

Interview 14, “George”

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I = interviewer, P = participant

I: Now so my first question would be how did the caring situation come about for you?
How did you become a carer?

P: My wife had frontotemporal dementia and although, in the early stages she'd been in [other country 1] and was misdiagnosed as well, we became aware that we'd got to go and see a doctor because I was here and then working in [other country 2] and she was in [other country 1]. Got her to [other country 1] my daughter came to [other country 2] as well. We bullied her to go and see a doctor (uhm)and that was in [other country 1] towards the end of 2013. The doctor in [other country 1] who was actually Polish couldn't speak English, this isn't racist, misdiagnosed her and said she was probably having had a stroke. They did various scans. When she eventually came back to the UK which coincided with the end of the work I've been doing in [other country 2], we had almost come to the conclusion that the problem was that it was a form of dementia. The form of dementia she had was frontotemporal dementia, otherwise know as early onset dementia, which has four, how would you say, the way it presents itself. There's motor neurone which is bad and there is behavioural which is bad. There is semantic which is where they don't understand and there is this dysphasia or aphasia where they can't speak or have trouble forming words. That's what my wife had so she could understand everything but she was beginning to lose the ability to speak and a certain amount of mobility as well. So that was the situation when she arrived back in the UK at the end of 2014 because to see just about the top specialist in, Neurological specialist, in [city] at this hospital. And he said straightaway 'frontotemporal dementia' and laid down what was going to happen. No going back etc. He was blunt. That's correct, that was his way of dealing with it. And it's one of those things. If she had got it when she was aged 40 for example, death would probably have occurred within two years. As it was she got hit just about at the end of the window at age maybe 65. Then you're looking at six to nine years for it to propagate, establish itself. So that was the situation when she came back in the end of 2014, being analysed in 2015, had voice therapy, speech therapy, which didn't work. If there'd been a stroke you expect to see improvement, with this it's just a continued decline. So I became her carer at that point. Well, as soon as she came back I suppose I was her carer. Then, her mobility decreased from there. She had a couple of falls which one, she was in hospital and they detected that she had something else wrong as well, she actually had colon cancer, colon cancer, and they removed that in May, June 2016. She had walked into hospital but she was wheeled out. So there was no easy, well you know at that stage I was having to dress her and so on, and help wash her. And then of course it was just a downhill after that. They wouldn't let her leave the hospital here until we had a care plan in place. Now I don't live in the town, I live in a

country house. And she couldn't get a care plan. The local care was coming in. There wasn't that facility available for us out there. If you're in the town, people can, carers can walk to the place. It's not so easy to get carers with their own cars. So we had a choice, we could leave her in the hospital which was a no no really, or we could look at the other prospects which were care in the home with a live-in carer. That's where we went. Now that's not a cheap option. It's about, I suppose in total probably came out about a thousand quid a week (a week?). And we were given by the authorities the maximum grant, or not grant really, where you are actually given funds to supply your own care, which came to about 450 and then there was the attendance allowance so net outgoing would probably still have been about sort of 4-500 a week. So that's not feasible for everybody. On the other hand, if she'd gone into a home that had a similar sort of problem, you know the prices are not too dissimilar. My home is reasonably well suited to care in the home and that is large, it's an old house. We're talking something in the order of 370 years old. Or longer or maybe it's been rebuilt in that time we don't really know, but a normal house, is a lot of space. The doors are wider, the corridors are wider. Although the main bathroom which had been done up, while she was in having the cancer op, was on the first floor, all beautifully done, easy access, but it was upstairs and she never even saw it. But then with a live-in carer, because it's a large house it was a separate wing, we could have the carer living in their own wing. So as you know we had a lot of advantages which a modern house would not allow you to do. Also of course from an electrical point of view, I had a lot of computer equipment a lot of comms equipment and at that stage I had stopped working as such on projects. All my work from that point on was trying to get paid for the work I'd done. So it was the legal stuff. But again I had the stuff there to do that with and. The big advantage with having a live-in carer as opposed to another friend of mine who was doing a lot of stocks and shares stuff himself with his wife, he could only really do it when he had carers coming in so he was almost in prison but he would get out part of the time, same class, the same group he was, he went to that my wife, so that's how we're acquainted. That was his chance to go and do some work as he didn't otherwise have that opportunity. But, erm, now I lost track of where I was going. Oh, yeah. Basically, I was then trying to do these other bits and pieces I could on occasion, well I could go out more or less when I wanted to because the carer was, a carer was there the whole time. I did eventually find local carers who could come in as well but that really gave the carer a chance to have a bit of time off. So I used my extra grant payments I received as a carer, respite payments really, to help carer as much as anything. I could ,with the care of downstairs with my wife, I could be upstairs working away quite happily (uhm) I could for instance come over and visit the lawyers in [other country 1] for a couple of days because there was someone there the whole time. So you know my situation is more flexible than most. My work situation was more flexible than most.

I: Uhm. Let's talk about your work situation in a moment. Just to talk a bit more about the caring situation. What would you say what kind of care did you provide for your wife?

P: [Pause as P drinks] Before we had the carer there it was a case of everything she needed I did. I was doing the cooking. I was helping her get dressed in the morning this sort of thing, helping her with the showering, except that she would, she had a couple of rules. I

85 didn't normally go into the shower with her, I'd help her get into the shower and she
 86 would shower herself but then you had these rules so thereafter I'd always wait just
 87 outside the shower. And that came eventually to the point where she couldn't do that
 88 anymore. And then of course I had the carers and they would be doing most of that but
 89 a lot of the jobs required two carers (Mm hmm). So you know it's occasionally there'd be
 90 two carers coming in. With one live-in carer, there's an awful lot that carer can do by
 91 way of being a companion, doing some cooking. You know my wife was able to sit down,
 92 watch TV and things like that because we'd move her from- the dining room was
 93 converted into essentially a hospital room with a proper hospital bed. I had my bed, a
 94 bed, down in the same room. We also initially had [patient lift?] so that we could help
 95 her onto, help move her off the bed and onto the steady and move her through.
 96 Eventually we had to use a hoist to replace that but again these are fairly large things
 97 which you couldn't have used in a smaller home. Do you mind if I just check that [checks
 98 phone]. Ok, not important. That was my son. Now I lost track again.

99 I: Yeah, so, the caring tasks that you provided for your wife.

100 P: Yeah. Well once we had a carer in place it was more a case of everything where we
 101 needed two carers. I was helping the carer to sort of get my wife dressed in the morning,
 102 that sort of thing. There were times when the carer would need to have a bit of a rest. I
 103 could do that, but I could also bring the extra carers in help and to give relief as well. So
 104 it was a bit more flexible than a lot of people would have. All my work I was doing I
 105 wouldn't do downstairs, I would be up in the attic of this sort of computer suite, office
 106 suite and just general mess and I could work up there quite happily.

107 I: Is it possible for a you to put a number on the hours per week that you spent on caring
 108 for your wife?

109 P: It varied as time went on. When I had the other carer there I was probably [long pause]
 110 in an actual caring role probably two hours a day and the accompanying role two hours a
 111 day. But that's to say that was with the other carer there as well. So it was, it could be up
 112 to four hours a day, that sort of period. And then I'll be with her when she was sleeping
 113 at night as well, I'd sleep down with her there.

114 I: So, before you had the live-in carer in place then-

115 P: There was a greater amount of effort obviously because I was having to do everything.
 116 At was a case that, I didn't like leaving her to just watch TV. She was never that sort of
 117 person. I did get an extra computer for her because she was watching a lot of I-player,
 118 BBC I-player. Then of course, because we didn't have a television set. Then they said you
 119 needed a licence even for the I-player and my father, and I had access to another TV. So
 120 that was alright, I got her a set-up box for that so it could work like a, a more intelligent
 121 TV. Again I had networks there already so it could wire it up anyway. So I did spend time
 122 sorting that out for her and helping out with that. But I had this other computer in which
 123 she in fact never used which had Windows 10 but, you know and a touch sensitive
 124 screen. But she never used it, never used it. I think she was finding it more difficult to
 125 learn new things at that point as well. At that stage, and of course I was doing all the

126 cooking for her before all that happened, so it was probably rather more before we had
127 that. So it could be eight hours or more a day.

128 I: So (yeah) talking about your work situation, can you tell me a bit about the work that
129 you did?

130 P: I'm a consultant mathematician. You probably haven't met too many of them (No, I
131 haven't; both laugh). My background is, I have a degree in mathematics from
132 [University], postgraduate on computer science also from [University] recipient to the
133 [redacted] fellowship back in 1972 to go and study do research and astronomy out in
134 [country 3] for a year. So that was all rather nice, came back and since then I worked in
135 the [company]. I designed the satellite, I designed and implemented and tested the
136 satellite section of the first indicator satellite system in Europe and then moved on to
137 GPS. Most people became aware of GPS in the nineties I was working on that in the
138 seventies, it was still top secret but theoretical rather than with hardware. Moved to an
139 underwater company in 1980 doing design stuff which kept the rigs in position, this sort
140 of thing. Underwater technology within a sorts. And then left that in 1985 and set up my
141 own independent consultancy. Everyone says you're your own boss, but in effect it
142 means everyone is your boss. So I was designing systems for people, underwater
143 systems, started using GPS for real then and again had some very great detailed systems,
144 looking at how systems behave in a theoretical way, applying new mathematical
145 techniques, this sort of thing. It was quite interesting. So that was as a sole trader, a
146 schedule D taxpayer. Then, because certain companies wanted more protection when I
147 became a limited company in 1993, although it actually kept the sole trade going as well
148 in partnership with working for people at the [redacted] Authority from 1993 onwards I
149 was working as a consultant to [redacted] in [city]. We're looking at air safety inclusion
150 risk over Europe. So that went on until...the last project I did for them, the last long-term
151 project I did for them in 2006 while still doing odd bits for them up to about 2010. (OK)
152 So I had an office in [city] until about 2010.

153 I: But it was always a one-person business, or did you have any employees?

154 P: I did subcontract work on occasions, not very often. It was mainly me subcontracted, or
155 my company subcontracted to somebody else.

156 I: Ok. How many hours on average would you say have you been working a week? Can you
157 put a number on that or was it very irregular?

158 P: About 176. Yeah about that [short laugh]. No, often it would be 100 hours a week
159 because there is, not that many people can do the work. And yeah. So you need to get
160 the work done. So it's a case of you work until the work is done. So I was living
161 separately from my wife a lot of that time. Now when I was in [city] the kids might be in
162 although, they eventually, but I went down to do some work in [country 3]. And just
163 after we moved up to Scotland, the house needed doing to it. My wife refused to stay
164 there by herself, so I went off, she said 'well you'll go off for three weeks, when you
165 come back in three weeks' time, then it will be fine'. Well three months later I still hadn't
166 come back. So she went off to [other country 1] with her mother, her father had just
167 died so they took the kids there as well. I said 'you should stay there until I come back'.

168 But when I came back the kids were already in school in [other country 1] then because
169 of the financial situation in 1988, you know you probably know the interest rates
170 suddenly went through the roof. We hadn't managed to sell the house down in the
171 south of England. So, the situation was we had huge borrowing, so we didn't know
172 whether we were going to be able to keep the house up here. Rather than let the kids
173 get used to a house which they couldn't, maybe wouldn't be able to stay in, they stayed
174 in [other country 1]. So the work and financial situation stabilized somewhat but by
175 stabilizing it also meant I disappeared. They came back here but I was somewhere else.
176 Then in '96 they joined me in [city]. My son got bullied here at school in [town]. He has
177 Asperger's but he's a bright lad. But he was just a bit different from the big, the kid from
178 the big house outside of town and so we found there was a loophole in the regulations
179 in [city]. We mentioned that our kids, you know it was a very favourable European
180 school in [city]. They got on very well there. So that's nice for the whole family to be
181 together for a while. (Yeah) But then I've had to come back here, and we came back for
182 some holidays, but I often came back by myself just to sort out, just check things over.

183 I: So when the dementia was diagnosed you said you had a couple of trips to [other
184 country 1] to sort out the business, but other than you spent most of your time here?

185 P: Oh yes, I was at home most of the time, yes.

186 I: So, erm, the current situation is that you are in the process of dissolving that business
187 (That's right). OK. When did that, when did you basically stop?

188 P: Well the last work I was doing for payment was in, it was between 2016 as well but
189 through an American company for the same customer in [country 2], which is the
190 [country 2's] airspace navigation systems. Air navigation systems. And but they didn't
191 like the [country 1] company, I didn't like them either because they hadn't paid me. So, a
192 lot of my time was spent fighting them through, basically it was then through lawyers.
193 Then taking the lawyers, who were disciplined because they, they hadn't handed over
194 the evidence to the court which was ludicrous. So, all this was really trying to get the
195 money back I was owed. I'm not talking huge amounts, but we are talking 150 thousand
196 pounds which is not insignificant. Particularly when coming up to retirement and when
197 you have spent a lot on care as well. So that's what that. But to say, there was still a little
198 bit of ongoing work in particular over the Christmas period in 2015. The same work I've
199 been working with an over in [other country 2]. I've only spent, so really I think about 50
200 or 60 days a year in [other country 2]. But again I was working from home on high speed
201 networks and so on. So, you know I didn't make a great deal of difference over the
202 Christmas period. My son and my daughter was up here as well and I was going up or
203 disappearing upstairs sitting at the computer to get things going. So it didn't take an
204 awful lot of time, you can do quite a lot in a short time.

205 I: So talking about how care and work sort of collided. Was there, were there instances
206 where you would say that care impacted on your work or work impacted on your ability
207 to care?

208 P: Probably in a mental way rather than a physical one because I could, as I say, work up
209 there when the carer was down with her. I could just be upstairs and I could work away

210 and I could work and with the sort of work I do it doesn't matter what time of day you do
211 it. So it's quite fortunate in that way, I'm not dependent on other people. I stand, I'm
212 also, I have my own data and my own analysis. I've got all the references I could need.
213 And I know where to find references that I don't have. It's useful having them, it's not a
214 particularly high-speed network that I have, both my lines. The idea was I could link
215 them, in fact I never did. I kept, I kept one as a reserve in case I needed it. I was getting
216 about, between 14 and 18 megabits per second which isn't too bad. You can do most
217 things with that. The, you might not be downloading big videos and playing games. Let
218 me be honest, no one needs that. It's just a complete load of codswallop. Most people
219 just don't need anything like it. The financial service would be better off without it as
220 well. They say we got instant access. Trouble is that instantaneous access and high-speed
221 communications makes for a very unstable system that's what causes those crashes.

222 I: So when you talked about more of a mental impact rather than a physical, can you
223 elaborate on that a bit?

224 P: Well you've got concerns for your wife and you think about that the whole time. You've
225 got the, a fairly stressful situation when you're trying to sue someone. And if I was going,
226 you know when I was doing the work there was a very short turnaround on the work, it
227 was only about two weeks and I had to get a lot of data through a lot of information.
228 Fortunately I had to, for me, actually it was re- and analysing data that I had already got.
229 So it was quite convenient. I could do that and I could process the data and get it sent
230 off. But the actual amount of data was huge.

231 I: So the concerns about your wife, was that more for her physical well-being or that she
232 might have a fall or was it more-?

233 P: Well not then so much because she was not mobile enough at that point to have a fall.
234 Not once, not once we had the carer in place. Prior to that it was a worry because she
235 would have, between sort of 2015 up until the time she went to the hospital in April-
236 May 2016 for the operation. She was becoming less able but she would still go up and
237 down the stairs and I had extra bannisters put in but she was using them particularly
238 well. So I knew she was going to try and get upstairs or downstairs in particular, I'll try
239 and get there and be there. She was fairly determined to do it herself because she didn't
240 fall on the stairs at all. She did fall twice in the shower and needed an ambulance on
241 both occasions.

242 I: So when you talk about you are trying to anticipate when she might want to go up and
243 down the stairs, how would that work? Did you have anything in place that would notify
244 you or would you constantly have to have an ear out basically?

245 P: I did set up a door bell system for her to use but she never did. Basically these sort of
246 things you dangle around your neck and I just put one through the wireless doorbells on
247 it and a couple of receivers around the house. So if she would press it then I'd know she
248 needed me on occasion, but she never did.

249 I: Do you know why she never did?

250 P: She never fell with them on and she never had them on in the shower and I'm not sure
 251 she would have pressed it even then. I really don't know that she, I don't know, she
 252 really understood quite what I had in mind. You know she could understand
 253 conversations quite happily, she was a bright lady. She was a journalist by training. But I
 254 don't think she really grasped that.

255 I: Yeah. So talking a bit more about support that you have received. So you talked about
 256 the support, the more or less practical support that you received from the carers. Have
 257 you, was there anyone from maybe family or friends that helped?

258 P: There was a friend who I used as someone who could come in if I was away [section
 259 redacted at request of participant]. Apart from that we had other friends that came over
 260 from time to time if we had friends there we'd always turn my wife around so that she
 261 was part of the conversation and she'd seem to follow the conversations quite happily.

262 I: And regarding your own needs, so how have you received for example a carers'
 263 assessment?

264 P: You mean, sort of mobility training that sort of thing?

265 I: Well, basically an assessment of your needs as a carer from the council?

266 P: Erm, not really. Although I did have, what do I call it, whether or not it was having an
 267 impact or not, there was something done but it really wasn't particularly deep and
 268 wasn't followed up.

269 I: OK. So talking about technology then. Have you used any technology to help with caring
 270 or combining work and care?

271 P: Only that I have special technological items that make working from home pretty easy.
 272 You know, big printers, I have big storage systems, I have fast enough internet, I have
 273 back up internet, I have external power supplies. So most of these things I have. I've got
 274 network shifted through the house where I was able to link up the smart TV in the room
 275 she was in. Prior to that she was using a network in different rooms when she wanted to
 276 connect to the interface, erm to the internet herself.

277 I: And, erm, so you talked about basically equipping your wife with those mobile doorbells
 278 (Yes). Were you using anything other than for example to help with caring?

279 P: Only at this stage when she was using the network to access the BBC I-player and was
 280 watching that a lot (So in terms of entertainment). As I was saying without having a TV,
 281 that was quite useful, to watch programmes on there. It must have been, was it
 282 September 2016 they changed the rules on that which is when she came out of hospital
 283 and by then was wheelchair bound. So you know we had to, by then to get a TV licences
 284 and bite the bullet and get her connected via the Internet.

285 I: Can you think of anything that, it could be technology but it could be not technology-
 286 related, that would have made it easier for you to combine working and care, to be a
 287 carer?

288 P: There was something earlier but I can't remember what it was now. I suppose I could say
 289 we could have had cameras, I do have cameras but they weren't used in any caring role
 290 at all.

291 I: Have you considered using them for a caring role?

292 P: I had thought about it,. You know, it would have enabled me to go out of the house
 293 without a carer there and see what was going on. But having got a carer involved as well
 294 it was fairly pointless. And there are potential problems with when you start using
 295 cameras. There was a care call installed. I kept that on now in my name rather than my
 296 wife's in case I have a problem. Whether or not I'd ever be close enough to it when it
 297 was necessary I don't know.

298 I: So this care call, is it just one home station (it's a home station). So do you have it as a
 299 bracelet? (It's a bracelet but I never wear it) Yeah. OK. Has your wife ever had to use
 300 that?

301 P: She had it but she never used it. (So it's never been tried out?) Not in anger. That's just a
 302 test, just a test case. Yeah. I have alarm systems in the house as well. But for general
 303 security as much as anything else.

304 I: So when you say alarm things you mean more like intruder alarm?

305 P: Yeah. Yeah. Or smoke alarms which are obviously necessary in a house. Particularly if
 306 someone's not well.

307 I: I see. Yeah. Just let me have a quick look what to address next. So, if you had a magic
 308 wand, or if you had had a magic wand back then, what would you have liked technology
 309 to do for you? So if there were no limitations what would have been helpful for you?

310 P: [Pause] I would have liked some way in which she could have communicated. The fact
 311 that she was getting unable to speak was getting a problem. She used to say 'no no no
 312 no'. That might mean yes, although I could interpret it partly by knowing her but also
 313 maybe there was a slightly different intonation. I don't know. I suspect that some means,
 314 well you know there was Stephen Hawking who was also my colleague as well so I knew,
 315 well, sort of knew him, he had that system where he could use his eyes. I'm not saying
 316 she could have done that but I think they're becoming more intelligent to interpret
 317 actions and such like. Maybe she could have communicated more easily. So that that's
 318 one area. Well that's for her specific form of dementia. What else? [pause] The one thing
 319 which was useful she started getting very nervous when I went away even for a few
 320 days. According to the carers she was getting quite agitated when I wasn't there. But
 321 what we did find was helpful was being able to use things like WhatsApp or Skype to
 322 communicate. She could see me. (Yeah) So that's something to keep in contact because
 323 they do become more nervous because they become much more dependent. That's
 324 something to consider. (So that's something you actually have used?) Yes. I mean on the
 325 phone, we could see each other.

326 I: Did you have the feeling that that helped in that situation, for her to see your face?
 327 (Yeah, yeah definitely.) Just to, just to continue on that, do you think is there anything,
 328 does anything come to mind how to improve that even more?

329 P: I suppose with a smart TV. I think that we're spending a lot of time in front of the TV. It
 330 might be easier if I had phoned for example and had come up on the TV and I knew she
 331 was in front of it, it wouldn't have been necessary for the carer to be there with her on
 332 the phone. One thing in which the extra carers were had came with was a dog, a dog,
 333 not a technological dog but a real one. (A real one, okay) So that was another thing. But
 334 that's not part of your remit I suspect. (Well it could be anything yes. Talk a bit more
 335 about that) About the dog? Well she was very fond of it. I was a bit pissed with it
 336 because it kept climbing up on my back. I didn't like that. She liked it climbing up (was it
 337 a small dog?) It was a cockapoo which is a cross between a cocker spaniel and a poodle.
 338 But they have one particular benefit which is they have hypo allergenic fur.

339 I: Was that, was it is specifically, was it a trained dog?

340 P: It was being classified as an MO dog or something to help with homework or (to give
 341 emotional support?) That's right. And my wife certainly liked it being there. [shows
 342 pictures on his phone] That was the last carer. Normally they stayed, it was a two month
 343 long stay and then they moved on. She came in March and stayed to the end. That's it
 344 [dog] (Oh he's cute). Interestingly enough they came round after my wife died. The other
 345 carer had come up as well. And we were having a meal in my room and that dog went
 346 whizzing around the house and into the room which we had used as a bedroom or
 347 hospital room. And then we couldn't find it when they were due to leave. We went in
 348 there and found it cowering in the corner in that room so who knows what else they're
 349 aware of. [shows more pictures] That was just at the end. That was in the last, about five
 350 to four, five days before she died. That's our daughter, was able to come up. If the live-in
 351 carer and myself had been there when she had that seizure she would have died that
 352 night. As it was the other two were much more medically trained and saved her till the
 353 ambulance came to take hospital. We refused. There was a non-pick up clause at that
 354 point. When the normal, the Marie Curie nurses came, they were aware of the non-pick
 355 up clause, speak to the driver and we were able to keep her at home until the end.
 356 [more pictures] not the best picture of either of them but they got on like a house on fire
 357 those two. May not have been trained medically. But just what my wife needed. So
 358 that's what they need most is a cheery face. (Companionship, yeah). That's just to scare
 359 you [picture] (laughs) That's the back garden. To give you some idea of the house, give
 360 you some idea of what sort of place it is so you can imagine (wow, it's a lovely home).
 361 Yeah it is old. And as I say the doors are wide, it makes life easier.

362 I: And so talking about the dog a bit more. Do you think, was your wife able to pet it
 363 (yeah), was it the physical contact?

364 P: Well maybe she couldn't really do an awful lot. She became awkward trying to do things
 365 with her hand but it climbed up on her as you just saw in the picture. I think she might
 366 have done a bit. Yeah but she was glad that it was there. Yeah.

367 I: That's really lovely. So is there anything else that comes to mind that, that might have
368 benefited your wife or yourself?

369 P: [long pause] One thing which I did well, because she was no longer able to go upstairs, I
370 fitted an extra shower room in the pantry. That's still in there, the shower, fitted this
371 extra shower facility, it was never that warm in there but we got some form of heating
372 there. I put bubble wrap on the windows to keep it warm. But she never liked being
373 showered but she probably only had about half a dozen or ten showers altogether, never
374 more than once a week. Towards the end she just didn't enjoy it. But one thing which I
375 did. Also we tried it out, got her back on the bed to dry her. I always then used a
376 hairdryer both on her hair but also to keep her body warm. It was just an idea but it
377 worked. So that's maybe sometimes people think about you know a directed warm air
378 source can be useful in drying someone. Not just the hair. Towels can sometimes be a bit
379 awkward.

380 I: Yeah. Okay. So to wrap up basically what we were talking about, what would you say
381 were the most positive and the most difficult aspects of combining work and care for
382 you?

383 P: Um I often felt guilty getting on with work when I felt I should be with my wife and also
384 felt guilty when I was with my wife and I knew that I needed to be doing something for
385 work, so that, that aspect which you really can't get away from. Because I couldn't really,
386 I could have taken the computer down quite happily and worked next to her. It's not.
387 Most people if they're doing some sort of work or sort of work I do certainly couldn't be
388 done down there. I need to sort of have my papers out all around me so that wouldn't
389 have worked. Come on brain [long pause], erm, I really can't think of anything. As I say
390 there was something earlier that crossed my mind, earlier on. It's disappeared into the
391 depths of my mind. My own memory has deteriorated considerably. You know maybe
392 it's just the extra stress of the situation so you can not recover from it in the way that
393 you expect you might.

394 I: And can you think of any positive aspects of-?

395 P: Of doing it (yes)? It brought us really close together. We have been spending a lot of our
396 married life by necessity in different places. But it did bring us together much more
397 closely towards the end. Even if it was a dependence of one on the other. Now I think
398 that is probably the only plus I can give to it really. I can't think of, I can't think of any
399 pluses from her point of view. Except that it's your destiny and there's nothing you can
400 do about it so.

401 I: Is there any advice that you would give someone who is in a similar situation, who is also
402 working and caring for someone with dementia?

403 P: I think the ability to have a live-in carer gives you much more flexibility. It's good to have
404 the backup of the other local carers but look again at this other friend of mine who
405 financially was way better off than me. I'm not, by the local standards I'm probably quite
406 well off, but compared to him I'm not. But he had moved from an old place, a bungalow,
407 into a more modern place which didn't work. He had to turn his office into the bedroom

408 because it was on the ground floor. The doors were that much narrower which makes it
 409 more difficult and he had carers coming in and he was run ragged by it because his wife
 410 had, she went downhill with Alzheimer's, so she didn't have the same problems as we
 411 but it was beginning to take its toll on him. He will probably be here shortly but I don't
 412 think he'd want to talk about it for various reasons.

413 I: So if you can, try to get a live-in carer?

414 P: If you've got the circumstances to make it work. The other thing is, that live-in carer was
 415 basically doing house cleaning as well and was also cooking the meals and that took a
 416 load off the plate as well. It wasn't part of the job, really. No, but she was feeding [wife]
 417 and feeding herself and I would supply all the food and I got a benefit from that. So it
 418 worked in so many ways. We're still good friends and now she's come out here a few
 419 times with her niece. She's from [place] and she was this bundle of fun. So that's been
 420 nice keeping that friendship going. You know she came part of the family for nine
 421 months. Let's face it. Yes it was, it was better but it depends on the carer you get, of
 422 course. [section redacted at P's request] So there is that side. You can get a good one
 423 there. Very good yeah. But you've got to get on with them.

424 I: Yeah. So just very briefly, you said that you had, you and your wife have children. Have
 425 they been able to help with caring at all?

426 P: No. My son lives in [other country 1]. As you know my wife is [citizen of country 1] and
 427 he has his own family there. He came over when he could. And also my daughter worked
 428 very, very hard and she got her degree at [University] and became a zookeeper but she's
 429 been living away. She didn't, she hasn't had the opportunity to come up there. She is
 430 working flat out doing what she's doing. I was down with her a couple of weeks ago.

431 I: So the final question would be, what do you wish for yourself? Or considering that the
 432 caring situation has ended for you now, what have you been wishing for yourself when
 433 you were still a carer?

434 P: As a carer? Well, I would have liked my caring role to continue longer. I was very sorry to
 435 lose my wife. Now I had a long time to be aware that it was coming to an end and I got,
 436 you know, from the beginning I knew the time was limited to three or four years maybe
 437 from when she was officially diagnosed in early 2015. So there's two and a half years
 438 afterwards. I know it's fairly obvious that she was going downhill, you could see it
 439 happening, we knew it was coming to an end. So in a way I almost had prepared myself
 440 but for all that it sort of came out about a year later. I've made a friend in the meantime
 441 but I'm not quite sure what that relationship is. I'm not sure that was probably the
 442 situation I should have been aware of before I started meeting other people. I was just
 443 that we're working on something else together, but we are good friends. I was out with
 444 her for lunch today. But it's, it got a bit awkward at times as well.

445 I: Thank you very much. So I just have a couple of very quick questions for the context. So
 446 how old are you?

447 P: I am now 70. I know I look 21 but (laughs).

448 I: How old was your wife when she passed?

449 P: She was 71 when she died. I was cradle snatched (I'm sorry?). I was cradle snatched,
 450 (cradle snatched, I've never heard that expression) when you are a bit younger than your
 451 wife. Well if someone is, if one partner takes out of a younger age but in our case it was
 452 two years so it wouldn't really count.

453 I: Yeah. Cradle snatched. I will remember that. Yes. So I think we have addressed
 454 everything else here.

455 P: But was it useful?

456 I: Absolutely. Thank you very much.

457 Tape continued after a brief chat as P wants to add something:

458 I: Go ahead.

459 P: Yes the care system as it is here. You know particularly when being in hospital and such
 460 like and as they go downhill, you've got to get a power of attorney. You don't get that as
 461 early as you can. In my wife's case because the problem was oral, more than anything
 462 else at that stage, the solicitor was, who knew her anyway, said 'Well I'm pretty certain
 463 myself that she knows what she's signing. But I'd very much like the doctor to say that
 464 she does.' And the doctor couldn't do it because it was a local test. So they eventually
 465 had to go to the [hospital] which was the men- not the mental hospital that deals with
 466 that sort of problem in [place]. So it's a psychiatrist or psychologist or I can't remember
 467 which it is. And came across a doctor that, whose name I won't mention. He was asking
 468 her questions, and this was, I should add, shortly after she'd returned from [other
 469 country]. And he was showing her a test with two pictures and one picture two words
 470 and one word or some combination of these. Where it was pictures she was fine, where
 471 it was words she was fine, where it was a mixture, she'd be down just a tad, you know,
 472 making relationships. And then he decided he ought to ask her general knowledge
 473 questions well, current affairs. And she couldn't answer them. Well, she had just come
 474 back from [other country], she hadn't been immersed in UK current affairs. So I said
 475 'Well you know, you're making your judgment based on that.' He said 'well she's got to
 476 go, you've got to go and get guardianship, you should be going through the courts.' A lot
 477 of old codswallop. This guy you know, part of his reason for it, she couldn't answer the
 478 British current affairs special. So I said 'She's back from [other country], you know that
 479 she's [other country's] nationality. Let me ask you a question. Who's the Prime Minister
 480 of [other country]'. The most, the biggest question of all. (Yeah) And if you'd been a
 481 [other country's national] you'd know this like that (yeah). And he couldn't answer it.
 482 And I said 'well, what you've just said about my wife equally applies to you.' (Yes)
 483 Fortunately there was another psychologist who was a psychologist for the area. He
 484 came over sat down with [wife] and was asking question. He was more like a researcher.
 485 He was following his nose and he was making notes. And he wrote down a complete
 486 description of this, said 'Right. She's fully competent from such she knows exactly what
 487 she was talking about.' And he gave the full reasoning why. He knew what he was doing,
 488 this other guy, forget him. But that's the problem. I mean you get to a point where it

489 becomes difficult for them to answer questions whether they are going to be compos
 490 mentis whether they can answer the questions about their own medical or financial
 491 matters in particular the medical ones. You don't get that sorted out early, you've got a
 492 problem. Even when you've got it in place as we have it here again I couldn't get her out
 493 of the hospital until that care package was in place and even then I had to make a
 494 decision, I had to sign her out. And again a doctor had to say she's reached that point.
 495 Fortunately, the same psychologist was there he was part of that meeting, and it all went
 496 smoothly. But that's an area which is very difficult. Another area that's very difficult for
 497 carers is the new rules concerning the way in which this money is given to you and the
 498 way you hire carers whether you become an employer or not. Well you've probably
 499 come across this as I did. It's basically the subsidiaries legislation that came in around the
 500 end of the nineties because a lot of large UK companies were laying off their staff and
 501 rehiring them the next day as consultants and this was known as IR 35 Inland Revenue
 502 (uhm). So, basically, they were doing that they got the company out of doing national
 503 insurance costs that sort of thing and it appeared to be better for the individuals as well
 504 that the amount of money and the less went into the coffers of the government. So, they
 505 really came down on it like a ton of bricks. I was actually used as a test case for that
 506 because I was over in Brussels and I sent my details in and as I say as a test case and they
 507 came back to me 'we think you are definitely caught under the legislation.' So, money for
 508 that. So 'Are you working for the [agency]?' I said 'Yes'. They said, 'There's an agency that
 509 settles it all.' That means they're acting on your behalf if you're actively employed. I think
 510 you need to know what the [agency] is an intergovernmental body governed by
 511 international statute. You've not seen them, and you've never run so fast in all your life.
 512 They backed off that very very quickly because that start's dealing with all sorts of very
 513 difficult subjects (both laugh). But that's it. There are these aspects of care which are
 514 more problematic. The average person myself included didn't know whether officially I
 515 should have been, you know, the live-in carer, there were two things that went out each
 516 month. There was a fee to the carer and the fee to her agency. Now they might have
 517 been the employer, but she had a relationship with them. So, I was paying a fee that I
 518 wasn't paying any taxes for her because I wasn't in control of her, that wasn't master
 519 slave, but this is becoming a very difficult situation. And that's what carers really need
 520 help on. There's not even the council to look at these funds seem to be able to fully
 521 understand and explain that. That's a big one needs to be sorted. It's going to become
 522 more and more prevalent. And it's going to be because they're trying to send the funds
 523 to the individual to buy the care rather than deal with it more centrally. Has advantages
 524 but it has its disadvantages that no one quite knows where it stands anymore. And it's
 525 not an aspect of tax or the average person unless I'd been an employer or someone
 526 running their own company as I had would've had any idea. But even for me it was a
 527 problem.

528 I: So at the local council there is no one that could really advise you on that?

529 P: Well then at that point they were learning as well (uhm). You speak to the tax authorities
 530 and they won't give you a straight answer. They dare not (they dare not?) almost no,
 531 because once they've given an answer it can be used against them.

532 I: So the system is even too complicated for the tax...?

533 P: One says definite answer though it's very difficult for them to backtrack on. And so what
534 they do is they say 'well, you know, fill in this form and we'll give you an answer.' In fact
535 you can do it yourself online and see what it says. It doesn't have to go through them but
536 they will then say 'well we think you were right but we reserve the right to come back on
537 it' or something (oh dear, that's really complicated). Yeah yeah that's got to be sorted.
538 Yeah because more and more people are going to be in this and you want to make it as
539 easy at this side of it, you want to make it really easy for the carer. They've got enough
540 stress and strain without having to do all that. Yeah there's more link workers in councils
541 than there are, you know, link workers between this system and you and that system
542 and you, you really want people in the system to be doing the work not someone linking
543 you to it, it's a bit useless, but they could put more people into actually doing the work
544 rather than linking to the work. Yeah. (Thank you) I don't know if that was a worthwhile
545 addition.

546 I: Yeah absolutely it was. Absolutely. Thank you.

547 END