 I: Oh, I'm such a big fan,

745 P: Right do you know the Cybermen?

746 I: Oh, I do,

747 P: Ok, the Cybermen, when I was a child, Daleks are fine, I'm not bother really, they are a bit
748 creepy, but the Cybermen scared me absolutely to death and I was really behind the sofa
749 moment and then Terminator, I loved the Terminator films but god they scared me to death,
750 so even now for me and I mean it's a bit of a standing joke in the family big metal men, I hate
751 them, I absolutely hate them, and I think the idea of, you know when I get to the age where I
752 might have dementia or care needs, I'm sure we will have robots, by then, as carers, another
753 10, 20 years, whatever and I think that would scare me to death, to have an inanimate object
754 coming in and it could go wrong and what would happen you know so it's a brilliant idea, but
755 I'm not sure if we are ready for that yet, [mm] so I don't know what they could do that would,
756 I don't know, it's a possibility we'd just have to get used to it I suppose,

757 I: I think we are now in a position we can actually direct where this is going [mm] whether we
 758 want these things to do and to look like and to interact, how do we want to interact, how do
 759 we want them to interact with us, [mm] that's really the stage that we are now I think in,

760 P: Yes, I mean it's people, it's like Skynet though you know they become self-aware and then,
 761 because already they've got, they've already got robots communicating with each other
 762 without intervention, they've already got them going rouge, [mm] and that's now you know
 763 when you create artificial intelligence like that you have no control over it, [mm] and then
 764 what happens so

765 I: So, it's something scary,

766 P: That's the only scary thing I think for us and that maybe in 20 years' time people are used to
 767 that, and they find a way of dealing with it and it's just because we are on the cusp on that
 768 development [mm] that we find it frightening, but at the moment you know I might say well I
 769 would really like it if an automated carer could deal with the incontinence stuff for example
 770 but that's for my benefit but mum how would she feel about that, [mm] that wouldn't be
 771 right, [mm] you know so, so you've got to think about all the aspects of that,

772 I: Absolutely, absolutely yes erm can you think of anything else that would make it easier for
 773 you to be able to work whilst caring?

774 P: Erm (pausing 10 seconds) err I don't know really, I mean one of the, one of the things, that I'm
 775 very conscious of is the fact that mum is there on her own doing nothing [mm] and I was
 776 thinking the other day could I read to her, would that you know even, and I was speaking to
 777 [name] about it and he said 'where would you find time to sit and read to her, for heaven's
 778 sake' and I said 'yes I know' and she wouldn't understand me, cos the other day I said 'are you
 779 more comfortable sitting up or lying down' I was putting the bed up and down, she's just
 780 staring at me like you know and I said 'comfortable, is it comfortable?' and she said 'what is
 781 that?' , [mm] so I thought well I can't read to her she doesn't know what comfortable means,
 782 but there's the sound of the voice you know just somebody sitting there, that would be good
 783 so we've got the radio on all time [mm] playing classical music, it's quite soothing, although
 784 the carers always want to play radio one because they think classical music is really
 785 depressing, and I say she likes it, leave it alone, and erm the television you know she doesn't
 786 watch television any more she doesn't she was never interested in it really, erm she used to
 787 read all the time, she can't do that, I don't know, something to keep her company, [mm]
 788 something to stimulate her, [mm] I don't know that would be, [mm] but you know I just feel
 789 cos a lot of the time when she is able to talk, in the days when she wasn't actually in bed all
 790 day so she would be sitting in here and then she would, I would see her walking past the studio
 791 door towards her bedroom and I'd say to her, 'oh are you away to bed mum?' and she'd just
 792 look at me and she'd say 'what else is there to do' [mm] y you know and she's I know she
 793 didn't mean it to come across like that but there was an element of not blame but well you
 794 know you're ignoring me, you're working, what am I going to do, there's nothing for me to do,
 795 it wasn't just you know, it was, there was a resentment in her voice, about it that she had
 796 nothing to do and she was bored and she was just going to go to sleep, and sometimes I think
 797 that while there is no denying the progress of her disease, and the reality of it sometimes I
 798 think that is she could be more stimulated she wouldn't have deteriorated so quickly [mm]

799 erm but we tried sending her to a care, a day care centre, she hated it, [mm] when she came
800 back she said 'never send me there again' right ok sorry, erm but you know you just try
801 everything [mm] and erm because she's not a very sociable person erm you know she not like
802 that, now even less, I don't know something to entertain her but I don't know if that would
803 be technology

804 I: It could be, it could be,

805 P: Yes, yes so I mean something to stimulate her mind and that would be quite good [mm] so I
806 wouldn't you know I would feel that she was getting something out of her life cos at the
807 moment I feel her life isn't worth living, there's no quality of life there [mm] for her, erm and
808 if she could, I mean it might even prolong her life and you might say well is that a good thing
809 I don't know, but to have some quality would be good yes,

810 I: Yes, absolutely, are there any positive aspects for you in caring for your mum being able to
811 work here?

812 P: Yes, definitely, I mean, it means that, I mean working here is really good err because it's a nice
813 environment to work in, it's my parent's home, I never lived here really but erm err and I'm
814 able to be with her everyday which I think is really good cos otherwise I wouldn't see much of
815 her, erm she gets the benefit of that, which I know she appreciates, erm so yes it's quite a
816 symbiotic thing, and it's good erm I get to err run my day the way I want to I don't have to be
817 at the beck and call of an employer, I can work whenever I like erm if gives me the freedom if
818 I want to, to take a Friday afternoon off and go down to see [name] I can do that erm I have
819 to be pretty much here in regular working times cos that's when people communicate with
820 me, but you know there is a lot of flexibility so that's really good erm and err yes there's lots
821 of positives, I would say, and I have to always just hold onto those, you know and know that
822 I'm, know that I'm doing the best thing for my mum that I can and, the only thing I suppose
823 that I'm, the thing that sort of, apart from the everyday stresses of it, and I do, I worry about
824 my health, I worry about my blood pressure, which was always brilliant, and is now not so
825 great, erm I'm not on any medication but I, I'm on the border line you know and I know that
826 that's to do with this, I mean it could be natural, normal things anyway, mum and her mother
827 both had it when they got into their later years, but erm she doesn't anymore strangely err so
828 yes there's that, I worry about the stress and the affect it has on me, I worry about the fact
829 that I can't spend as much time with people and doing things that I enjoy, I worry about the
830 length of time this is going to take, this chunk that it takes out of my life, and whether you
831 know I can't go away on holiday and relax and enjoy it because, I don't know what's going to
832 happen, [mm] my partner and I met when we were both living in the middle east and err we
833 want to go back to [country] in November, for a fortnight only but we never go away for a
834 fortnight, we only ever go for a week, and err so I've been trying to organise respite care for
835 mum, and honestly you wouldn't believe it, I've been told that, we were waiting for a social
836 worker for, since June 2017 we have been waiting to get a social worker allocated to mum,
837 that's coming up for two years, and I eventually got a letter the other day, that said it will be
838 14 weeks before you get a, even a discussion with somebody, so erm I thought I was organising
839 it well in advance for it being in November and now I'm not really sure that I have because [oh
840 gosh] you know, so that's sort of the thing I find really challenging [mm] erm and I just don't

841 want to ask my brother to come up cos he will make such a fuss and he will not come up for
842 the whole two weeks, he'll sort of come up in the middle for three or four days and you know
843 it won't be enough erm so yes, err it has very many good things about it, very, very positive
844 things but I feel, I feel the most difficult thing really is not knowing how long it's going to be
845 and if what and I sort of feel like I'm in limbo I can't plan anything, I can't commit to anything,
846 my partner and I can't live together, erm he can't come up here because he can't get work up
847 here, and he's got a lot of good work down there, erm [mm] err I don't know, yes I just feel, I
848 just feel erm a bit stuck, really so it just goes from day to day, but then lots of people are in
849 that situation, it's not unusual,

850 I: What advice would you give a person who is in a similar situation like yourself, who is trying
851 to combine work and care for a loved one with dementia?

852 P: Pff gosh, look after yourself, really put the oxygen mask on first, that's what you have to do,
853 it's really important cos you burn out, [mm] really I mean I have, I've always been really
854 healthy but I have, at the moment terrible stomach trouble and I know it's tension, I know it
855 is really and it's debilitating cos it means that I can't work and I don't even know what it is you
856 know I keep going back to the doctor and they, it's kind of reflux really [mm] erm but it's a
857 digestive stuff and it's just all about anxiety, [mm] it's all about stress and resentment and
858 everything, so yes counselling is really good I think, having an outlet, erm having a support
859 system is essential err having oh yes I guess, erm being really pragmatic about it you have to
860 be really practical you have to just face up to stuff which my brother doesn't do, so he's too
861 caught up with the emotions of it and I get very, very emotional but I just have to be brutal
862 cos you have to, just you have to say to doctors you know what is going to happen erm we
863 need to know, you know, but actually, it doesn't really, in the end you can't do anything but
864 wait, it's just you've got no control over it, you know so, so you just have to wait and see what
865 happens every day and deal with every situation so you are always firefighting you can't plan
866 anything, so yes you just have to keep your mental and physical health in order, [mm] that's
867 the most important thing, and that's the thing I think that carers don't have time for mostly,
868 but I'm really lucky cos I have such a big support network, I've got friends, I've got my partner,
869 I've got the family erm you know but lots of people don't have that, [mm] so organising,
870 organisation like [name] are really good cos they supply so much support for people, [yes] and
871 erm you know the stuff that they do like the reflexology treatments that was fantastic, it was
872 £260 worth or £300 worth of treatments that they paid for which was an enormous help, you
873 know erm so yes things like that are good,

874 I: That's really good advice, [mm] that's really good advice, do you have any wishes for your own
875 future, in the next year or the next 10 years?

876 P: What, not unconnected with this you mean?

877 I: Just general?

878 P: Oh yes, (P is crying here) [I'm sorry] it's ok, sorry, (pause here, crying) you see you don't even
879 know, you don't even know what the triggers are until somebody asks you a question, I
880 wouldn't have thought that would, you don't know where that comes from,

881 I: You don't need to answer it,

882 P: Yes, I want to live a life, I'm 62, I'm not young, I'm not old but I'm not young, I'm not 37
883 anymore and you know I sort of think in ten years' time I will be 72 that is, that is getting gold
884 and that's, the last 10 years went past in a flash, if my mum lives another 10 years that's me
885 snookered you know I don't want to be taking up my life in 10 years times and the reality is I
886 mean mum is 89 and she's not well, I realistically don't think she will live 10 years, but at the
887 moment it feels like every single day, that I can't get on with my life, is really problematic,
888 [name] wants to travel, I want to spend time with the kids, I want to live with him, we want
889 to get married you know, (P upset here) one of the kids asked us, the wee one we've got,
890 [name] who's the eldest she's 24, [name] is 23 and [name] is 22 and [name] asked us about a
891 year ago she said 'are you ever going to get married?' and err and [name] said well yes, but
892 he said I'd like to be living in the same country as the person I'm married to, and I said well
893 maybe we're not going to be able to have that luxury, you know maybe we will have to live in
894 two different countries and be married or I mean does it matter whether you're married, we
895 were both married before and that didn't work out so it's not the be all and end all of
896 everything, but you know I want to live with him, we want to be together, and do things, and
897 we've already as I say put that off, we got together in 2002, that's 17 years ago, and yes it's a
898 long time, and you know as I say we've put it off because of the kids and now we are putting
899 it off because of my mum and I think I know that my mum would not have wanted that you
900 know all the time when she was not demented, she used to say get on with your own life,
901 don't bother about me just put me in a home, and I think ok, now she wouldn't want to be
902 put in a home, actually and that's the thing that's very difficult when you, when you look at
903 the ethical question of people writing stuff down when they are compus mentis and they say
904 when I'm not able to speak for myself I want this to happen but actually they change their
905 minds [mm] that's their euthanasia question you know erm they decide and I know that mum
906 wouldn't want to be in a home now and I wouldn't put her in a home so it was all very well
907 for her to say, when she was sixty and healthy, 'oh just put me in a home' erm so I don't know
908 but yes I have loads of things, I have a life to live yet and I don't want to be too old and too
909 decrepit and too demented to live it, and I suppose that's part of the reason why I worry about
910 the stress that this has on me because I can feel my head going I can feel, I can feel my body
911 going because of all the pressure and you know I should be more comfortably off as I get older,
912 not less comfortably off, but actually I'm you know I was much more, I had much more money
913 earlier and now I have much less and that's a real worry, cos I don't, can't earn enough money
914 cos I haven't got enough time, and it's also to do with exhaustion [mm] so at the weekends
915 now I'm supposed to be studying or if I'm not studying I'm supposed to be here working and
916 now at the weekend I just want to lie in bed cos I'm so tired, I can't be bothered doing anything
917 at all and that's really, that really worries me, you know erm so yes, it's, it's you know if one
918 is being brutally honest it is a really difficult situation and our society has to find a way because
919 I think hither to in historical societies you had much bigger networks of families so families all
920 lived together in many generations so the elderly generation were looked after by everybody
921 in the household and they were, it was all shared, nobody moved away from their family,
922 [mm] background you know but now they do so, so there's just me left, erm people live longer
923 you know my brother goes to [place] and doesn't come back, erm my kids are away doing
924 their own thing, they go to university they are not living in the house helping out, my partner

925 because of the way that we have to live and work in our society I can't get a job there, he can't
926 get a job here, so, so we have to live in two separate countries, erm you know the way that
927 we live is so fragmented and so we can't, we don't have the support network for looking after
928 the older generation erm so there's, so society and the government has to step in to help us,
929 because in a way they've created the society or we've created the society which has become
930 fragmented so they can't, they can't really say you know, I know that the government relies
931 on people like us, all these unpaid carers all over the country doing what I'm doing and I listen
932 to, there's loads of programmes on radio 4 about it and I listen to them all, there are people
933 in far worse situations than me, I have it really, really easy compared to so many people and
934 you just think all these people are unpaid you know one of things I think is a proper carers
935 allowance, it's pathetic and I can't qualify for it cos you have to earn less than £15,000 and
936 that is, who earns less than £15,000 who can live on less than that, I mean they should give
937 you a carers allowance for a proper salary and when you get it even if you are earning less
938 than £15,000 I don't know what the carers allowance is but it's nothing, you can't live on it,
939 you know so if they want to save money, here's me ranting on the soapbox now, if they want
940 to save money by relying on members of the family and friends to look after people then they
941 are going to have to support them somehow they are going to have to support them
942 psychologically, physically and financially [yes] because otherwise we can't do it, you know I
943 don't have a pension cos I've always worked in the arts, people in the arts don't earn a lot of
944 money, they don't have proper pensions, I've got you know little bits of pension here and
945 there from various employments but I've been self-employed a lot during my life and you
946 know I can't live, I can't retire now, I can't retire until I drop dead, you know so, so yes, what's
947 the solution, it's a huge socioeconomic social problem,

948 I: If you want to be optimistic, I'm sure that there will be a solution some day?

949 P: Some day long after I'm gone though, as my parents always used to say, I used to laugh at that
950 expression they say 'after I'm gone such and such will be sorted out' and I think yes I'm saying
951 that now cos I can't see you know it seems to be getting worse, worse and worse,

952 I: Yes I think that's the thing, we're kind of reaching a pressure point [mm] and something just
953 has to change,

954 P: Yes I think it does, but I don't know, I don't have an answer to it at all, and I know people are
955 working in lots of different fields so the technology is developing, the medical research is
956 developing you know but at the same time, there's this massive waste, I suppose that's one
957 of the things that I've find really frustrating and that's maybe where technology could come
958 into this, indirectly so not maybe so much actually in the home but as I said you know the
959 amount of waste of money, my son works for the council at the moment and I mean he's just
960 gob smacked at the waste of money and you know they say we don't have enough money to
961 provide this service and that equipment and this medication actually they do, but they just
962 don't managed it properly and they don't manage their systems properly and they waste
963 money all the time, and they are totally inefficient and [name] says you know he's working in
964 the licensing department and he says that technology that they have, so we get the trams, the
965 trams use up all this money, the software that he's using, he says it's so antiquated I can't do
966 my job with it but they won't replace it because they can't afford to, it means replacing right

967 throughout the council system, it's too big a job, so you know so he says it's so totally
968 inefficient what I'm doing, [mm] constant repetition of tasks you know duplication of jobs erm
969 so yes technologies could be really good there,

970 I: Yes, I would definitely agree with you,

971 P: And then you could free up money and time to do the stuff that technology can't do [yes] cos
972 I think there really isn't much technology use in this situation unless you are going futuristic
973 robots and all that stuff, but if you are talking about right here and now the reality of what
974 existing technology can do then yes it can free up people to do a better personal human job,
975 [yes] you know, there's your answer,

976 I: That was, that was, I think that was the perfect closing statement, [mm] for our interview,
977 thank you so much again for taking the time [it's a pleasure] for talking to me.

978 END