

Interview 13, "Gavin"

Date: 5.6.2019, Duration: 72min, Setting: pub

I = interviewer, P = participant

I: OK. So to start with can you tell me a bit more about your caring situation? How did that come about? How did you become a carer?

P: I became alerted to my family's situation back in 2008 approximately, which was whilst I was still in full time employed work and I was really alerted to my father's circumstances. He had some financial issues that seemed a bit strange and in probing that a bit more he was talking about releasing a substantial amount of money from his, from his house. He recently remortgaged, I became aware that he was having a lot of difficulties and over time as I got closer to my mother and father and spent a lot more time with them, my father died 2014, I became aware that they both were developing signs of dementia that went through with a diagnosis that was confirmed for my father I think relatively soon after that, 2010ish and my mother some 4-5 years later. So since that time over the last 10 years it's been a major change to my life and has affected my circumstances.

I: Can you maybe talk a bit more about the sort of care that you provided for your parents?

P: OK well, initially I got involved with the local authority's social services, social work and took up their standard care package for my father. Using available agencies to provide medication services and periodic orientation and help which then led to investigation of whether day care was appropriate which didn't really work out. But of course, at that time my mother was still able to get my father. So, I was rather more passive in that respect apart from the financial households. So fortunately, my parents had both had the foresight to engage a solicitor, somebody as previously, and I was given the opportunity to take power of attorney for them both which was registered at a later date but at least it gave me the communication channel for legal and social sort of, social work to be able to do that for them. So as time progressed, and then I had to progressively do more and more both in terms of health and in terms of welfare and today with my mother still living at home I really do everything for them that I do for myself and more. The personal care side of things, I only do a relatively small amount and didn't undertake that for my father. But now if a situation occurs for my mother in between the visits of the personal assistance then that does involve very close personal care.

I: Can you say roughly how many hours a week on average you think you have spent or are spending on providing care?

P: Well in the last three years it's been rather more than previously, and it's probably affected by the peaks and troughs in between changing the care plan for my mother as

39 that increased and in terms of the changes of the options that I was given by social work
40 in order to manage the care. I can go into more detail about it (Please do). Okay, so, two
41 years ago, approximately two years ago I had a discussion with them as it became clear
42 that the services that they provide where the Local Authority manages the services,
43 chooses the agency, I have no control. They operate according to the care plan of so
44 many hours a day, that was along the lines of half an hour visit in the morning, a half
45 hour visit at lunch time if my mother was there, another visit in the evening which was
46 normally half an hour but invariably the length of the visits were dictated to by these, by
47 the actual carers themselves. Very simply they might do what was necessary in terms of
48 medication, general orientation and questions of personal hygiene, meal prep if it was
49 really required. Simple meals that is, prepared meals. But if they could get through that
50 within 15 minutes, they left within 15 minutes. That was allowable within the contract
51 that they were on. But it quickly became evident that despite mother's condition
52 progressed that the amount of care was far, far short of what she really needed in order
53 to live a comfortable life. When she ceased to be able to prepare meals and she ceased
54 to be able to take care of hygiene then I had to consider either full time residential care,
55 and I did go down that route of having a trial arranged for her just over two years ago,
56 but it didn't work out very well. It was defined as a respite so there was a beginning and
57 an end although that wasn't how it started out but that's what I was presented with. And
58 she was extremely disorientated and confused and upset. She was very glad to get
59 home. And then I started to look at more extended care as to what was available
60 through local authorities and what, if you like, I could apply for in terms of support to
61 help her with that. I'm just gonna have a mouthful of coffee.

62 I: So, talking about proximity to your mother, how far away would you say do you live to
63 your parents?

64 P: Well, that's an issue because I am close to 400 miles away. So, a journey here is not
65 something I can make in a week and back. Apart from the expense, it's the time. And
66 particularly whilst I was working it was impossible, so I've had to work on a remote basis
67 and I've planned, probably when I look back at it, made pretty regular visits every three
68 months but then it reduced it to two months but several weeks at a time until I got the,
69 the change administered with the local authority to take on what was called self-
70 directed support. So this may be something you know about but it's what it was, I felt
71 was the best way forward. I read the information provided, it gave me control over a
72 certain budget because my mother was qualified as requiring or be enabled eligible for
73 residential care. It meant that for her condition I had relative to the financial assessment
74 that was concerned at least a significant contribution towards the care costs. But as time
75 has progressed my time and funding has increased. So, whilst I could look towards a live-
76 in carer type arrangement I haven't done till now because I have managed to find two
77 very, very good carers that work together. Initially started on a self-employed basis but
78 because of the way self-directed support works, they were more comfortable, the
79 workers themselves, with an employed situation.

80 I: So in each of these casers it was you was having to find the information, organise the
81 support, coordinate the support or was that-?

82 P: I was given a certain amount of help by the local authority. (Okay) And in fact whilst I
83 had initially a self-employed carer, not one that I employ now, that was only a temporary
84 arrangement and wasn't really sustainable. I needed that at the time but it formed a
85 little bit of a bridge until I got the introduction to the two carers who probably prefer to
86 be called personal assistant as a proper title because they are able to do contractually
87 much more than just fulfilling the standard carer type job.

88 I: How does that usually work with self-employed carers? Is it you saying to them what you
89 want them to do or are they, are they assessing that themselves?

90 P: Well, initially they had the mindset of self, being self-employed because they were used
91 to doing that and that they had other clients that they worked for. They have their own
92 cars, they move from place to place and so they could legitimately claim to be self-
93 employed because they were effectively running the business dictating what hours they
94 could provide services and when they couldn't with a large degree of automation,
95 autonomy, autonomy I should say. And that as far as HMRC are concerned it is a
96 requirement for them to be recognised as self-employed. With employment it is a
97 different matter. They have a lot of autonomy in terms of the way that they conduct
98 themselves. But ultimately, I am responsible for their payroll, for their hours, for all the
99 employee circumstances and benefits that they have has rights to be employed people.
100 That includes optional provision for pension. It includes potential qualification for sick
101 pay or holiday pay or all those other things that people take for granted in terms of
102 employment. Having said that, again their mindset and the way that they work, because
103 I'm away, and not being directly supervised all the time they work in a very good
104 motivated manner which is more than can be said for the previous arrangement.

105 I: I can see that. And in terms of, it sounds like a lot of administrative effort for you.

106 P: It is, yes, much more than I might have initially hoped for but it's inevitable. I can reduce
107 some of that and I don't need to micromanage but I make use of an app on my phone for
108 communications which, which I'm using daily, as well as direct phone calls.

109 I: So is that an app from the (It's WhatsApp). WhatsApp...

110 P: Ok, ok so both, both personal assistants and I have visibility of all the chats. I just use it
111 simply just to, to share, share important notes or it can be anything such as 'Shall I get
112 some potatoes on the way' if I'm up here, to communication that relates to an
113 appointment to the doctor's.

114 I: Was it your initiative to use WhatsApp to communicate (No, it was theirs), it was theirs,
115 ok. (Yeah) OK. Are you happy with the app, WhatsApp, or is there anything you would
116 like, any improvements you would suggest?

117 P: It's adequate for what I use it for. Periodically I delete, I don't require archival usage of it
118 but it, it's useful for example if I need to check perhaps days when we had a particular
119 conversation and cross-reference it to make sure that I'm referring to the right PA who
120 was there on site at that time when she communicated. It could be any particular event
121 because they send their time sheets to me and if they make a mistake or if I make a

122 mistake then we've got a record for the last month of communications we've had during
123 that month.

124 I: Yeah, that sounds quite useful.

125 P: More useful than a telephone because it's recorded (exactly), alright, maybe only
126 temporary, but it's effective as a tool and all that.

127 I: Is it possible for you to put a number on how many hours a week you spend coordinating
128 this kind of care support from a distance?

129 P: Well I guess that there's a, there's a, for everything I do there has been an initial time
130 which is gathering the information, understanding what I might need to do, I need to
131 communicate with, particularly in the original set up of the care plan, because I wrote
132 both the job descriptions for the carers, submitted the plan which had to be approved
133 for by the local authority in order that I could make use of the budget that was provided
134 to me. But because I have been used to in my profession doing that kind of admin meant
135 it was not particularly arduous. So, to try to answer your question more specifically, it's
136 not something I keep an account of in any way. I don't claim a carer's allowance. Haven't
137 done so far. So, it's whatever is required. I think if I just think mentally now about the
138 hours or a week or the hours a month I might spend [pause] the actual WhatsApp
139 communications is probably three or four messages a day something like that. So, you
140 can count that in minutes, but you could find a chat might last 5 or 10, 15, 20 minutes
141 depending on what the issue might be. So, it can be as little as five minutes a day to a
142 half hour or 40 minutes a day and that's just on the general communications. Then in
143 terms of employment then I will be getting either a timesheet which is a schedule for
144 their month but that's pretty passive. It's more a matter of when I then get their time
145 sheets later in the month I'll need to verify, cross-reference it against any records that I
146 keep just to make sure that there are no mistakes. I want to be fairly accurate and fair.
147 So that is used to send to a payroll company so I outsource that to an accountant. They
148 also provide services for nannies as well as carers etc.. Fortunately, this firm know what
149 they are doing, and they provided a lot of help in terms of both information and number
150 crunching really. So, I don't have to work out National Insurance and tax and pension,
151 they do all of that. All I have to do is make sure that they have the hours that were
152 worked, that I get timesheet back from, sorry, the payslips back from the payroll
153 company that I then send on to the carers and then arrange for the bank transfers.
154 Either, either directly or through the local authority tool that is provided for me. So on a
155 monthly basis that could be three or four hours.

156 I: Are you happy with the whole process and how this is going, or would you like that in
157 any way improved, maybe more efficient?

158 P: Well I have fed back some information to the local authority. The main issues that I had
159 at the start of the service was honestly this question of self-employment versus
160 employment. When I first started my search for carers most of the carers worked
161 through agencies. A number of them are from overseas, either from Europe or other
162 English-speaking countries and therefore the agencies were supposed to be their
163 employers. In practice they were no more than introduction agencies and the workers

164 themselves were self-employed. So, when it came to me asking searching questions as I
165 was to prove that they had registered with HMRC as self-employed people and I needed
166 their tax codes. It was a big 'no, no we're not, trust us, we know what we're doing, but
167 you're not having that information' and that threw us into conflict. So that whole area
168 and the way that I was more or less being pushed by the local authority because of their
169 compliance with HMRC for taxation in order to prove to be the recipient of the monthly
170 funds for care planning that I had to be seen to be whiter than white as far as
171 employment law is concerned because so easily self-employed people can abuse the tax
172 system. I'm not saying that they would, but that's, that was the concern that local
173 authorities have if I, they wouldn't stop me from using the self-employed people, but
174 they put obstacles in my plans. So that area could be a lot, a lot better managed, for the
175 sake of the person, as it left me an awful lot of work and conflict.

176 I: Yeah. Yeah, I can imagine. So, talking about, a bit about the work situation. Maybe first
177 let's talk about the job that you have left a couple of years ago that you told me about
178 on the phone. Can you tell me a bit more what the job was about? What was your job
179 description for example?

180 P: Do you mind if I just go back one step because I didn't actually fully answer your
181 question about time. (Ok. Yeah) We'll come back to that. So, because of the way in
182 which I utilized the carers I make sure that I fulfilled the quota of the number of hours
183 involved in the care plan. There can be some interruptions for that. For example, my
184 mother was hospitalized. She was out for, for a month and also into any rehabilitation
185 that she needs after hospital. If it's better that I'm around for that. So there has to be
186 some flexibility in the way that my role integrates with the carers' role and I'm happy
187 that they fulfil everything that's in their job description as appropriate for the local
188 authority but because I'm staying with my mother, I am there all the time. So, she's
189 getting help during, or when she has a problem or even just sitting watching television.
190 It's, it's 24-hour care in that respect, but she doesn't get 24-hour care from the carers.
191 So, if she has a physical problem if she's unwell or if she's just having a bad day then the
192 amount of care is much higher. I'm usually preparing all the meals so when I'm resident
193 myself it might be that the carers, the personal assistants, are there at the same time
194 and we overlap, but when I'm not in the house the carers can sometimes provide respite
195 for me, allow me to get out for a couple of hours, which is great. So, it's very difficult to
196 actually put a time on how much care I give. When I'm not present, which is the best way
197 of looking at it, then it's the amount of time I spend on the telephone or computer and
198 that probably does run, I've got to be careful not to understate this, but I would say it's a
199 good 8 hours a week, if not more. That's when I'm not resident (Yeah). And that's
200 because there are a lot of things that need to be managed in people's everyday life. So,
201 to come back and give you an example if you like. That's so, that's if you like the
202 background on top of whatever care is provided through the personal assistants. So,
203 they obviously need holiday time as well. So, if there's some opportunity, I will look to
204 provide them with a lot of flexibility when I'm there with my mother. It works. The
205 number of hours that she is generally getting from personal assistants averages some 50
206 hours a week, so nominally three times a day but that's also making use of day care so

207 five days a week. Pretty much she will have 3, 4, 5 hours each day at day care clubs. Does
 208 that help?

209 I: Yeah it does. I will come back to it in a while when we talk about your work. The
 210 question basically was when you were still at the firm that you left a couple of years ago
 211 (Right). Can you talk a, tell me a bit about what your work was about back then?

212 P: Okay I think it's probably more appropriate to talk about my most recent work (okay)
 213 because my, my main profession, I was made redundant in 2012. So, before 2012 I
 214 wasn't doing an awful lot of care. I was able to support my father on frequent family
 215 visits and generally make sure that the other carers were doing their work. I mean I was
 216 caring but, but not to the extent I'm doing now. I then started self-employment because
 217 I found that I couldn't easily find another job at my age in my profession at the level that
 218 I wanted or even at any level to be honest. So, whilst looking for work I became self-
 219 employed and I'm still registered as self-employed today but since 2015 I've not really
 220 pushed. You know, if anything comes up I might follow it up and see whether it leads to
 221 anything but it will be very casual in terms of income. But prior to that from 2012 to
 222 2015 it provided a small income stream and I could have grown it. But it meant I would
 223 have had to invest much, much more than I did. So, what I did was, was look around and
 224 broaden my, my outlook for work and through jobseekers, opportunities with the
 225 support that I got, I applied for a job in the civil service and then worked and a major
 226 [city] airport in border force, that's immigration controls. (So that was in 2015?) That
 227 was from 2012 to 2015. In 2015 I made the decision to take an extended leave because
 228 at that stage the pathway for my mother was a little uncertain as to whether she needed
 229 residential care, whether she'd move into residential care or to change the amount of
 230 care that she would get at home and I needed a lot more time closer to my mother in
 231 order to do that. I still kept the opportunity open to return but my mind wasn't really on
 232 it and so whilst I had the opportunity to go back I pretty much decided, come 2017 the
 233 end of 2016, that I wasn't going to go back.

234 I: And to talk a bit more about that job. Can you maybe tell me a bit about your ability to
 235 have control over your work schedule? Was there any, was it a 9 to 5 job?

236 P: It was shift work, so I had to fit a rota that everybody was in and that was both early
 237 mornings and a combination of early mornings and late afternoon, evenings with a few
 238 nights as well.

239 I: Did you have any control over the rota? For example, were you able on a month to
 240 month basis, were-?

241 P: There were different rota options so there was a choice which, there were effectively
 242 two. They were constantly looking at it from a management point of view and then the
 243 pattern did actually change whilst I was working there so I was working there really for
 244 just under three years. But it gave me a steady income on top of whatever I could have
 245 earned outside of that so there was no conflict of interest. So, I couldn't really influence
 246 it other than did I opt for A, B or C and there was different remunerations according to
 247 which rota you took (OK). But frankly there's been a lot of modernisation of civil service

248 employment patterns to maximise productivity as far as possible to the detriment of
 249 many of the workers. That was one of the reasons I didn't stay.

250 I: Yeah. Was there any ability to maybe swap shifts with colleagues?

251 P: There were some shift swap options so, but they were pretty limited because you could
 252 only swap with people on the same sort of pattern as such. As I said, there was a bit of
 253 modernization really, because it's an internal civil service thing, and it's probably
 254 changed since then. What was available to me was pretty much fixed time of work with
 255 very little downtime or off time. And that was really just respite. So apart from being
 256 able to make the odd phone call in a break period (OK) that was about it.

257 I: That would be my next question. So, did you, was it possible for you to take a phone call
 258 when you got one, maybe to respond to anything that was going on with your caring
 259 situation?

260 P: No, I shouldn't take a phone call. I could see if there was somebody who tried to reach
 261 me, the message service, so I would try as much as I could to at least be alert to any
 262 issues. My wife at home would have been able to have taken messages if there was
 263 anything urgent.

264 I: Okay. So, in case there was something going on with your mother when you were at
 265 work that would have required your attention, how would you have been able to handle
 266 that?

267 P: With great difficulty. I mean actually at the time it would have only been had there'd
 268 been an emergency that I could have then have requested permission to have a false
 269 break. But for day to day routine needs or even if she was just getting a bit anxious or
 270 distressed then there wasn't much I could do.

271 I: Did that ever happen? Was there ever a situation where you maybe got a phone call
 272 when at work and it was an emergency and you would have had to leave? Was that, did
 273 that ever happen?

274 P: Well, the biggest emergency that there was, would have been in 2014 when I got the
 275 message that my father was very poorly and likely to pass away very shortly. I actually
 276 even knowing that from the message that I got went to work at 5:00 in the morning. I
 277 probably could have made do with a telephone call. But I was immediately given leave to
 278 be able to respond to the issue. So, I packed my bags. In terms of anything else, there's
 279 nothing that I can immediately think of as having to take a particular enforced break at
 280 the time.

281 I: Did your employers back then, where they aware of you having these caring
 282 responsibilities? They were, ok. Were they supportive of that?

283 P: Largely yes. I mean, their main concern was that I was available to do the job, but they
 284 would have encouraged me to make use of shift swaps to try to manage any needs
 285 because they were long shifts and it was only generally about a four-day week. It did
 286 enable me to add quality breaks to long weekends to make five, six or seven days so I

287 could use effectively a week to make a trip up. So that's what I did, or I took holiday onto
 288 it, I took a couple of weeks. But during that time, I didn't have very much in the way of
 289 family holiday was all centred around support from my mother.

290 I: That sounds very hard. So back then, was it a regular thing for you to come up to see
 291 your parents or was it like on a needs basis when you, when you were aware that there
 292 was something requiring your attention then you would go up?

293 P: No. It was still pretty, pretty regular. It probably started around four times a year to
 294 maybe six times a year. But I would try to make, make longish visits if I could.

295 I: OK. Yeah. So maybe talking a bit more about how caring potentially impacted on your
 296 work situation. Was there anything like that where you would say caring impacts on
 297 work or maybe work impacts on caring?

298 P: Well I realize that the framework that I had after her, after my father died, my mother
 299 being left on her own. It was not sustainable. Something had to give. So, had I been in a
 300 different type of employment, had I still been engaged with my main professional
 301 vocation, it would have been a very different circumstance and I wouldn't have given
 302 that up lightly, not least because I had many, many years of service and it would have
 303 impacted on that if I just resigned. Whereas it was much easier to resign from a job that I
 304 didn't have a personal connection to and didn't really enjoy so much and just felt that
 305 this was not for the long term. So, I did try very, very hard not to let my circumstances
 306 affect my work in any way. What effect there was, was probably through my own health.
 307 (Can you tell me more about that?) It's, it's difficult to know what's, what's a direct
 308 consequence. I would certainly say that mentally I have suffered a lot of anxiety and
 309 stress as do most carers in a family situation like this and because of the hardships as
 310 well and the difficulty of being remote. Even if it had been close, there would have been
 311 different problems. So, one of the advantages of being so far away is that I found it
 312 easier to compartmentalize, that I knew there was nothing I could do. I couldn't just
 313 jump in my car to render help. I had to rely on local services. So, I have a sibling who is
 314 more local but hasn't really been able to do anything. And it's not easy for two people to
 315 do the kind of administration work but it's just a comfort to know that somebody else
 316 could have stepped in had there been an emergency.

317 I: So, is your sibling involved in caring at all or is it just like, like a backup solution or
 318 something?

319 P: It's really only a backup. There's not really any care. So, it's a social visit. (OK, so you're
 320 basically the main carer). Yeah, it's maybe to, somewhere else to go. Just company, if
 321 you like, but there's not an awful lot of time given. That's partly because of my sister's
 322 responsibilities and other commitments and outlook and perspective as so often is the
 323 case.

324 I: Yeah. So, to talk about your self-employment then (yes) can you tell me a bit more about
 325 the circumstances of that. So, is that project-based work, or?

326 P: It's a service that I have offered, a professional service as a consultant engineer, so in the
 327 field in which I worked. So, it was really making use of a network of people and

328 acquaintances and firms in my previous job in the field. People that I knew just say well,
329 let's see if one thing could lead to another. I wouldn't say that I have a significant social
330 profile in any way, social media that is. So, it was really built up over years.

331 I: On average, how many hours would you say do work at the moment?

332 P: At the moment, I would say, yeah, I can only think of the time that I would invest in
333 maintaining my equipment and following up the odd leads. In the last year it's, I've not
334 taken any income from it in the last three years. It's only been a bit of expenditure in
335 making sure that I could continue to work if I so wished. So, I have had to maintain some
336 tools and software, computer and information for a longer time. As time goes on the
337 more difficult to maintain a up-to-date business both in terms of personal contacts and
338 in terms of equipment and technology.

339 I: Have you ever found that caring made it more difficult to maintain your business or work
340 as a self-employed-?

341 P: Well I think the difficulty, first of all it would be far easier for me to be self-employed to
342 be able to make it fit with my personal circumstances. That's the attractiveness about it.
343 So, if for example I was to grow it to provide a steady enough income then I could work
344 whenever I like, what days I like, take breaks when I like. And there could be some
345 consequences to that, of course. So, what I was finding that at the time that I started
346 out, I quickly realized that this was going to be something I'd either have to physically
347 invest quite a bit in both into full time but also in terms of money. And I was reluctant to
348 do that. And at the same time as I had to research work opportunities and I found a
349 solution that would enable me to potentially do both. Such was the pressure of my
350 employed work that I was just too exhausted, exhausted to do much else as well as
351 manage my, my mother's situation, mother and father's situation at the time. So, bear in
352 mind that that was the last two years of my father's life and the beginning of the decline
353 of my mother. So, there are things that certainly were a lot easier from a self-employed
354 point of view. The one difficulty to it is it's easy to employ yourself but you've got to be
355 self-motivated. So, when the barriers started coming as well as the physical exhaustion
356 and the stress and anxiety the enthusiasm waned. And I found that, well, this is just too
357 difficult.

358 I: So, talking about support that might have helped you. You talked about the carers that
359 you have that help with the more practical day to day aspects of providing care. Are you
360 or have you been using any technology to help with care?

361 P: Yes. So, we mentioned already WhatsApp, so that's just a simple tool. One area that I
362 have invested in for my mother and actually a portion of her care cost goes there, is a
363 home-based system that you may have heard of which uses a passive infrared system
364 around the house called, I can mention the name? (yes). 'Just checking'. They produce a
365 software tool available as an app but also provide a portal through any kind of Wi-Fi to
366 enable you to see – I can demonstrate if you wish to see – movement around the house
367 to see which doors are open and to set up alerts if there is unusual activity at a particular
368 time. It helps me understand when my mother has left the house and helps me
369 understand when the carers arrive, understand when she's settled in bed or she's just

370 dozing in the house. There are things that you can't do, things that I'd probably like it to
371 do but it is really just a tool kit for providing a kind of remote non-invasive system. So,
372 it's no cameras surveillance. It's just purely a matter of movement sensing and door
373 closures.

374 I: So what would you like it to be able to do that it currently can't do?

375 P: The system is not completely fool proof and the experience I have is you rely on the
376 sensor technology, so sometimes you have to be careful what kind of conclusions you
377 make from the data that you've got. For example, if you've got two people in the house,
378 it's not possible really to determine who's doing what around the house. If they both
379 leave the house at the same time or not. So, for example the carer could leave the house
380 and immediately there's no activity from my mother because she's immediately asleep
381 or she was asleep before the carer left. So, then I have to be careful about well is the
382 house empty or is my mother actually there but inactive, that's just one example. So, you
383 just have to be careful about what conclusions you develop from them, from the data. It
384 may be possible that the app or software could be improved with more modern artificial
385 intelligence and data analysis and collection. I'd like it to be able to offer actually some
386 kind of security system as well. (In terms of...?) So, you've got interlocks on the doors,
387 but if there was something that linked into it by way of home security or even something
388 that was more, or more linked to the client themselves, perhaps a voice activated
389 technology or a message server or a prompt or something. For example, 'You are leaving
390 the house now. Do you need to leave the house' things like that which I know are
391 available today. And to be offered perhaps an interface to other devices such as cameras
392 or bells or alarms or some kind, something that may be more directly interrelated to the
393 next responder. So, if for example you've got a personal assistant that says that she can
394 be contacted. At the moment we have to rely on telephone numbers. So, if my mother is
395 up during the night and ill or distressed for any reason, she has to make a conscious
396 decision if she needs help. Unless I have to be awake at the time, I have to sleep myself.
397 So, I, the alerts are not that good from that point of view. So, if it was more able to
398 detect any unusual activity, too much time in the bathroom maybe or constant
399 wandering around the house, that could provide another way of providing the input of
400 some kind or response action.

401 I: And ideally you would not only want it to link to your own device to check up on her but
402 also-?

403 P: Well, if it was programmable so that we could for example, given you have to be careful
404 what kind of decisions you make and at the moment whilst I have an arrangement with
405 the carers that they are happy to respond as, as the best responders. I use a local
406 authority sponsored system called 'Care Call'. So, that's another service which we pay
407 for. So that's as an emergency button on your wrist, or it can be your neck, so if you've
408 got a proneness to falling it can set the alarm off and it then provides an intercom
409 service as you probably know, whereby the call centre would try and define whether
410 they can make contact if they don't make contact, what kind of attention responses is
411 required. It's very primitive, it relies totally on a link to your telephone. (Yeah) And these
412 days you have other forms of networking. It's, it's very primitive.

413 I: Coming back to the sensor technology that you are using. How did you learn about this?

414 P: Because it was under trial by the local authority. So, you could use the service for a short
415 while to find out whether or not it was something that was beneficial. So they alerted
416 me about it.

417 I: How long do you have that in place now?

418 P: I think it's probably about two and a half years, something like that.

419 I: And in terms of setting the technology up, was that also done by the local authority? Did
420 someone come in and say we need a sensor here and we need a sensor there or how did
421 that work?

422 P: Initially they had an engineer come in, yes. To set it up right. But when I purchased it
423 commercially, I rent it commercially, and I rent it for my mother. It's, you set it up
424 yourself. It's not too much, not too difficult.

425 I: OK. Do you get any help with deciding on where best to place the sensors or is that up to
426 you as well?

427 P: It depends on where they work best. And frankly it has its own router. But that is not
428 great by the, it depends on the local, it uses the local telephone networks. So, if you
429 haven't got a good mobile phone network it can fail. You have a gap in your data until it
430 restarts. Sometimes you actually have to do a physical reboot on the router (oh dear)
431 yeah. (That's not very good especially when you're very far away...?) So, there are tools
432 around this type of application that are beneficial if somebody is remote or even, even
433 when I'm there in the house. I found that my mother was ill recently, and she was
434 getting up an awful lot during the night, I had to be much more alert and I could use a
435 system with a little bit more stealth to decide 'All right. I know she's awake. Do I need to
436 disturb her'. Because obviously if I do then I wake myself up fully or I can just 'yeah, I
437 think she's going back to bed'.

438 I: So when you, when you got that technology set up, was there a conversation with your
439 mother as well to tell her 'this is no going up, are you okay with that'?

440 P: Sure, sure. So, if you were to ask her now she wouldn't know what you're talking about
441 but routinely I remind her because it provides her some reassurance to know that
442 somebody is looking out for her because she's on her own and like from 9 o'clock in the
443 evening till about 9 o'clock roughly in the morning, which is a long time. Fortunately,
444 she's sleeping most of that time and she, she's able to get up to find her own services,
445 she has an en-suite, and returned to bed. So it's rare at the moment that she'll walk
446 around the house but there are times when she does.

447 I: Okay. So when that happens at night you would get a notification on-?

448 P: It's only if she leaves the house. I have set up notifications or if the external doors are
449 opened or if the system goes off-line for whatever reason. But at least myself and my
450 wife have got two sets of ears.

451 I: OK. So regarding cameras, you mentioned that is something that you would like to have
 452 as an addition or is it is it more like-?

453 P: I would only consider it initially externally, (external) from a security point. I wouldn't like
 454 to go down that route internally unless it really became strictly necessary. And I don't
 455 think it is. It is too invasive.

456 I: Yeah, yeah absolutely. Okay. So, the alarm button that your mother wears around the
 457 wrist or around the neck, is she able to press it when something happens?

458 P: She is able to. Whether she will or not is another question. Obviously, it depends on
 459 what the circumstance has been. I think she's pressed it maybe once out of need, maybe
 460 twice, once or twice and it worked under the circumstances (that's good). But it does
 461 rely on having another party to be able to provide the response if it's required. If they
 462 can handle, handle it via telephone communication to my mother and get the right
 463 answers, panic over, no problem. But that's not normally the case because the system,
 464 it's great in a one room environment, but when you start putting a whole house there,
 465 and even with a loud intercom, in an old house with thick walls you can't hear it. And if
 466 you then have a client who is not of good hearing, it just doesn't work.

467 I: So has that happened that the alarm went off and your mother was not able to respond?

468 P: Well it's not, isn't it, it's not, all right, so we're talking now about what is called the 'Care
 469 Call Service' (Yeah). So, I don't think we found a situation where she's alerted it nobody
 470 has been able to respond so they have managed to engage a person to try to come to
 471 the house. (Oh yeah, okay) I mean, on one of those occasions they called a paramedic
 472 and then my mother went for a check-up. She'd had fallen. So, it's worked but the
 473 weaknesses is really the intercom communication between the client and the call centre.
 474 Ideally, you'd want something in every room. And for the person to be comfortable that
 475 they know 'where's that sound coming from? (Yes) Who's that?'

476 I: Yeah, they could be scared of that. Yeah absolutely. So, can you think of any, of any
 477 other device that you're using to help with caring?

478 P: There's one thing that I have taken the steps for recently and that is acquire a mat with a
 479 pressure sensitivity switch. So, we're not actively using it at the moment, but should
 480 there be a need for overnight monitoring in particular, that was what I had in mind at
 481 the time. It provides a wake up whenever the client steps on the mat. (So, would you
 482 place it in front of the bed?) You'd find the ideal place. (Yeah) I mean it's probably best
 483 by the bed.

484 I: And again, was that something that the council made you aware of or did you get it
 485 through (through a friend), aha, a friend. Can you think of any other technology maybe
 486 or maybe something other than technology that would make it easier for you to care?

487 P: Well, first of all going back to the administration. I use standard off-the-shelf software,
 488 Microsoft Excel for keeping sheets which I also use for any kind of reporting with the
 489 personal assistants. (Yes) I guess there could be something that was more customized or
 490 more appropriate. I've generated my own medication chart checkbox et cetera. A simple

491 spreadsheet, but for people that don't have that, shall we say ease of familiarisation,
492 then maybe something that is more appropriate. Maybe tools that could in some way
493 help focus a particular type of plan for writing a care support plan, employee job
494 descriptions, that sort of thing. For me it wasn't too much trouble, but it still took time.
495 I'm trying to think of things that would help from my work point of view. In terms of
496 work management is really a matter of being able to fit the time in so that one can be
497 more productive. But with today's technology employed much more use of AI than
498 anything that helps manage data, both analytically or provides a summary, I believe
499 there are tools available now today for example that can help anybody who's using large
500 amounts of text, researchers, maybe doctors, lawyers whatever to do the reading for
501 them and to produced summaries. And then to even suggest action plans or whatever as
502 a result. So, if you're in the nature of work where a lot of time is given over to working
503 through reports, working through information, numbers and information, that could be
504 something that might be useful as you can be more efficient then in the time that you've
505 got in your workplace.

506 I: Thinking back to when you were working at the airport, can you think of anything that
507 would have made it easier for you to cope with both working and caring? That could be
508 technology, but it could be something else as well.

509 P: I have to say that the nature of the work I was doing required pretty much 100 percent
510 concentration. So, whilst deployed it would not have been, it wouldn't have been
511 appropriate, and it probably wouldn't have been supported, to know that somebody
512 could potentially be distracted in that way. Of course, it probably happens with
513 everybody in the nature of their work. We all have private lives. We all have home lives.
514 So, I think, I, it would be very difficult in that environment. Other that may be something
515 that could perhaps help you organize the fact that you, you're working shifts so you
516 know what hours you're going to be out of contact for example and they are not
517 necessarily hours that fit with domestic care in any way. So, for example, I used to be
518 able to make sure that if my mother was up after the carers had left the house, that I
519 would monitor her activity and see whether or not she'd made the decision to go to bed.
520 If she hadn't gone to bed, then I would ring and try to get her to prompt. So maybe if
521 there was something that was more automated, that could provide a kind of a robotic
522 approach, that could in some way, in a compassionate, you know it could even replay my
523 voice perhaps to her, just giving her the message, you know 'Are you still up, mum? It
524 might be time to go to bed. I'm working at the moment, but I will speak to you in the
525 morning'. That kind of...

526 I: Yeah. That's a really good idea. Okay. I've got a bit of an abstract question. If you had a
527 magic wand, if you knew that there were no restrictions, what would you like technology
528 to do for you?

529 P: Well it's probably well known that with the advance of robotic technology, even
530 personal assistants could potentially be replaced by a care bot of some kind. I don't
531 really know how far that technology has developed. A lot depends on the actual pathway
532 and how far down that pathway the client might be in terms of the acceptance or
533 resistance of something. But after all, people use household appliances and I've seen my

534 mother gradually pull back from those appliances. She's still able to use a toaster, still
535 able to put the kettle on. So, there are domestic appliances or domestic helps that could
536 be more automated and probably products are available today as it is made available but
537 so, yes it would be possibly perfectly able today to, to have a household that was fully
538 automated that could shout a command to Alexa for example to do this, do that, and it
539 would be done. But to try and do it in a way that was compassionate, and caring is
540 difficult.

541 I: Is that something that you would like, process being more automated basically around
542 the home?

543 P: Well I'm thinking for the time. At the moment where I've got the human contact, I can
544 only really run to those costs and affordability for so many hours a day. Even if you
545 employ a live-in carer you've still got to have cover for the time when the live-in carer
546 has, has hours off. Otherwise you end up multiplying and having a rota or two or three
547 people covering. So, I'm sure that there is space somewhere for automatic, automated
548 or robotics to be a support to that support. Obviously, all comes at a cost. These things
549 have to be planned in terms of, you might not put the time into doing things yourself,
550 but you have to put time into the thought process or the 'how am I going to use this,
551 how am I going to set it up. So what kind of things do I want it to do'.

552 I: Yes. (Does that answer your question?) It does, yes it does. Anything else come to mind
553 that would make it easier for you in your personal situation or maybe back when you
554 were still working at the airport?

555 P: The self-driving car. (Yeah. For you or for your mother?) Well, when my mother is
556 needing to go out, she still thinks from time to time that she does drive, she runs a car.
557 (OK) Then I bring her back to reality. This isn't always easy. And sometimes one has to
558 back away and change the subject. But when you think about it, many people who need
559 social care have barriers caused by remoteness or just location or even just getting to
560 the shop. But again it needs to be controlled. My mother will think that she does all the
561 shopping now, but she doesn't. So, this is unique to her particular pathway. But there
562 was a time not that long ago when she struggled with the shopping and even with the
563 ability these days to order your shopping online and have it delivered, it still needs to be
564 coordinated and requires some interface of technology. So, things can be done more
565 automated. The shopping list is not that easy. There are some essentials that need to be
566 repeated sometimes but usually it's a matter of demand and response.

567 I: So we are approaching the end of the interview. So just basically to sum it up what
568 would you say are the most positive and the most negative aspects of having combined
569 work and care.

570 P: Having combined work and care. Well certainly the most negative aspect first of all is the
571 fact that effectively it meant the end of my employed work. That was a decision that I
572 said could have been different had the nature of my work been different. So, if it had
573 been something that would have enabled me to have continued longer, then that would
574 certainly have been of interest. Fortunately, the kind of work that I was doing up to
575 2012, I had a lot of control of my own hours in terms of when I worked and when I

576 didn't, I could spend a certain time home-based working. So, if you, if you've got the
577 motivation to do things and the flexibility to work around that, that environment works
578 better when it comes to this, something that's more rigid employment, it's difficult.

579 I: Are there any positive aspect as well of being a working carer?

580 P: Well the positive aspect obviously is the direct ability that one is earning money, some of
581 which can be focused on your client, your family and whomever. I would say it's been
582 eye opening for me. It's been a challenge. Perhaps other negatives in terms of the effect
583 on my overall health. But I'm the kind of person that takes a certain degree of
584 satisfaction from problem solving and am sometimes guilty of talking too much to my
585 own friends about my own family, domestic situation. That comes from actually having,
586 wanting to share problems but also letting people know that actually it doesn't all have
587 to be negative. You can find the right kind of solutions.

588 I: What kind of advice would you give someone in a similar situation?

589 P: What kind of advice? Try not to despair, first of all, because there is help around.
590 Network as much as possible with people who have similar experiences. Don't believe
591 that, that the local authority can do or will do everything for you but also exploit the
592 flexibility that those local authorities who can offer self-directed support have, because
593 whilst it's not perfect, I wouldn't be where I am now if I hadn't actually gone down that
594 road. My mother, I'm sure, has had a much better life around the home that she's
595 comfortable with, despite her own anxieties. So, it's, it's kept her at home for longer.
596 And it's a matter of trying to find what works best for you because it's not for everybody
597 to take on this role. Does that help?

598 I: It does, thanks very much. Thank you. And the final question would be what, what do
599 you wish for yourself? What are your goals or aims or wishes for the next maybe five
600 years?

601 P: It's very obvious, medical aid to reducing the symptoms, prolonging life even, dare I say
602 it, a cure would be up there. Definitely. I am not of a mind generally, to be too outward
603 generally to people ,so I will be feeling uncomfortable if I published anything to the
604 wider public, so it's only to my own inner circle of contacts.

605 I: OK. Thank you very much. I just have a couple more questions for the context. So, the
606 first question would be, how old are you? (Today 63) Today's your birthday? (No) On this
607 day 63. How old is your mum? (She's 86) Right. So, you talked about being married. Does
608 your wife help with caring for your mother? (No) And how many hours would you say
609 have you been working when you were still working at the airport, a week? (Erm,
610 nominally 41 hours. That was, that was the shift work) And the final question would be
611 the highest level of education do you have. (A bachelor's degree). Thank you very much.
612 That concludes the interview.

613 END

614 Additional quote from participant after the interview via email: "finances were not the reason behind
615 self-employment idea and have not been a critical factor. It is something that I had done before. I viewed

616 my pension as my main income, and I started drawing this a few years ago although any extra income
617 was welcome. Certainly, the family carer role and overall impact on my health detracted from my drive
618 as a consultant.”