

Interview 15, “Ian”

Date: 6.6.2019, Duration: 72min, Setting: participant’s home

I = interviewer, P = participant

I: Here we go. So, to start, can you tell me a bit more about your carrying situations? How did caring come about for you?

P: So, mum and dad bought this house in 2000. Before that they'd been just around the corner from my brother. Literally a 10, 20-minute walk from where my brother lives now even still in [city 1], down in [area]. Me and my then wife were living in [town] and not far off the [motorway] in the [city 2] area. And my sister and her family were just the other side of the path along the [motorway] in [city 3]. So, there we were all happily lined up along the [motorway] and everyone could get to everyone else in reasonable time. That was great. However, all of a sudden Mum and Dad decided that they didn't like the brand-new house that they built. Not that they build that, they bought a four-bedroom two bathroom, views out to the hills at the back of [city 1] and just didn't like it and decided to move back to Scotland where, to be fair, they had lived for 18 years previously. So, they bought this place much to the annoyance of my much older brother and sister, but they felt that they had, this is more like home for them. So, I didn't mind it as I'd spent time growing up in Scotland myself as a youngster, I'd grown up in [town] which is up the [motorway 2]. And so it didn't bother me so much, but it really rankled with the rest of my family. To be fair, it caused a bit of a rift actually. So, long story short, they were already in their 70s when this all took place and for the first couple of years everything was tickety-boo. Then my dad died three years after they'd moved up here of cancer and mum has battled on in one shape or form as best she can ever since then. First of all, she's been quite ill off and on, she spent, at various times, in and out of hospital with infections or with hip problems or whatever – she's actually in hospital at the mument, funnily enough, she went in last week after I'd spoken to you the first time. So, for them, a significant help for them was the Scottish free care for the elderly which would have absolutely wiped my family out in terms of money for that. For example, if this had been in England, I don't know how people in England survive, absolutely no clue. So that's, so over the years I've spent many a time either driving up from [city 2] and then from [city 3] where I lived for six years then, to bring the whole thing up to date, the reason I'm here now is because in 2017 the firm that I was working for down south got bought out and that was at the same time that mum, I could see my mum was going downhill, was really struggling, and this is a big old house, I'll show you around later, you know it's a big old house and a lot for one little old lady in the latter stages of her lifetime to look after. Again, she chose, she chose to live here but how long do I keep on holding it against someone. You know, is a lovely place, so, what gives? So, I took the decision in 2017 that I would move up here, quit [city 3] and move in with Mum as her full-time carer which brought its own fresh set of challenges, not least of which mum is

41 easily the most difficult person I know. They say hurt people hurt people, well, mum is a
42 hurt person, you know, and although she doesn't realise what she's doing, I'll give her
43 the benefit of the doubt, just not really what my brother or sister would do. But you
44 know, she, if you were to meet her, she has the air of 'I've had a shit life so you're gonna
45 have a shit life too'. But that aside, I took a decision and I'm glad that I took it when I did.
46 If I had taken it any sooner, I'm sure I would have lost my wit with long before now. I've
47 just about held it together. We've had our ups and downs but overall, I'd say we won
48 more of the time than we lost. So that's how I'm here. What's made it possible at all is
49 that in addition to having a full-time job, I, like many other people, have a little side-line
50 which I started in 2009, just got a few little sites down in [city 2] which I've built up trust
51 with my clients over 10 years now. And it was, I didn't actually tell them I was, or even I
52 told them that I'd moved, and I still think better to ask for forgiveness than permission.
53 So, I got forgiveness from all of them and everything's gone fine. So, I've been going
54 down every month and so I go to [city 2] for the last two working days of each month
55 and in fact that was supposed to be last week but because of Mum going into hospitals
56 and everything else and I had to pull out for the first time just because of external
57 circumstances in regard to mum. So, it's been absolutely a mixture and quite a ridiculous
58 mixture really of managing multi-million pound sites and managing hundreds of
59 thousands of pounds of other people's money with wiping puke off Mum's blouse or
60 whatever ridiculous, you know, kind of caring thing will be, and you're constantly in that
61 juxtaposition of trying to manage a small property management business in [city 2] with
62 a little old lady in [town].

63 I: Mhm. Coming back to the caring situation, does your mother currently have a diagnosis
64 of dementia?

65 P: No, she, she, we, I did take her to the doctor for dementia tests which surprisingly she
66 passed with flying colours, but if you asked Mum what day of the week it was she
67 wouldn't have a clue. I mean when she went into hospital last week, the nurse, you
68 know they come in and ask you 'do you know where you are?'. Well, she thought she
69 was either in [city] or [city] but she wasn't sure. Did she know what month it was? 'Oh
70 yes, it's November and it's my birthday tomorrow'. So, you know. But if you ask her a
71 question like, that was on that dementia test, she can answer it. No problem at all. But
72 she doesn't know what day of the week it is, she doesn't know where she is.

73 I: And when was that, when did they do the dementia test?

74 P: I'd say it was probably about a year ago.

75 I: About a year ago, okay. So, regarding your role as her carer, what would you say what
76 kind of care do you provide?

77 P: So, it's grown. I came up with a few Theresa May style red lines. Those went by the
78 wayside as I quickly realized there wasn't anyone else to do it. So, I really ended up doing
79 everything. So, to start with, for Mum, I was just making sure she was taking the pills at
80 the right time of day. Then extended to, well obviously managing the house, cutting the
81 grass, so take it as read that the maintenance of the house fairly and squarely fell into
82 my hands, which is fine. And I brought in some tradesmen when I needed to, when it

83 was outside of what I could cope with. So, then we're talking specifically about mum and
84 so it would be cooking all of her meals, checking on her first thing in the morning and
85 taking her a cup of tea, helping her out of bed, putting her shoes on and sometimes she
86 would walk down the corridor, in the latter stages, more recently I would wheel her
87 down in a wheelchair because she couldn't stand anymore. So, I mean getting all her pills
88 out, setting her breakfast table, because in about four or five months after I moved up
89 here all of a sudden, just one day without even mentioning it Mum just stopped eating
90 porridge for breakfast and she's done that for every day for as long as I've been around.
91 So, she's been on half a banana and one slice of bread with butter and jam. So, I'll do all
92 that. So, it's doing all the washing up. Then again increasingly helping mum get washed
93 and dressed. There was a lady coming in, well there was, not now obviously, but there
94 was a lady coming in three days a week, Monday, Wednesday and Friday to help give
95 Mum a bath. Obviously, we had to buy one of those electronic lift things to get mum in
96 and out of the bath. Obviously that all stopped in the days, weeks leading up to Mum's
97 admission to hospital because she couldn't even get that done. So, she was just getting a
98 wet wash. So, I mean, Mum would have sustained bouts of constipation which would be
99 followed by what I can describe as days of arse spraying mayhem, I don't know what a
100 polite way of saying it is but suffice to say, we've had whole carpets replaced. I have
101 spent hours, literally hours on my hands and knees scraping up and scrubbing off puke,
102 pee, poo in various parts of the house, I could give you a guided tour, but I won't. But
103 just take it from me. Managing Mum's numerous urinary tract infections, her UTIs and
104 just dealing with the disgusting musky foul smell that comes with UTIs, and then
105 obviously all the bad moods that Mum would go in and out of in order to deal with it. So,
106 pretty much, I would say that I would try and get three hours in the afternoon off so if I
107 could, Mum needed a lot of managing through the morning but once after, by about
108 eleven o'clock when she was sat down in her chair by the window, she'd be there for the
109 rest of the day. In the early days she could get up, and would get up to go to the loo on
110 her own, but increasingly however, because I was just putting her into incontinence
111 pants, she'd just sit and wet herself and then I'd got to take it all off last thing at night
112 when I'm putting her into bed and put fresh ones on and put her in bed, pyjamas on and
113 all the rest of it, with her pills and whatnot. So, it was, I had to deal with her hearing aids
114 cos she lost them that's all another one. Thank God we took out insurance policy on the
115 hearing aids that we got from [company]. You know, I could go on, but it basically is
116 everything, everything. The only thing I didn't touch was her vagina, you know wiping up
117 everything, absolutely everything.

118 I: Is it possible for you to put a number on, on average how many hours a week do you
119 spend caring for your mum?

120 P: That depends what you mean by caring. If it's actively hands on, is it, because a lot of it is
121 just being there in case something happens. So, does that count? (It does, yes) Okay, so
122 what's eight times seven, so 56? I don't know, my maths isn't what it should be. (So, 8
123 hours a day?) Oh easily. Yeah, yeah. Because although it wasn't, so I could go out and
124 play a round of golf which I have been able to do, take three hours out, the day starts at
125 half past 7:00 in the morning and ends where mum goes to bed which could be any time
126 between nine and half eleven. I tried to get mum into routines but she, she feels that

127 she's being manipulated in some way, she's very quick to pick up on it and to fight back
128 against it. So, you really have to treat her with kid gloves. So yeah. So, it's not a full
129 working day. There are bits where you're not doing it and there are bits where I'm sat at
130 my desk doing my business work, but mum will be either sleeping, on the toilet, or sleep
131 at the kitchen table, or sleep on a chair or any combination.

132 I: How do you personally feel about the care that you provide?

133 P: It's, the fact is it was either that or Mum going into a home and this house being sold.
134 But this is our inheritance. Now, if I had a stellar career with a medal from the Queen, 4
135 kids and a mortgage blah blah blah and I had loads of business trips to take abroad and
136 all that sort of thing, maybe I wouldn't have thought so hard about it. For whatever
137 reason I haven't. I'm a humble simple soul if you like. So, for me it's very much a
138 question of helping mum from the point of view that she always wanted to be here and
139 be at home. She doesn't like institutions like hospitals, she doesn't like homes and she's
140 not, we did try to move her into [care home] in [city] but to my certain knowledge, she's
141 the only person ever to be evicted. She was so rude to everyone. We actually had the
142 manager of the home come say 'look if your mum doesn't go, my volunteers have
143 threatened to leave because she's, she's that rude to them'. So Mum's not really cut out
144 to have other people around her. She really is, she will just sit on her own for hours. And
145 I will come in, make her a cup of tea and sit down her, watch the news with her, try and
146 have a chat with her. But yeah so there's, from mum's point of view, form her own wish,
147 from the point of view, the fact that mum's better off on her own. If she's with other
148 people, she'll just upset them. Sorry, it sounds awful, but I'm just being honest with you.
149 And then there's from my point of view is that this house is our inheritance and to have
150 to sell it only to see mum go in, and we've already tried moving her to [care home] and
151 you know our inheritance was going to pay for that rent down there. It's not like we
152 haven't tried it but....

153 I: So, talking about your work situation, can you tell me a bit more about your day-to-day
154 job?

155 P: So basically, I am a residential commercial property manager and what that means is I
156 manage on behalf of the owner. There'll be an owner of the property off the site and
157 they will want an agent to do the legwork for them which is what I do. So, there will be
158 people living and working in those places that will have signed a lease, whether it's
159 commercial or residential. To say that they will contribute towards the upkeep of the
160 communal areas whether that's a flight of stairs going up a block of flats or the, you
161 know, the drains running out of a commercial Cash and Carry/ artist studio. So basically,
162 what I do is I'll figure out what's needed in terms of services, what are they gonna cost.
163 And that makes your service charge budget and then you bill, to cut a very long story
164 short, you then bill that out to those tenants again whether it's commercial or- it's the
165 same principle. I mean there are, they are governed generally by separate laws, but the
166 principles are the same. So, they then pay it. So, then I say I've got bank accounts for
167 each of these properties, sometimes I've got several bank accounts. Depending on what
168 pot of money it needs to go into. So that's the money that I then use to then pay out for
169 the services, be it the insurance or electrical repairs or whatever, my own management

170 fees, or paying someone else's fee for looking after certain bits of it that I've employed
171 to do and so on and so forth, and then the rest of it in the commercial sense goes back
172 to the owner of the site, in the residential sense it stays in the pot and then they get,
173 gets carried forward into the new financial year if it's a resident management company.
174 So, I've got about, I've got one big site in [area], that's the largest one and that's 90
175 percent of my business. And that's after about, we've got about 35 artist studios and a
176 large cash and carry. And then we got, one separate part of the building is taken over by
177 [tenant] and he uses it for storing his big paintings and all that sort of thing. So, it's an
178 interesting little place, creek side in [area] and it's being labelled now as a creative,
179 creative enterprise zone. So that's 90 percent of it then I've got a little office block in
180 [area]. It's just currently being converted into sort of like a, you know, these rentable
181 office spaces. So that's currently ongoing. And then we've got two little blocks of
182 converted Edwardian villas in [area]. So, it's just enough but it was so good, I'm so glad
183 that I did it because if it wasn't for that I would have had to have gone out and find work
184 around here. So yes, mum gets a couple of hundred quid a month in attendance
185 allowance, but I've never seen any of it. I've always had to go out and earn my own
186 money so if it wasn't for that in [city 2] and the fact that I can then, as long as I can get
187 my, those two days in [city 2] it is just enough. Everything else can be done off Skype,
188 email, phone and I could be anywhere.

189 I: So, you regularly go down to [city 2] two days-?

190 P: It's four days away really, because it's a day to get down there. Two days on site and
191 then by that, by the time I've finished on the last Friday of the month, I then swing by
192 [city] which is where I've actually got my business registered and that's where my official
193 post-box is. So, anything from lawyers, solicitors, accountants, companies, that will all go
194 there. So that's all I need, to check that on a monthly basis and then I swing by [town]
195 and go back home. So, I'm usually back here sort of nine o'clock on a Saturday morning.

196 I: Regarding your, your work schedule, do you, do you make that yourself or do you have a
197 fixed schedule?

198 P: Just as and when. Generally, I do it in the morning, so generally until mum went to
199 hospital, that has thrown me off a bit I have to say, but when at once, and after I'd got,
200 so when I woke up before I went to get, so, I wake up early, so we're talking about half 5,
201 6 a.m. onward, I'll be sat at my desk and work and then when we get to about half
202 seven, eight o'clock I make my mum a cup of tea, not because she's able to drink it you
203 understand just, just to check she's still alive. So, I'll take that and assume that she is still
204 alive and everything's tickety-boo. Then leave her so that she'll go back to sleep and then
205 I'll get her up for about nine o'clock when I either walk her down or wheel her down to
206 the kitchen for her breakfast and again she'll just stay there for a while because most
207 days she's just waiting for the lady from the agency to come and give her a bath. And
208 that's at ten thirty. So, there's no point in mum trying to do anything before then. So
209 then again, you see in that time with mum just sitting there sleeping, not doing anything,
210 I would do some work but obviously every five, ten minutes I get up and check she's all
211 right and come back, do a bit more work. Yeah, it's kind of like that but generally
212 speaking, you know, by the time that's done, most days what I need to do on that

213 particular day is done, which again by then I'm giving mum her elevenses which is coffee
214 and then eventually her lunch, soup and a sandwich. And then by that time I'm usually,
215 because I get up so early I usually get a quick sleep myself and then I go out and play golf
216 and I'll be back for about half five, which again if there's any emails or anything come
217 back, come in in the afternoon, I'll deal with them then. Erm, but generally I'm just back
218 into the, mum needs more pills by then, she'll need a cup of tea, she needs help getting
219 to the toilet. Yeah. So that's what I do. That's how it generally works.

220 I: So, you were talking about Skype calls and stuff like that. Is that the people who are
221 renting some of the buildings that you manage?

222 P: Yeah it's, it's contractors. I speak to them, you speak to contractors, people from local
223 authority, lawyers, accountants, the freeholders themselves, it's whatever is needed at
224 the time. So, anyone remotely connected will get funnelled through myself.

225 I: Do you have any, any chance of maybe scheduling that or do they just come in?

226 P: To be honest, if I try to be too rigid about it that would make it difficult because you
227 know, you sometimes just have to deal with things when they come in and when you get
228 a moment as well. So definitely, if an email came in at 8pm that night unless it was really
229 urgent I'd wait until the next morning to answer it. So, but generally, I mean for me
230 personally, being a morning person, I mean if it's not done by 11:00 a.m. chances are it
231 won't get done that day. Yeah, I have my burst of energy between seven and eleven so
232 that's usually when everything gets done (OK).

233 I: On average, how many hours a week do you spend on your work?

234 P: I would say if we had said three hours a day times seven, so it's about 21 hours, give or
235 take. So, not as much as looking after Mum but enough.

236 I: So, erm, do all of the contractors that you're working with and the people that you
237 manage the buildings for, do they know that you are a carer?

238 P: So, the one in [area], they do and it's useful that they're in their 60s, they're a bit older
239 but they've got their two fathers who are actually owners of that site. Basically, it's
240 power of attorney who's been enabled, so they're not looking after it because it's
241 actually two old boys that are actually my clients. But they understood because they've
242 got fathers that are now failing themselves and so they were actually very, very
243 understanding when last week, for example, when I said, it was the first time ever, 'I'm
244 not gonna be able to come down, Mum's gone into hospital everything's a bit up in the
245 air, you know I can't really leave her'. Whereas before, when you know, there will always
246 be a lot of organising every time I went away, who was going to go in and when and be
247 responsible for what, I mean.

248 I: And the other people that you manage buildings for, they know?

249 P: The other lot, no, not a clue, but I mean they know that the office address is in [city] but
250 I don't have that close a relationship, on the office block in [area], they've never agreed
251 to meet me there, never even met me, never signed my management agreement and

252 this is going back ten years and then every year I ask them and say 'look can I come and
 253 meet you, so as to have a face to a name'. Not interested, not interested. So, I've just
 254 toddled on.

255 I: OK. So in that case it was not a problem when you said last week you were not able to
 256 come down?

257 O: Well, I don't see them so often, you know it didn't matter. I mean they don't even ask
 258 me where I'm going. I mean the office block, so I tried to go to four times a year but even
 259 then, you know it doesn't matter if I go one month as opposed to another. No one's
 260 holding me to a schedule in the way that the big site in [area] is. But bear in mind the big
 261 site in[area] is 90 percent of my work. So yeah swings and roundabouts.

262 I: OK I understand. So, thinking about combining work in care. How would you say does
 263 caring impact on your work and vice versa?

264 P: Well the point is you can't leave one, you can't just delve into one for too long without
 265 going back and paying attention to the other. So, it's the constant switching. I think I said
 266 at the outset that it's the juxtaposition of talking to my client who is sort of the head of
 267 property litigation at a global law firm, you know, talking about, you know, suing
 268 someone or, you know getting a lease renewed or, you know 'have you done the
 269 schedule of condition for the premises that they've just vacated'. You're sort of having
 270 that conversation to going and wiping poo off the floor or whatever it is, you know (So,
 271 it's that role switching?), a complete role switch and you're going from being a nanny,
 272 from being a bloke in a pin-striped suit in the city of [city 2] almost, not quite, almost, to
 273 being a nurse. It's the constant switching between the two is quite bizarre, bizarre.

274 I: Can you think of any other instances where caring makes it difficult to work or work
 275 makes it difficult to care?

276 P: Well, you have to be flexible. That's the point. If you get too rigid, because you know I
 277 don't know when Mum's next bouts of constipation is going to happen. I don't know. The
 278 next time she's gonna be sick, I don't know the next time she's going to fall over. So, you
 279 just have to be prepared to snatch those moments, whether it's getting a round of golf in
 280 and whether it's going down the pub for a beer, whether it's staying here and just say
 281 I'm going to stay here and keep an eye on Mum. I'm not going to do any of that you
 282 know. So, you constantly have to play each day, each hour, each minute by ear. And if
 283 you say you are 'two to three I'm going to do that and then four to five, I'm going to do
 284 that', you're going to fail. It's absolutely understanding what's needed not just what you
 285 want to do, what's actually best for you, your mum and your customers. Yeah. So,
 286 there's, there's no way you can structure it. It's the lack of structure that actually makes
 287 it happen. Unfortunately.

288 I: You mentioned the person that came in, comes in three times a week to give your mum
 289 a bath. Is there anyone else that helps you with caring?

290 P: No. No. And indeed, in the latter stages before Mum went into hospital, mum couldn't
 291 even stand up. So I would just be picking mum up. Fortunately, she's down to 40 odd
 292 kilos, certainly not heavy but apart from running the risk of breaking a rib or pulling out

293 some arm of a socket or me doing myself a back injury. Fortunately, our sister left us a
294 little wheelchair that we could wheel mum around in. But mum's in so much pain,
295 everything hurts so much. Even as she banged her elbow, banged her ankle, I tried to
296 move her and she'd scream with pain and in the end I just ended up dialling 999, I just
297 couldn't handle it any more.

298 I: Would you like more support from caring services?

299 P: OK well in terms of, well I've got a meeting tomorrow with the doctor in the hospital and
300 she's told me that the guys from OT, social services and someone else was gonna be
301 there and it's gonna be sort of like a best interest type meeting if you like. Realistically,
302 there's no point sticking mum in a home because she's way past that point. I'm a trustee
303 of a local home here and you know those people, they can still walk, they can still talk,
304 you know they can come down sit and have a cup of coffee and a chat and have a laugh
305 about the old days. Mum's years past that, years and years. So, if she's not going to be in
306 a hospital the only thing that she can do is come back home. But we'll have to get a
307 hospital bed and she will need people in five, six, seven, eight times a day and there'll
308 need to be a proper hoist. We'll need two people. And the problem with that is to be
309 frank with you, sorry for rattling on, but there isn't, there isn't anyone around here that
310 can deliver that. So it's, it'll be interesting to see what they come up with. But what I'm
311 thinking of, they might try and get mum stuck into a home but I can't see how that
312 would work. And frankly, you know, I'm a trustee and we wouldn't take anyone in like
313 that, she's way past that stage. So, it'll be interesting.

314 I: So, tomorrow is going to be an interesting day.

315 P: Yes, yes, yes. Because all that will be gone and so, so yeah. So, if Mum is going to come
316 out of the hospital, as long as she's in a hospital, it can be [town] or [city] but as long as
317 she's in a hospital then that's fine. But what I don't want is for mum to be put into a
318 home. That's not what she wants. It's not what the home wants. It's not what I want. So
319 it'll be interesting.

320 I: Is she, is your mother still able to communicate her wishes and her needs?

321 P: She can just about speak a few lines at a time. She doesn't talk in more than one, three
322 or four words and she'll only speak when spoken to. So, it's not often, a lot of the time, a
323 lot of her conversation now is actually spoken in numbers. So, you say 'What did you
324 have for lunch, mum' she'll say '542'. Or, the last time we went to a doctor 'And how are
325 you?', she is like '36', you know? So, a lot, a lot of being asked to 'what was that about?'
326 and she'd say 'I'm just trying to contact my consciousness'. Whether that means
327 anything, I don't know.

328 I: Do you receive any support from charity organizations?

329 P: Well [name] who put me in touch with you in the first place, she's a part of
330 [organisation], she's great, really supportive and in fact it was [council] that she got to
331 give me a grant of 150 pounds last October to pay towards membership of the golf club.
332 Not that I'm any good at it but it gets me out of the house and it's three hours of, it's a
333 three hour walk if nothing else, so that's better. And that's been a godsend. I mean, I

334 don't know why I didn't think of it before then. So, they've been great. And then you've
 335 got the carers' lunches where male carers can go around and talk to each other about
 336 the trials and tribulations of it. So [name] is brilliant and that's the [organisation]. So,
 337 they've been superb. Really good.

338 I: How did you get in touch with her originally?

339 P: Well that's a good question. It was, I was going to [pause] [town] and I can't remember
 340 what took me to that particular building, but it was, I think it might have been some sort
 341 of training thing or something. And it was that trainer who introduced me to [name]
 342 who's got the office upstairs. But yeah, I mean the thing is, they don't, [pause] I don't
 343 know that it was necessarily a deliberate thing by someone, but it should be, because
 344 [name] could do, well she's absolutely brilliant, absolutely great. All they've done.

345 I: So it was a chance meeting really?

346 P: I would say so. But I think [name] would like to think that she's got a way of hitting the
 347 carers. But I can't remember that being so, because it would have to have been someone
 348 from the doctor's, the medical side. I can't remember them doing it.

349 I: So, talking about technology, is there any technology that you have been using or are
 350 currently using to help?

351 P: Well, because this is a big house, I would always have to keep my eyes peeled because
 352 Mum would be calling for me and if she's here and I'm down at my bedroom dozing or
 353 whatever then I wouldn't necessarily hear and then there's the whole thing 'I was calling
 354 and calling you, you know blah blah blah'. So then you're into these things or should we
 355 get these baby things that you plug into the sockets and, but then I've got no peace
 356 because if I want to listen to music she's gonna hear and be bothered by it, especially if
 357 it's a two way thing, I don't know if there's a one-way thing, but yeah, you get over
 358 sensitized cause every single little sound goes 'oh, is mum calling for me?' and you jump
 359 up like this. So that's a bit wearing in itself. I think just getting mum around a house,
 360 especially in her declining days, was obviously difficult because there was the walking on
 361 a trolley, which is incredibly slow, you know walking from that chair or just even decided
 362 she was going to get out of that chair, getting down to that corner where her bathroom
 363 was, you know you're talking half an hour, easily. Yeah, I mean it's like 10 minutes just to
 364 stand up, you know, but then it got to the point where I would literally have to pick her
 365 up put her down in the wheelchair, wheel her along, pick her up literally, carry her
 366 through, you know, onto the toilet, trousers down, pants down, toilet roll, everything in
 367 reverse, wash her hands for her, dry her hands, all the time holding her up or picking her
 368 up again, putting her back in the wheelchair, then either bringing her back in here or
 369 taking her down to the bedroom.

370 I: So, the baby phone thing that you were talking about, have you actually tried that out?

371 P: No. No, I didn't in the end because, you know, what can I say. I just didn't. (Yeah) Sorry
 372 [laughs].

373 I: OK. So is there any other technology like for example the community alarm or something
374 like that?

375 P: Yeah, Mum's got, she's got that for a few years. That was about 44, 46 pounds a month
376 to the council, so she was, she was wearing that on her wrist. I mean it's no good at the
377 moment she's in hospital (Right). Yeah, she's had that for a while and we've got the lift
378 thing in the bath which she paid for. The other thing we have, because we're on the side
379 of a hill here, so it's steps of the back, steps of the front. Pretty daft when you're in your
380 70s to buy a place like this but never mind. We've got one of these from the council free
381 to use. It's like a sterner build, so it's got wheels that will enable you to go, so Mum just
382 sits in it, and then I've been trained to use it, and you basically press a button on it and it
383 goes down the stairs and then coming back up again I'll show you it when we walk
384 about. I think it'll be worth you seeing as it will put everything into context for you. So
385 that's in the dining room at the moment, not being used now as mum's in hospital.

386 I: So that was paid for by the council?

387 P: Yeah. They paid for that. Mum paid for the, the thing for the bath, that was 300 quid.
388 Yeah and then there was like we say the call button. Yes, I think that was probably it.

389 I: So regarding the call button, did the council tell you about that or was that you saying
390 'that would be something that I would like'?

391 P: No, mum's had that for several years. So, I think we knew about that from way back. So
392 that's been around a while. The trouble was, the first responders were getting caught up
393 too much as Mum would accidentally hit the button and then you had people shouting
394 out the module in the hall. And then I had to go and talk to them 'my mum's just pressed
395 it by accident. Sorry. Everything's fine' or that kind of thing. But we haven't really needed
396 it, the only time is when Mum's fallen over when I've been, away which has happened
397 and yeah we've got the neighbours at the back who have come in and looked after mum.

398 I: OK so that, that's something that I wanted to ask you about. When you are away, what's
399 usually the arrangement?

400 P: Right. So, there's three women, [name1] who comes in three days a week and then I just
401 pay her a little bit on the side to go in in the evenings, but that's not official. But it's
402 helped, but it helps massively and she's very good. Then the lady [name2] who is our
403 cleaner, who comes in once, I kept the cleaner on because you don't want to change
404 things too much. I'm a lazy bloke and I'm quite happy to pay some 11 quid to do an
405 hour's cleaning and she's very nice, so that all works fine. So, she will also, then I will pay
406 her separately cash to come in and look after mum on a day, so each day that I'm away
407 I'll say like 'you come in on a certain time' doesn't really matter when, but in the
408 afternoon would be good, and then the neighbour at the back likewise. So, between the
409 three of them, all go in at some point during the day, we just about got by, although it
410 got harder and harder each time. But yeah, just about got by.

411 I: And so, when you are away, do you check up with them?

412 P: Well, I'm always asking them to text me but they're not so good at texting. They either
 413 don't want to spend the money, or they just forget or whatever but yeah, I mean I
 414 always want those like 'guys, talk to me, talk to me', you know I can only push them so
 415 much. (Okay, so, you're sitting down there in [city 2] waiting all the time) absolutely, all
 416 the time, and because mum doesn't answer the phone anymore, you know, you couldn't
 417 speak to her, it was very rarely, it was increasingly difficult to speak to Mum. So yeah, a
 418 lot of the time you just haven't got a clue what's going on. And just wondering what the
 419 hell is going on. You know you can't force people to contact you.

420 I: Has that ever happened though, that you've been away, and something happened and
 421 you have been contacted saying 'oh this has happened, what shall we do'?

422 P: Well, it was very late at night, as about half past eleven, I just finished doing a radio
 423 show in [city] and I was just driving back up and I was sort of between [city] and [city 1] I
 424 just happened to be messing around with, I shouldn't be doing that, I could get myself in
 425 trouble, But you know I just happened to have my phone with me when I was driving
 426 and it went off and I could see it was a local number up here. So, I quickly answered it,
 427 pulled over as soon as I could obviously, and there was the neighbour saying that mum
 428 had fallen over and that she, you know, they were on the case, you know, she was all
 429 right.

430 I: So they handled it, just called you to let you know basically?

431 P: Yeah, yeah but as I'd started the drive home by then anyway.

432 I: OK, can you think of any other technology that, that might make it easier for you?

433 P: Wearable clothing, you know technological clothes that can pick up a heartbeat or, you
 434 know, when there's a change in the body's temperature and constipation. A lot of the
 435 time Mum doesn't drink enough fluids which I think has always been a problem for her
 436 UTIs and constipation and fecal impaction, so you know, if there's a way of somewhat, of
 437 something telling me that Mum needs to drink more fluids, that would be good.
 438 Something that would act as a chair that was comfortable enough for mum to sit in but
 439 then could also be rolled around, because a conventional wheelchair isn't comfortable
 440 enough for someone to sit in all day long but then I mean, with a comfortable chair, once
 441 you're in it, it's difficult to get out of because it's so comfy and laid back. But then also
 442 for a little old lady to get herself out of it even by- and of course the trouble is, you could
 443 always press that button there, but Mum doesn't press the button anymore, she can't do
 444 it. Rheumatoid arthritis in her hands, I mean she couldn't, even if she knew which button
 445 to press so (So, that is actually one of those armchairs that help you to get up?) Yeah but
 446 again, it only works if that little old lady is still able to press the buttons and still got
 447 enough up here to know what to do.

448 I: Thinking about when you are away and desperately wanting an update, can you think of
 449 anything that you would like in place that might make that easier for you?

450 P: Well, given that it's too much trouble to get people just to send me a two-word text to
 451 say 'mum okay', I'm not saying they never did but nothing like enough for me to relax.
 452 So, they've said 'mum's all right'. To then give them another piece of technology given

453 that most people, especially around a certain age they, they wear their anti-technology
454 hat with pride. It's almost like a badge of honour around here. 'I'm not doing emails, I'm
455 not doing this, I'm not doing that' you know. 'I'm a real person, not an online person',
456 you know, to expect them to then go, you know, if they were young techy people, 25-
457 year-old all bright eyed and whizzy and techy, that's fine, that's another thing isn't it. You
458 know, it's difficult. How would you do that, again unless it's a wearable watch.
459 Everyone's got the Fitbit and you just press a button which sends a message even it's just
460 a blip with a green tick which is a way of saying 'Mum's all right'. Yeah but how would
461 you do that?

462 I: So when you're saying 'Mum's all right', basically what you want to know is that she's
463 had her medication or...?

464 P: Yeah well, I mean, like you can get these, it depends at what level you're talking about.
465 We're out in the sticks here, I mean I'm just doing it as an informal thing. So that would
466 just mean someone's sending me a text to say 'I've seen mum, she's okay' or whatever
467 but there are like, care companies out there that will actually transmit a full report. So a
468 carer will go in and they'll have their i-Pad, they'll ignore their patient completely
469 because that's what they'll do, do this and they'll press send and then that'll get picked
470 up at the home of the son and daughter in-law, or whoever it is and they'll get that
471 report and to say 'this is what I did, this is what I fed her, this is how she was, I did any
472 washing, any caring, was she all right, was she babbling' or whatever so you can get
473 those as well but those generally tend to obviously be a lot more expensive because of
474 the technology involved. And the one thing of course that the coming generations are
475 not going to have is any money. Just debt. (Yeah) Just debt.

476 I: Would that be something that you would like? Not taking into consideration what
477 technology would be needed to provide that, would you like to have a report or is it just
478 enough to say 'I've seen mum'?

479 P: Yeah, I mean, I could see that on my phone so I could just log into the app on my phone
480 and then just download whatever the latest report is then that would work for me. Yeah,
481 (yeah?) definitely.

482 I: Thinking more along those lines, if you had a magic wand, so, if there were no limitations
483 whatsoever, what would you like technology to do for you?

484 P: I think in my mother's case it would be [pause] something upon her person that could
485 record any significant changes in her constitution that could then maybe make my phone
486 bleep. It's a bit like workers in Sweden now, I believe they have a chip under their skin to
487 check in and out of their offices. You know it's a, we're all being turned into a robot,
488 aren't we. But you know, something like that, that would report the changes,
489 professional footballers even go this way now. (Really?) Yeah. Yeah. No they have a
490 different diet, specially curated, to use that word, based on how much salt they have
491 going through, how much sugar they have going through, you know and then how that
492 translates into energy and all the rest of it, what they drink will be specifically suited to
493 that. In the way that an elderly person will the same thing supposedly done for them. So,
494 it would have to be wearable, I guess, and it would have to be fairly straightforward. And

495 I'm thinking from the Dementia point of view, we were talking about how do people stay
496 safe when they go walkabout, you know. So maybe if someone's out of their room,
497 maybe a sensor to trip an alarm on a phone for the on the on-duty carer you know 'go
498 and look after Nancy in number 14 cause she's just left the front door' sort of thing
499 rather than, I know it sounds like coldness but how else do you put it, I don't know.

500 I: But it has not been an issue for you and your mum?

501 P: No, this hasn't but in [care home where P is on the board] it's a massive issue. (Yeah)
502 [redacted as it pertains to said care home]. Yeah. No, it's quite, it's an issue. It's a thing. It
503 absolutely is a thing. So, when you're thinking about converting a unit into a dementia
504 unit it's all about the security and also about keeping tabs on, dare I say the inmates,
505 because otherwise you could have chaos, and this is the problem. So, we've got. The
506 trouble is people go, who go into care homes now, they're getting older and older and
507 frailer and frailer. And it is becoming more and more of a burden on the staff. They're all
508 very good, very helpful. They want nothing more than to be nice and help people. But
509 you can only spread yourself so thin.

510 I: That's true. Can you think of anything else, that could also be not technology related,
511 that would make it easier for you?

512 P: So, I think the, again thinking of it in terms of my mum specifically, mum's got a very set
513 way of how everything should be. And because it's her home, she paid for it and blah
514 blah blah. You know that's, so that, her day chair is there and her bedroom is right down
515 at the other end of the house which is not the greatest idea. I mean really. You know
516 that, what is now the dining room should have been her bedroom and you know, try and
517 get mum to do that, it's not worth the effort it's just easier to go with the flow.

518 I: So, wrapping up, what would you say are the most difficult and the most positive aspects
519 of combining work and care?

520 P: So, for me, I live rent free in a very lovely part of the world. I have the, I have had the
521 opportunity and still have the opportunity to develop a relationship with my mother
522 which would otherwise not have been there. I mean, she's damaged me greatly, but this
523 was an opportunity to develop a relationship with her which sort of almost enabled me
524 to forgive her and to try and show that you don't hold a grudge all your life. So, I've been
525 able to do that. And it's given me experience in another completely unrelated field. So,
526 I've been able to develop sort of more interpersonal skills and caring skills and things like
527 that. And it's given me leads in, a lead into sort of a medical/social work field and an
528 organizational thing as well, because it's all been micromanaging mum down to the last
529 minute of every day. So, it's been, it's been a great opportunity. I think it's bettered me
530 as a person if I'm honest, because I think if you're just stuck in your one little role you
531 can get a bit, sort of, closed and you don't realize how closed you could become to other
532 people and doing things in other ways, so that's good.

533 I: And regarding the difficult aspects?

534 P: Yeah well, I'm exhausted. I have, I book a holiday in extremis because I mean, I knew just
535 how much work it's going to be just to get away. And then when mum went into

536 hospital, then you have to unwind all the things that you've wound up to be in place. So,
537 a lot of people that were going to earn a few bob, albeit casually, off the back of looking
538 after mum when I'm away, all of a sudden they're not getting the 150 quid now, they're
539 not getting that 50 quid for looking in. So, there's all that stuff and it's difficult 'I'm really
540 sorry, but'. That's a difficult moment. So, I've had a few of those to deal with this past
541 week, so, and the other thing of course is because this is the big house, we're the
542 foreigners around here, being English, the big house up on the hill. Last time this house
543 was empty for a time it got completely trashed by locals. And so, a lot of the
544 organization has been organizing people to come in and keep the house occupied while
545 we're away. So, people don't get the idea that it's just there. So, the car's getting left
546 outside. You know there were people going in every day. Got it all organized. I've even
547 asked people to stay over so I'll change the duvet on my bed just so they can sleep over.

548 I: That's rough, wow. So, if you met someone else in a similar situation like yourself, who is
549 combining work and looking after someone with dementia, what sort of advice would
550 you give that person?

551 P: I think you need to look after yourself, as well if not put yourself first before the care, I
552 know this sounds counterintuitive but if you're not right yourself, you can't be right for
553 other people. And it's a much, much harder work than it looks. I'll never forget when I
554 was a student, I worked in the hospitality industry, you know I worked behind bars, I
555 worked in restaurants and, you know, the number that, apart from the number of miles
556 you have to walk, the organizational stuff, the short-term memory skills, interpersonal
557 people skills and things like that. It's, much harder work than it looks and it's knacker-
558 ing, you know, and it's the same sort of thing. Doing this, it takes me back to that a little bit,
559 pussyfooting around people, you know, we have cross words sometimes when it needs
560 to be said. You know, unfortunately Mum's not good at not holding a grudge. So, you
561 know, it's very difficult. You know, you have to package it in a way that will sound right
562 to her. And it's constantly putting yourself in her shoes and it's that action that is, that's
563 what takes it out of you. That's what's exhausting. The physical, I couldn't care less about
564 cutting the grass, picking Mum up out of a chair. That's nothing. (So, it's the emotional
565 labour), yes, it's emotionally exhausting.

566 I: What are, what do you wish for yourself, for your own future?

567 P: So, for me, I've just turned 50 and if I was like really clever and I had some high paid job
568 that I could go back to down south, well then I probably would be thinking along those
569 lines and indeed it may come to that anyway if there's nothing out here, but if I can't
570 stay up here I mean obviously I dunno how long I can manage a business in [city 2] from
571 up here about that. That said, if there was a way of doing it, I mean managing agents
572 increasingly employ people that work from home and then only go into an office once in
573 a blue moon and sit down with the accounts team or whatever it is, you know,
574 technology has moved on in that sense. You can log on to, you log on to your own Citrix
575 database or whatever it is and off you go. Yeah, same with us, so, it may be that you can
576 live away from a big city and not have to pay high rents or stupid prices for property but
577 also so long as you can do your job from your desk, from the computer. I don't mind
578 getting in a car and driving out to site two, three days a week, that would, that, that's

579 fine. But obviously it just depends on the what and the where. Short answer is, if I can
580 stay here, not in this house but in the area, I will, but I have to be realistic and practical
581 and flexible. Well, I'll go where the work is.

582 I: Thank you very much. That already concludes the interview. I just have very briefly a
583 couple of questions regarding the context. So, you already mentioned you are 50 years
584 old. How old is your mum? (89) 89. OK. Do you currently have a partner? (No) What's the
585 highest level of education that you have?

586 P: I did a post, I did a degree, then I worked for a couple of years and I did a postgrad
587 diploma. I did other stuff, like, I did the most complicated exam I ever sat for me was the
588 Institute of Woods science which is the practical application of timber where you go at it
589 from a biological and chemical point of view, because it's the biological and chemical
590 make-, molecular makeup of wood that determines is eventual use. (Oh) Yeah, that was
591 complicated, that was, that was really hard. So that was after I, that was after my degree
592 but before the postgrad diploma. (OK) So, that's probably the hardest exam I've ever
593 passed.

594 I: Yeah and apart from your mum, have you provided care for anyone else?

595 P: When I was a kid I probably did a little bit of it for my grandmother when she was
596 younger. Yeah, she was declining when I was in my teens, but I haven't held official roles
597 in the caring sector. No. (Yeah) This is the first one, but you see most of the people that
598 do get these sorts of roles that like female, typically female, typically in their teens or
599 early 20s. You know a guy my age that wouldn't take it on because my back would
600 probably give out anyway.

601 I: Okay thanks so much.

602 END