

Interview 8, “Betty”

Date: 10.4.2019; Duration: 130min; Setting: participant’s home

I = Interviewer, P = Participant

I: It’s started, good, so to begin, could you maybe tell me a bit more about the caring situation you’re in, so how did that come about for you?

P: Right, ok, about er, I would say, about four years' ago, there was family circumstances where I needed to go and visit dad, up until then he had tended to always be visiting us (aha) because he was out and about so much you know, throughout his 20 year retirement, he was always busy with working groups and we had to make an appointment with him, so it just, it just came year on year that he always visited us rather than us going to him but when I had our, my Godmother was very ill, I needed to go and stay there to be close to my Godmother so it was first time actually visiting the house because my mum and dad are divorced, it was the first time I'd been at his house for a good number of years and that sounds odd but he was always very regularly over to our house and when I went in the door it made me realise he was just not coping at all. The house was a disaster (mm) an absolute disaster; it became clear that it was just really unsafe. I think he'd, because he'd been living on his own, he had and had so many projects, he was really using the house as a workshop to the point where it had just become overwhelming with tools and every bit of floor space, but we lost niece you know, my dad's grandchild that year and I don't know if that had an impact with drinking, which would make things worse but it became clear that he wasn't coping at all and we weren't sure if it was the level of drinking or if it was underlying, so the first thing husband and I had to do was really take control, to transform the house to be a safe and comfortable place to be in. He'd never, he'd never cooked on his own (mm), he's quite a good cook actually but just the nature of being on his own, he never cooked so he'd always been in the habit, during his retirement of going places to lunch. That could be hospital canteens where you could you know, do really nice meals, or the supermarkets and I think part of it was by going out, he was, he was a social person, so he enjoyed the social experience but it meant if he did want to invite anybody to the house he couldn't, I mean absolutely couldn't, so my husband and I spent two years every weekend, that we more or less gave up everything else that we did, including being here for my teenage son at weekends to try and transform the house, it was that bad. Seeing my dad more regularly over that period has made us conscious that during that time he has started to become more forgetful, for maybe minor things to begin with. I think maybe two years' ago, two years into that four years' ago period, we became aware; examples such as we were at a barbecue with my dad and he had brought a bottle of wine for my cousin and he asked me to go and get the wine to give it to my cousin, which we did and within about half an hour he'd said 'can you go and get the wine' to give to [name] and I said 'we've already done that' and he looked a bit embarrassed and shortly after that, he just, you know it was a sunny summer's day, we were all outside and he just disappeared and I found him in the house, just watching television and I wondered then was he forgetting more things that had happened in the very recent past and as that making him more uncomfortable to be in company because we'd found he'd started to withdraw from lots of groups that he used to be involved with. He used to be involved with hospital groups that took challenges that

people were finding being at home and they would come up with, so he would make things to compensate and help them be in the house, and again it was problem solving and using his hands, which was ideal for him, but he, he gave up being part of his disabled rambling group and all sorts of communities that used to keep him busy and he explained, he explained a lot of that, that it was just circumstances, you know the rambling groups, when he joined, a lot of the people he was friendly with were maybe even more disabled with Polio, or they were older and one by one they had died or they were no longer able to take part themselves. with woodworking groups and forum, it was, with his hands it was a case that his, he started to have rheumatism (mm) in his hands and he's no longer able to work with tools, so that became a barrier to be involved with groups that were about projects and making things. My dad's never been as good at explaining to others how you might go about it, which might have helped him find another role in such groups; he was more somebody who would want to be left alone to figure it out and do it himself, but when it came to articulating, that's difficult for him. So that's you know, narrowed opportunities to remain inclusive for him and so six months' ago, we became aware dad had had a couple of falls and quite you know, within weeks of each other, that he'd hit his head and stuff and we had wanted to take him to hospital and he'd said it was fine, but it was clear that he was struggling to sit up and stand up; his shoulders impacted, so we insisted and his older sister insisted as well that we take him to shop and that gave the opportunity while he was there being assessed for his arm for the hospital to also do some scans on his head because he'd hit his head (mm) and I suppose that, that then meant we had some detail for the doctors to look at in terms of his memory and whether it was, whether the falls were drink related or actually whether there was other things going on and as I said over the last six months after he came out of hospital, that was when I would class myself as performing more a carer role. I suppose the three and a half years before that were just some that my dad was really struggling and as a daughter, you know, you're just trying to help him you know, get back to a better place but since he came out of hospital one of the impacts of being in hospital and we weren't sure and the doctors weren't sure whether it was drink or, or perhaps a dementia related impact, but it was decided that he should stop driving (aha) and although he wasn't happy about it and said 'I'm going to appeal', he didn't and I'm unsure whether it's because he knew in himself there was, it wasn't worth appealing or actually whether he just couldn't get his head round how he would go about doing it. You know in the past, my dad would've been very clear on what he needed to do to challenge something but that was indicative, the way he'd just like that go, erm resigned that part of what he presents was is he's happy for someone else to do it but any kind of administrative or paper, you know, he's, he'll put the letter to the side of him and he thinks that he's being organised but he's not acting what's in the envelope, whether it's a doctor's appointment or whatever, he'd write it down but on the basis that he's not remembering what day it is and he'll say 'well I've got my diary' but for the diary to work you've got to know, you've got to know what day it is and even six months ago he was clearer on what day it is than now. What I would do now, so, so when he has letters I say we have a day a week when we go and half of that day will be taking him out, I drive, which is a big deal for him because he doesn't have the car but the other half a day is changing his bed sheets, doing any dishes that he's left in the sink, doing hoovering, but more importantly going through any papers, any appointments that come in from doctors or whatever and make sure that he's entered them in his diary. I make sure that he writes them so that he's familiar with it, but I then write the core information in here, so but I get up in a morning before I start work, I look to check, say 'what do I need to do for dad'. So whether it's carer or whether it's personal PA (aha), it's taking on that kind of role and fitting it in along with other, because a lot of the agencies that you have to deal with are nine to five, so you've got to contact them with what is essentially your work hours, so the flexibility of the [place of work] and my line manager is happy you know, I know what

96 my hours are that I need to work, I'm full time, 35 hours so it's roughly 7 hours a day but
97 when I start and when I finish you know because I'm not in a customer facing role, I do
98 pieces of work analysis so when I do it really I've got a lot of flexibility as long as I get it
99 finished for whenever people need it but it means that if I need to talk to a doctor on a
100 morning, I can do that and just build my time up later in the day. So that's not necessarily a
101 technological thing, but it is a, it's a work around that helps, and obviously working from
102 home helps. So, so to go back, so I have the diary if you like to trigger what I need to do to
103 make appointments. Now that my dad doesn't drive and he doesn't cook, one of the things I
104 had to set up was lunches, meals to make sure he was getting nutrition. It had become really
105 clear that he was, he was forgetting to go to the supermarket to get food, so he's maybe
106 going all day without anything to eat but maybe going to a local shop for some drink and we
107 weren't sure if that was an alcoholic thing or it's just the judgement's been impaired- he's
108 84, so we put in place meals on wheels for the weekend and on Monday but then four days
109 a week he goes to a lunch club so this lunch club, there's a minibus comes and picks him up,
110 which is motor technology I don't know -laughs- and they bring him back as well. I don't
111 have to book that, that's part of the service that's up and running and he gets a lunch there
112 but what it means is I need to phone the agency if he has a doctor's appointment or if he has
113 a reason why he can't attend the lunch club so the phone is indispensable, really, when
114 you're at a distance from the community that he lives in and my dad lives 40 miles away, the
115 phone is essential (mm) so in my phone I've got numbers for the contact for the lunch club
116 and I'll let them know if he can't make it that day or they'll let me know if he hasn't noticed
117 that the bus is outside or if he's forgotten, which is less the case, he's now got his brain into
118 the routine so he does, he remembers that. If he has a doctor's appointment and the doctor
119 was local, it means that you have to organise transport to get him to the doctors, so there is
120 that. In the community there is a set up called 'ring a ride' and you can book, and a minibus
121 will come and pick you up. What you have to do is phone the day before and give them the
122 time that you need to arrive somewhere and they will have your address and your postcode
123 and then they use technology to enter all the postcodes and the times of where somebody's
124 picked up and where they need to go to for a certain time and then they use some kind of
125 advocacy package to work out who they're gonna pick out and what the route is for the
126 driver to take during the day to get everybody picked up and everybody dropped off for the
127 times allocated. So, they're using technology and I benefit from that by phoning up and
128 organising, but you can only do that the day before (aha) you can't do that, you know, when
129 the appointment comes in or whatever, but this technology only works on a day ahead basis.
130 That's been invaluable and it's a similar kind of set up for patient transfer to the hospital,
131 which is nine miles away, if dad needs to go there for scans or different types of
132 appointments I can book ahead, I can book weeks and weeks ahead for that, as soon as the
133 appointment comes in. The only problem is they don't seem to have quite as reliable
134 technology to work out routes and he's missed appointments (oh dear) because they
135 haven't come in enough time to get him there. So that's still you know, the patient transfer
136 services is still a bit hit and miss-

137 I: So, when something like that happens when that transfer doesn't come on time and your
138 dad misses the appointment, are you getting notified about that?

139 P: So basically what I do is I, if it, if it was something like a hospital appointment I'm phoning
140 my dad in the morning to remind him that he's waiting on the bus and that he won't be
141 going to his lunch club that day, if appointments are Tuesday to Friday, and what that then
142 means is I would then phone up the Council and organise for him to have a meal on wheels'
143 lunch that day. If it falls in that lunches are delivered at one and that doesn't necessarily
144 work you know, if it's an appointment that's two o'clock, dad might have to be ready from

twelve o'clock to be picked up, just appearing on the rota, in which case he would miss his lunch if you like (mm) but that's how that system works. So I'll use a phone to contact my dad and remind him where he's going and remind him that the person's gonna take them to his border clinic but remind him to have his diary with him so that if he forgets it's written in the diary that he can call out to you know, the ambulance person or whoever's taking him there. I use the phone daily to remind him to take his tablets in the afternoon. He remembers to take his morning ones but later in the day, it just slips off and I think part of that is going out to the lunch club and then coming back, he's just not thinking. I've tried to say 'the trigger is you're coming back into the house and the first thing to do is go take your tablet before you sit down at the television' but once he sits down at the television he's not really thinking it through so you know, so he's, he takes five tablets in the morning and there's another two that are supposed to be straddled over the later part of the day and he invariably misses taking them. Now one of the technological solutions suggested to that is that he can get a device that you put all the pills into and it gets plugged in and it's on a timer and the timer goes with a loud buzzer that increases to let the person know to take the tablets, but the problem with that is the pharmacy would no longer be organising which tablets to take at what time and I would need to take that on board and at this point in time, I didn't want to be responsible for sorting his drugs (aha) and I wasn't sure that he'd remember because my dad, my dad is partly deaf and with the noise level of the television, I wasn't sure he would even hear it. Maybe he would but the main reason was because that was gonna be me ticking all the boxes and organising all the tablets from then on, then on in. At the moment that felt a bit more than what I wanted to take on at the moment. So that's the kind of technology that's there and we might pick that up at some point. The other thing we organised for my dad because of the falls, the Local Authority there has a fall contact service, so we have signed up for that and my dad now has a bracelet with a button and it means that if he was to fall, or get stuck in the bath, he could press this button and somebody would come, so we've got keys put into a little key box on the outside of the door and the central office know the pass code for that so they would be able to get access to the house for somebody trained in lifting my dad to help because over this six months I think it was, I think it was about four weeks after he came out of hospital in October, he had taken a bath, I wasn't even sure my dad used the bath, there was a lot of fluff in the bath! So I wasn't even sure, I thought he maybe just washed at the sink, but he'd went into the bath and this was when his arm was still you know, causing problems and of course once he was in the bath, tried to get out, he didn't have the power to lift himself out so again that to me was you know, indicative that he wasn't thinking it through (aha), he'd got into the bath on a Saturday, which was not a day that we normally come, he got into the bath knowing that he was struggling to get out of the chair and yet he got into the bath which is more complicated to get himself out of and he got stuck and it was a pure fluke that we decided to visit on the Saturday and had got into the house through the keys we'd provided and I thought it was odd he wasn't on the ground floor and went upstairs, I said 'dad where are you?' and he said 'I'm in the bath, I can't get out' and it was horrifying because I thought what would you have done if we hadn't arrived and I said 'what are you doing in the bath with your sore arm?' and he says 'I just felt like a wash' -laughs- and I says 'but of all times to have a bath, the fact you've got your sore arm means you're struggling to get out of the chair' but the logic wasn't there but when my husband came and tried to lift him out of the bath, we were worried that we were actually going to hurt his shoulder because we didn't know quite what was the best way to try and get him out of the bath and we contacted the ambulance service to come and they tried to help and it needed two of them to do it and that still caused a lot of pain to dad. So that was a trigger to us, I think the ambulance service gets called out for that sort of thing and it's not really what they're there to do so getting this technology of the bracelet and a patient transfer if dad doesn't take the bracelet off, which sometimes he does, the

196 idea is that he could sue the bracelet and contact somebody and they would go out and if
197 they find it was something that dad needed to go to hospital or whatever, then they would
198 contact us (yeah), so that's how it adds value you know to me that we could do that
199 because, ah erm, what was I going to say? What was it? Just trying to think [pause] I'm
200 maybe getting mixed up, there was an occasion my dad had to use the bracelet and he
201 thought the electricity, I think that's part of the confusion coming in, that's where the
202 technology is reliant still on my dad's ability to use it. He'd press the button and he'd contact
203 them and he thought that the electricity was off and they said 'well, we're not here for
204 electricity, it's more if you have a fall, we have somebody who could come out who's trained
205 to lift people who have falls, so you need to contact an electrician to check it'. As it turned
206 out, he just couldn't find the gadget for turning the television on and he'd said electricity and
207 but they had contacted us because they thought well, if the electricity's off that could mean
208 there wouldn't be any power for the gas heating system. So we went across, that's how we
209 figured out it was nothing to do with the electricity, yeah -sighs-

210 I: Do you know, was there an instance where he did have a fall and used the bracelet, or did
211 have a fall and not used it?

212 P: So, so, touch wood, he hasn't had a fall yet but he's just started on medication this week
213 which is supposed to help when you're in the severe, moderate to severe stage of dementia
214 and it's one of four approved medications by NICE but it's only one that that causes dizziness
215 and potential falls and my dad's had a long-standing problem with balance and it's to do
216 with ear issues, so I've said, I said to him Sunday, 'this is a period where it's really important
217 you wear your bracelet all the time because we don't know how the medication is gonna
218 impact you; it may help keep things clearer in your head but the side effect could be that it
219 makes you dizzy and affects your balance' so I said you know, I'm replying on him using his
220 bracelet so that if he does fall, he doesn't try to get up himself, well he still might not be
221 right and that he's able to access somebody to come out and check him, oh, I was gonna say
222 that there was one time a neighbour had went to the door and I forget what it was but the
223 neighbour had gone to the door, the chap on the door and my dad saw them and he came
224 but I think he'd got up out of his chair too quickly, which had made him a bit light-headed
225 and he had went to the door and he'd fallen back and hit his head. So that was one of the
226 two episodes where he'd hit his head before he went into hospital and on that occasion the
227 next door neighbour had phoned us straight away but because my dad had hit his head I
228 wanted to get somebody out to check him (yeah, yes) quicker than we could get across and
229 we still can't assess dad's whereabouts mentally but NHS24, we were on the line for half an
230 hour and we still hadn't got through and in the end the battery on my phone was pretty old
231 and it had died on the landline, so we got cut off. So rather than risk go through that again,
232 we just jumped in the car and we got across. It took us an hour to get across in the car but
233 that made us realise that we couldn't rely on just phoning NHS to get a doctor out to dad if
234 there was a fall, so that's where the technology of wearing the bracelet or the necklace can
235 be a godsend to get somebody there who's trained to assess whether they can help the
236 person up and get them into bed, or whether they assess that actually they need
237 hospitalised so they can monitor him if you know, if he's knocked himself badly and that's
238 about as much technologies we use, so basically-

239 I: It's quite a lot-

240 P: It's basically phone and bracelet.

241 I: I was gonna ask you some more detail about the bracelet, do you think your dad knows what
242 to do with it?

243 P: So, so on the basis that he, you know when he couldn't find his thing, he buzzed it, the only
244 problem was it was for the wrong reason (ok) and I think he was, he took it off after that
245 because he wasn't happy that they didn't come out, so it was trying to explain to him that
246 this is a service that, you know, he only pays two pounds fifty a week for this so it's a
247 nominal sum of money but it's like any kind of insurance, you know, you're hoping you won't
248 fall and I've said that to dad, I've said 'they're not there at the end to do anything you like,
249 they're there in the occasion that you have a fall, there's somebody that's trained in falls and
250 trained how to assess if you need further help' because it may be that he's had a trip and he
251 just needs- put back into his chair, maybe made a cup of tea and just made more
252 comfortable again, or it could be something well, my neighbour noticed when my dad had
253 stepped back, he'd had a bit of a trip and he'd knocked his head, it took him a bit to come
254 round, took him maybe a half a minute or something to just come round, in which case that
255 maybe needed somebody to be there for a bit more or to call us to go and stay overnight
256 with him just to make sure he wasn't concussed (yeah, yep, yep). So, So, at the moment he
257 understands what it's for but I mean what we find with the dementia is you know, you might
258 think you're in a routine but things can change and at the moment we're managing, which is
259 fine, you know I'm still working full time and as I say if I didn't have the phone there to check
260 my dad, albeit he gets quite irritated with me checking you know, checking your tablets he'll
261 go 'I'm not two' I'll go 'no, but you do forget, so it's easy for me to pick up the phone and just
262 prompt' but you know, it's frustrating for the person who's forgetting (mm, of course)
263 almost kind of the sense that they're being told what to do and they're being monitored and
264 my dad's always been a pretty free spirit, so the idea that I'm not on his case checking this,
265 that and the next thing irritates him (mm). I remember being on a bus, I went when he
266 started the lunch clubs, I said 'I'll go and with you and just see what it's like' and I thought
267 my dad would be quite chatty because my dad had always been a noisy- you know my mum
268 was a very quiet person but he was always somebody who was quite gregarious and would
269 chat, and I was really surprised just how quiet he was and partly you know you see other
270 people as old people, but you won't necessarily think of yourself (yep) like you'll see young
271 people at the lunch club struggle with conversation or struggle to pick up their food or
272 whatever and I think part of it is not really wanting to associate. I think you know I've said to
273 him, I said to the lady that runs the club, I goes 'how's my dad settling in?' and she said 'well
274 he keeps himself to himself, he reads the paper' and I goes 'it's not really the point of the
275 lunch club, he could read a paper at home if he wanted' the idea is I suppose to be that
276 stimulus, that social stimulus and maybe it happens on a different level that at least maybe
277 not engaging in the conversation or I can't see him engaging in the bingo, but he's there and
278 he's observing what's going on and there's the routine of the bus coming and when he's in
279 the bus I think he quite enjoys that it's a hurry to pick everybody up. So, you're going round
280 the streets, you're seeing the dogs come out the garden, you're just seeing what's going on
281 in the community, not necessarily taking part in it but you're more involved in it than you
282 are, than if you were just in your own living room (mm, absolutely). So it's, it's just subtle
283 things but you know, we're in a, we're in a kind of a learning thing you know, seeing how it
284 goes and say he just got his diagnosis formally a month ago and I was a bit taken aback you
285 know, of the 'moderate to severe' I mean I thought he was at the start of this journey, I
286 didn't think he was more than half way through and I'm still not sure he is so far that way, I
287 mean the doctors did say it's not an exact science (yeah) but obviously the later stages you
288 know if it comes to the point where he's not able to manage his food, not able to manage
289 getting himself dressed, not able to get himself up in the morning awake or whatever; these
290 are other challenges that we need you know, my husband and I we need to start thinking

about what we do for then I mean I never really wanted my parents to have to go into Care System but and I would still try and do as much as possible to avoid that. I've thought about what could we do with the house to make this work better but becoming more aware actually that it is, if the end points of the disease if you're not lucky enough to have a heart attack or something beforehand they could end up and most of the time ends up that you're left you know as an individual that you don't recognise your family, you can't do so much for yourself that it almost seems inevitable. The medication talks about how long the medication can help manage the behaviour before you're institutionalised and it almost seems a done deal that you're institutionalised, which is a really scary thing for me. As someone I think who will no doubt end up with dementia if I don't already have! -laughs- if I'm not already on it, it is a scary thought that it you know, it's a series of events and that, that is the assumed end point so you know, going on this journey it's you know, can we cope, can we cope as a kind of family, can we bring in additional support into the home setting and help for that? Another thing is if my dad gets irritated with at the moment with the level of support we try to find, I could see then why families then think it needs to be a care situation to divorce being the carer from being the family member (aha) because it is quite hard you know to you know, you're working around full time work, you're coming back over, back and forward, you've got a long drive there and back to get there and you're doing an outing drive as well to have something stimulating and interesting to go and at the end of the day it's like oh god, it's going on and on. It's, can be draining (mm) but then you know, you have to decide I think as a family member being a carer you know, what do you want out of this and I presume anybody who's choosing to be a carer wants to continue with the relationship with their parent or their child, if that's the thing, for as long as they possibly can and my dad, his house four years ago was filled with stuff and sawdust and all the rest of it but he's also been a collector, he also, you know he went to a lot of auctions in his days and took me when I was young to auctions and he collected stuff so he's got all sorts of interesting things which actually as prompts for conversation (aha) you know so it's not about 'when did you take your medication' or 'have you done this or have you done that' you know, I can, I can take a drawer of spanners and tools and stuff and say 'I'd quite like to sort these out, dad; what's this for and what would you use that for and what was that?' and that triggers a bank of memories that aren't yet impacted by short term memory you know, they're ingrained there as tools. So, I think then with caring, I'm personally energised when you can have good conversations that because you know if you can find, if you can find a stimulus that isn't based on short-term memory, you can have quality conversations which benefit the carer as well as the person with dementia. I know dad quite enjoys and will end up taking stuff away to look at for a while, yeah. I remember that from my husband's grandmother who had dementia and we saw that play out, that her youngest son took on the primary carer role and the dynamic changes so much from being the favoured youngest child -laughs- over time, the dynamic, my husband's grandmother almost resented the son and his wife almost you know, rationing out her whiskey toddy at the end of the night, rather than just leaving her with the bottle to decide yourself how much you wanted to drink. He wouldn't leave the bottle in the house, he would bring it with him and pour a half measure for her heart and that was all she was getting (laughs) and the door was locked until the next day when he came back to visit her and the relationship wasn't good at the end and yet he was, you know that was, that was ten years ago and there was maybe less visibility of caring and stuff then but he was doing it, he was still full time working before he retired doing a job and working then coming back and night and stuff and again sapping his energy by no longer getting a 'thank you' but getting almost a really defensive person so, I'm working really hard to try and avoid that or if you can't avoid it, if that's just what happens, to try and delay that becoming like that as far as possible (mm) because I think that's quite a sad, that's a sad reflection of choosing to be a carer, you know, it sounds as if it would be

342 something that would be welcomed and with kindness about it, but actually you know, the
343 whole spirit of needing to care means somebody needs to be cared for and if that's a child,
344 they're expecting a parent to care for them, but when that's a parent and they're having to
345 give up being the decider, that's a really hard thing (mm, mm) and yet you know, you can't
346 you know, you can't do workshops with a person with dementia, say 'right this is what you
347 can't do' you know (mm). So that's a sad bit of it. I think it's all very well knowing it's all very
348 well documented but it's not an easy thing.

349 I: Yeah, dementia is really a very tricky disease in that respect.

350 P: It is. I mean I supported my, my aunt who went through three bouts of cancer and
351 unfortunately for her you know the last one was long, drawn out and very, very painful and
352 mental torture and actually we didn't really appreciate until quite near the end of her death,
353 her husband was fifteen years older than her. So she was 57, he was, actually no she was 68
354 and so he was early eighties and because despite her cancer mentally, she was strong as an
355 ox and her mental strength had been compensating for her husband that he was in probably
356 more direct stages of dementia, probably similar to what stage my dad's in now but I
357 suppose it's coming to light, the more infirm she was and because she was still mentally alert
358 it was causing her a lot of stress because he always used to be the one that paid the bills.
359 They didn't, they never set up any direct debits and everything; everything was paid when
360 the bill came in and neither of them wanted to change their routine that had been there for
361 forty-odd years of marriage which became a nightmare for anybody trying to support them
362 in a token carer way you know, they both felt they were each other's carer (mm) and that
363 was really hard. Even the technology of direct debits and stuff has, actually that's something-
364 that yeah the technology the Banks have setting up direct debits' payment systems, regular
365 things takes all that financial admin out you know, take that for granted now. Unless I'd seen
366 it with my aunt and her husband- what a mess they were in, the husband, her husband
367 always paid the bills but when he had dementia he was taking the money out to pay it but
368 then forgetting that he was just, drop off at the Post Office and forgetting and the first my
369 aunt knew about it was when she got a call from the Council that the rent wasn't paid and
370 'well we've never ever in forty-odd years, we've never missed rent, we're never in rent
371 arrears' and she had to take on a level of administration that her body just was not able to
372 do and we said 'you just do a direct debit' but my dad, really he remembers his PIN number
373 so he can get money out himself from the bank machine, that'll be another issue if he
374 forgets that but if it's the same number hopefully that sits with long term memory than
375 short but he's managing that, so he can get whatever cash he needs out but it means he
376 doesn't worry about all the bills because the bills are automatically being paid with the
377 automatic triggers that technology enables. So, things like that and making sure that these
378 things are all in place, because if you had to, on top of a caring role, if you had all that other
379 stuff going on, you really would be full time; you would be running two households (yeah, of
380 course). You know, I mean it's surprising even how organising one or two appointments, I
381 mean when my dad first came out of hospital he had a number of appointments in
382 succession and it could take the best part of a day between eventually you know, getting the
383 letter for an appointment and the appointment either being too early or too late in the day
384 to get the patient transfer service, so then having to go back to the hospital to organise an
385 appointment that was within the time frame where we could organise transport for him,
386 then going back to the transport people to organise him that and then once you've got an
387 appointment, working out that's, he won't be able to go to his lunch club so then contacting
388 the lunch club people and because he wasn't going to lunch, thinking about how, what we're
389 going to do to make sure he has some nutrition for the day, which means he needs to have
390 cash and then having to manage to remember to make sure he's at an ATM on the Sunday

391 and work out how much cash he's gonna need you know to pay for lunch clubs plus extra for
392 more expensive meals at hospital or whatever like that-

393 I: And all of that having to do from a distance-

394 P: Yes, yeah, well apart from like the physical cash which it's planning ahead what we need to
395 do on a Sunday when we need my dad to do something which is you know, work out what
396 he needs so he has physical cash. It's about the only thing that we, that he needs to do if you
397 like, so that he maintains a sense of financial independence. I mean another way about it
398 would be he relinquishes completely under power of attorney, which it took him a long time
399 to get his head round, so we've just really got that in place now; he resisted that for quite a
400 while but we've kept that that he has the independence while he has the capability to do it
401 and I think actually the important you know, I think my dad would lose the will to live if he
402 were relinquishing being able to sell the house or take money out of his account and stuff
403 like that so I think it's important to my dad that you know, he's the one that manages his
404 banking, albeit he has had the neighbour go to the bank, ATM to get money out for him and
405 she contacted me later and says 'I don't feel comfortable about this' and I'm thinking well I
406 don't feel comfortable either, not least because he's got quite a lot of money in his current
407 account because he's not, you know, long ago he would have shifted that into another kind
408 of product, banking product thing but he's not thinking like that now so it's just sitting there
409 in a current account but that would kind of be an eye popper (mm) you know for someone.
410 So, I had to have conversation with my dad to say 'your terms and conditions for the Bank is
411 that you don't share this number with anybody. You contravene, you have a contract with
412 the Bank, it's not a case of you're doing what you want, the Bank is very clear about that,
413 and you could have got yourself a taxi to the ATM and asked them to wait and then come
414 back'. He says 'I never thought about that' (mm) you know and then so that, I says 'that's
415 what you could do but the alternative is you nominate somebody to have a different, you
416 nominate somebody to take money out of your account but the Bank will give them a
417 different card so that when they withdraw, there's a record that it's that card holder that's
418 taken the money out and not yourself, in case you then challenge you know, but you mustn't
419 have somebody take out. I can't believe you did that, you'd never give me your card to take
420 out!' But he'd got the girl to take out £300! (mm) So yeah, so there's all sorts of things you
421 know (yeah) that's a case where technology was too easy-

422 I: Yeah, absolutely. So maybe coming back to how caring impacts your work and the other way
423 round; so, you were talking quite a bit about the flexibility that you have with work, you
424 being able to work from home, you being able to manage your work hours (yeah, I mean-) is
425 that-

426 P: Yeah, I mean the working from home has saved me the time and energy for traveling there
427 and back (aha) but I think more importantly than that it's you know, if I have to be available,
428 I mean sometimes if it's been the lunch clubs that phone up or something and he's not
429 there, or his neighbour has been concerned that she hasn't been able to get him the next
430 day, it means that I can stop work and I could pick up the phone and speak, whereas if that
431 was at work I'd have to find somewhere to do it or if I was in a meeting or whatever. So,
432 there's that flexibility which is good. When my dad had some appointments to get the
433 formal assessments done, he had two occasions for that or other appointments with the
434 doctor that he thought it's appropriate that I start to go with him- if my dad goes he'll just
435 say he's fine and the doctor needs to know you know, what the behaviour is and that's
436 helped move things to the next stage, so and he's again, these are scenarios where other
437 than me take annual leave for that, I can work up hours and take the day off instead so

438 there's that flexibility as well which is really good and it puts less pressure on saying like a
439 dependency leave. So, we got, so when my dad fell and I'd to go and that was the call when
440 the neighbour had called us to say he'd fallen and we couldn't get NHS and we'd went across
441 and got my dad and he seemed not too bad but we were worried about concussed. I stayed
442 overnight so of course I couldn't go to work the next day, I contacted my work and took that
443 as dependency leave if you like because it was a one off thing (aha) but generally speaking
444 for support what we try and do is say I will keep an eye on hours and work up time if there's
445 something coming up, like an appointment so that I can take that time off because it's not a
446 case of just going out for an hour and a half, I have to get across, myself over to Fife, get my
447 dad, take him to the appointment, take him back. So it ends up being a whole day thing but I
448 tend to work more hours just you know, because you're at home and I'm not travelling I
449 tend to start earlier and maybe finish a bit later anyway to get work done so that helps to
450 balance out and obviously home working relies on technology (yeah) so you know it's, they
451 have something called DCS, it's a virtual client server (aha) so with the technology that
452 makes me, that allows me to plug straight into the company systems that I have access to.
453 The, because the team is, because my team is scattered, some people work in [place], some
454 people work in [place], some are [place], some are [place] and [place], so the fact that I'm on
455 [name of road] doesn't really make any difference. Our team meetings aren't held in a room,
456 they are held through an audio call and we're now going onto something called Zoom which
457 will mean I'll have to do my hair before, I'll have to shampoo my hair because [both laugh]
458 you can now, you know, it will be like a video conference thing and it's through, you know
459 some kind of Facetime like thing so it will be cheaper to operate than nine people in a team
460 using a phone line, it will be a Facetime sort of, a low rate thing but it will mean that all the
461 girls in the office will now have to do their hair and thing [both laugh] if they're working from
462 home! But it means that whether I work here or whether I work there because I'm not using
463 a laptop, I'm not transporting work from one area to another and then having to take it
464 back, that you know, everything I do is always in the system, is always in the Bank's systems
465 because of the technology that the company has. I mean the, my husband works for an
466 organisation where what you do has to be more secure so nobody can work from home and
467 access documentation and stuff which means that if this was his father, you know whatever,
468 he wouldn't be able to be as flexible in terms of his day to day work arrangement as I've
469 been able to, working in the Bank but I think these systems they work for people who want
470 to juggle childcare but they equally support people like myself (yeah) yeah.

471 I: So that arrangement, was that set up when you became a carer or was it something that you
472 had in place already?

473 P: Um, no, I've, so, so that arrangement partly has been encouraged by the Bank as a
474 recognition that people at different stages of their life may have different reasons for
475 wanting to work from home. You know you could have, let's say people who have young
476 family, so if they're working from home they can still be delivering young children to the
477 gate of the school at nine and easily start work at quarter past nine if it's just fifteen minutes
478 to get back to the house, whereas that could be an hour and a quarter to get themselves
479 through a bus and a tram or car or whatever to go over the other side of the city. So you
480 know the recognised benefits to young family; if people are doing sport, they might want to
481 be doing stuff early morning or finish work really early to get back, so it gave people
482 flexibility to juggle work/life balances and I suppose the win/win for, one of the win/wins for
483 the company is obviously that if you have a hundred percent of your workforce working in
484 an office, you need a hundred percent of an estate able to accommodate them (mm, mm)
485 which is you know, computing, desk, furniture, heating, lighting and all the rest of it and
486 rental cost for accommodation, but if you have 70% or whatever percentage of a company

487 chooses to reduce that estate footprint that enables the company to make substantial
488 savings in their operating costs which means they don't need to charge their customers as
489 much for services. So you know, I work from home, I get the benefits from that and I have a
490 bigger heating bill because I'm choosing to work from home so nobody's forcing, you know
491 before this became more convenient for me, nobody was forcing me to, to work from home
492 for one day out of five or so, but if you chose, if you chose to recognise that as flexible
493 working that actually added value to your work/life balance then you could choose to do it
494 but you know you don't ask the company to pay for a seat or a desk or your heating bill you
495 know (mm). If you were a remote worker, so if there was a need for them to have a worker
496 in a particular part of the country where they didn't have a building that you could go and
497 work in, then obviously they would be set up and given a financial package to set themselves
498 up as a remote worker but for anybody else it's a case of well, you balance that out, you
499 know what's right and stuff [talk at same time (?? yeah, yeah)]. But, but so no, I tended to
500 work a day or two at home before using that time to support my dad, before challenges to
501 dad, I had challenges with my son -laughs- you know when he left school at 18 and I think
502 that can be a really challenging time. Up until then you're still very much, certainly my son
503 was still very much doing what he was told and he was involved in groups and clubs and
504 activities and all sorts of healthy things, and then he went to college and you just meet a
505 whole range of people and opportunities for whole other things so there was time when I
506 was working at home because my son needed support, yeah between the ages of 20 and 21
507 but he seems in a better place now (that's good) and as you know we need him, we need
508 him to be because it would be hard to split energy you know, as my husband and I get older,
509 if we had to split that energy in you know looking after somebody at that age where it's, if
510 you have challenges, a lot of them might be that you've brought on yourself, it's not like an
511 aging parent where they've got limited control of what's happening yeah so, but, but
512 homeworking has helped an awful lot to just keep me same and to be able to stop work at
513 five o'clock on a Tuesday and go dancing and just kind of get a little bit of balance back.

514 I: Can we maybe talk about support that you received for caring, or that you would like but
515 you don't currently receive? So, we've already talked a bit about the lunch club, about Meals
516 on Wheels, how was that organised, how was that set up for you?

517 P: So the lunch club, although my mum and dad are divorced, they live in the same town. My
518 mum tended in the past to be someone who didn't have a lot of things to go out and it's
519 ironic that as my dad's network has shrunk, my mum's network has kind of expanded, so
520 she, I don't know how she got involved but she involved with this forum and it's set up to be
521 a forum where organisations can go to provide information on their services and get
522 feedback from their target population to give them ideas about whether their ideas to
523 develop the service, are what they need; the right way to do it you know (aha) or just, just
524 generally to have that interaction. And so my mum was there and they'd had a talk from
525 somebody who'd come to do a talk about this lunch club that was run by this [name] so
526 when dad came out of hospital and we were looking to work out what to do and I was
527 broadly aware of Meals on Wheels, I wasn't sure that, I had a look on the internet basically,
528 first of all I plugged in Meals and Wheels and Fife or whatever and I think through
529 [organisation], they had a really good website that pointed you in the direction of, it must
530 be- yep, [organisation] and various facilities and services that were available in each county
531 if you like (aha) and they'd give you links to go to. So, I contacted the Council to ask about
532 the Meals on Wheels and they came out and did an assessment and obviously dad met the
533 criteria for that, and then it was mum that mentioned the lunch club. So she got the phone
534 number of the lady that had come to her forum to talk about it, so I phoned her up and
535 that's how we found out about that but it's not that transparent (aha) you know you, I don't

think you'll see it in the library or whatever so, I suppose it relies on the right people, the right audience being there to tell about these things through word of mouth and I don't know, again through technology. There is, I think there is a [place] carers' association, I contacted them as well because I found that on the internet and they spoke to me about things and they said 'oh you know your dad, you can maybe get a stair lift' or whatever but when the nurses came that were helping assess after dad came out of hospital, they were assessing what he could do on his own and they said 'these things, you're on a waiting list forever' so it's again about you know, finding out information that's reliable and it's relevant and helps you plan and whatever but some sources might be trying to help but they mightn't not be a point of authority on it and then maybe sometimes the points of authority are maybe not telling you much either, but generally speaking I found the Local Authority sites have been helpful. The nursing staff have brought leaflets to the house, given lots of names and addresses and for different kinds of care services; a lot of it that dad's not quite at the stage of needing yet. You know he doesn't need help with washing, help with getting up, he does need help with cooking, he's managing to make a breakfast of Weetabix and milk or porridge in the microwave or something, because he knows he's getting his three course lunch with fruit juice but you know it's great that the service is there, I mean the lunch club- my dad would be in a completely different place if he didn't have the lunch club. I think nutritionally is gonna be probably more interesting, definitely the fact that rather than getting a foil carton delivered, heated that you've got to eat now, so that's a bit controlling (mm), it's the fact that somebody's coming for him on a bus, it's an outing because the bus journey's an outing; you're sitting down at a table, it's got a table cloth on it, it's got a napkin, a nice glass for your juice and a three course, freshly prepared meal as like a treat that you're going out to four days a week. My dad had to, my dad well, they gave him a service form, I don't think he remembered to had it back in but I read what he put on it and he was acknowledging you know, they were asking you to rate the value and whatever, you know he did say it allows him to get out every day and it allows him to be with people every day and the quality of the food, so his responses were really logical and meaningful I think in his circumstance and because he was always somebody who went out. He's desperate to get out, if he couldn't get out I mean, over the Christmas/New Year they closed down the lunch club (ah) so he was here for a longer period over Christmas. Normally dad comes for Christmas and we're lucky if he'll stay until Boxing Day and then he's off you know, he's had enough of us he wants to be doing his own thing, but he can't do that now, he's stuck; he's stuck with his family! [Both laugh]. And it just about drives him daft. He was one of fourteen and I think he's just always been part of that, that bigger thing so, so the fact he's got something to go to four days out of seven that it's, I don't think it's as mentally stimulating as I hoped it would be. As a carer, it's the one thing I think is missing is mental stimulus, but that's what I'm thinking as somebody that's hoping that my dad uses the brain that he has as much as possible for as long you know (mm, mm). Whereas when I look at dementia literature, they do talk about people withdrawing, becoming less interested and it's part of that thing about if the brain's just not coping to process information, I mean even- my dad's not really reading now. He'd maybe pick up a paper if he's elsewhere to read but I've said to him 'would you like me to get the paper delivered everyday, so you've got something fresh to read every day?' He goes 'no, I don't want that, I've got the television, why would I want that?' but the television's passive (mm) but he doesn't want that and it's, I've, I've got to choose my battles, otherwise everything would you know, well, just because you think it's a good idea, you've got to allow somebody the right to choose it (yeah) and if they don't want it, you know; I think it's their quality of life to be able to say no. I mean it's even like when I went to the doctors about, and the drinking issue had come up and the doctor says 'how is he getting his drink?' I says 'well my dad's got these balance issues but he's walking along to the corner shop and I've never known him to walk that distance before'. The corner shop

587 would maybe be at the end of this long street and the doctor said 'could you not get the
588 shop to not sell him the drink?' and I says 'well a) I don't know if a shop would do that,
589 they're in the business, they're there to trade, they're not there to monitor what people
590 consume. They're there to sell stuff, so I says 'so I don't know how that works, but also what
591 of my dad's self-respect? I says 'what does it say if I'm telling a stranger to tell him he can't
592 do it in a public, I don't really want to do that' you know and I says 'I know the risk is that he,
593 he buys drink and drinks it too quickly but the positive thing is he's out walking -laughs- and
594 he's never done that in all the time that he had the car!' So, he's actually you know, he's
595 moving the body a bit more if he does that, but it's a difficult, it's difficult you know, to know
596 where the lines. In a care institution you would have no choice; you would have no choice
597 and my dad has always been so independent, that's the biggest worry about living in an
598 institution, is just not being able to make any choices (mm, yep) you know so, so at the
599 moment he can choose -laughs- he has his bank card and he can choose to go to the shop
600 with it which is you know, I think is right. He's at 84, he never expected to reach that age. He
601 had high blood pressure from I think his early 40s, I don't think he ever thought he would
602 reach 84 and I hope he's got a few more years in him yet but you know, in taking on a
603 passive role, I just hope that I can allow him to be his, in doing the caring bit and using
604 technology whether it's phones or the internet or homeworking to give him a bit more
605 flexibility if I've, if I've been you know, if I haven't slept until really late during the night
606 because I've been worrying, trying to figure out what the next thing is, I could be really tired
607 if I'd had to travel in the next day, but if I start, if I log on later, I just know that I'll just finish
608 later and it just helps even in that subtle way (mm, Yeah) you know (yeah). Information as I
609 said, information would be about the mental stimulus thing, but I, I just, I'm not sure how to
610 resolve that or whether just to accept that actually the level of stimulation he's got is the
611 level that he can cope with, and it's a lot less than what he's done in the past but he's, he
612 doesn't seem to be looking for anymore. I wondered would, if he had an iPad and access to
613 another source of information, that he was, he had to go and seek rather than just scroll
614 through the television, but he's not looking for it. I don't know, what do other people come
615 up with in that scenario?

616 I: That actually what you just mentioned- stimulus, is something that does come up quite a lot
617 (yeah). So, regarding support that you do receive, the technology that you talked about, the
618 alarm button that your dad has and the medication dispenser that you were thinking about,
619 who was it that told you about that or that organised that for you, how did that work?

620 P: So, the little alarm was mentioned as a service in a leaflet that we got from a team called the
621 [name] and they're a group of nurses that if someone leaves the hospital, it's called is it
622 called Nursing in the Community? It's something like Community and Nursing (aha), it's
623 when they feel that you can be discharged from hospital but in discharging you, they're
624 recognising that you're, you're, you've got to pay to go on your recovery, before you're at
625 full competence again. So, with my dad, because of the fall that he'd had, so this wasn't
626 dementia related but because of the fall, he had nurses going in in the morning and in the
627 evening. The morning nurses were checking that he was getting out of bed, was able to wash
628 himself, was able to dress himself, mainly because of inability issues and that nursing team
629 gave me the leaflet because they were aware there was memory issues that hadn't yet been
630 formally diagnosed. So they gave me the leaflet of organisations that could provide services,
631 personal care or shopping or befriending services; that kind of thing and the, the alarm
632 service was listed in there as well but I'd already, I'd already on my internet search, found
633 [organisation] and they had a brilliant pamphlet; I would show you it, the coverage of it but I
634 have got, I printed it all off and put it in a folder to kept at my dad's house because as I was
635 thinking about services, so first of all the Meals on Wheels I used the information that I'd got

636 on the internet but because dad doesn't have the internet I printed it all off, put it in a
637 binder and I used that to talk him through so that he could see where the service came from
638 etc. how much it cost etc. and what it covered and I'd said you know 'if you're not gonna be
639 driving any more, dad, this is something to make sure that you have a lunch without having
640 to prepare it yourself, or without having to go shopping to get it' because he wasn't gonna
641 have a car and his mobility issues are he wouldn't be carrying bags. So, he'd agreed to that.
642 The pamphlet we got from the nurses had about the, did it have about the lunch club? No,
643 they just verbally told me; one of the nurses told me about the lunch club but as I said my
644 mum had already told me about that. So it's two sources there (laughs) for the lunch club
645 and the alarm was in the [organisation] information pack that I found on the website. And it
646 was also in this little leaflet that the nurses so, from that perspective they're both joined up
647 in the kind of information that they're providing and certainly I'd been thinking about that,
648 but after dad had the fall, I took him back to the page again and I says 'look we talked about
649 that and you'd said no, but you've had the fall and for whatever reason you decided to get
650 into a bath with a really painful arm that you couldn't put any weight on. How you thought
651 you were gonna get out, even before you got in, I don't know. So you know, but you can see
652 my husband's quite tall and quite strong, so you can see how [name] struggled to know how
653 to get you out of the bath, so for any kind of injury, we can't just rely on a neighbour helping
654 you up and if you hurt yourself as you did with your arm before, you don't know and we
655 don't know what's the best way to get you up and whether you need assessed. So, you
656 know, what about getting this alarm set up?' So, he agreed to that and as I said, I think it's
657 two pounds fifty a week or whatever and in the scheme of things, it's like a hundred-odd
658 pound a year and that's not a lot of money; that's the difference between somebody lying
659 and you know, lying for almost maybe twelve hours or so you know (mm). If he, if it was, if it
660 happened on a Saturday, it could be a full twenty-four hours if we weren't coming until the
661 Sunday, because although I phone him, if he's gone to his bed, he'll take his hearing aid out,
662 so he's not going to hear the phone. I mean I don't, maybe there's the thing I've thought
663 about with technology- is there something you could put a mobile phone on to charge that
664 could light up or something so that if he doesn't have his hearing aid in, there's a trigger
665 there to know, but when he's asleep he won't hear the, he won't hear his mobile going off so
666 I just hope that you know, when he's in his sleep, when he's in his bed he's comfortable and
667 he's getting up when he's awake you know and that's what it is so far. If it got to a stage
668 where he didn't want to get up and if he was in his bed, he wouldn't have any reason to put
669 his hearing aid in and if he didn't put his hearing aid in and he wouldn't hear the phone and I
670 wouldn't have a way to contact him.

671 I: Mm, yeah so-

672 P: And that, and that happened, when did that happen? I think that was a year past, in
673 November, it was before Christmas, so it was before he had his fall, but after we were
674 visiting him on a weekly basis to get his house organised. So a year past November he'd
675 taken one of his really bad flu's and we hadn't heard from him for a few days and to begin
676 with we thought he was just being really lazy, not charging his phone up and then it got to
677 the weekend, we got across and we couldn't get into the house, he'd left his keys in the door
678 so we couldn't get in and we ended having to get the police to knock the door down, or to
679 take the lock out and thankfully we got up there and dad was in his bed and you know saw
680 the policeman and 'what you doing?' We said 'well we're worried about you, we can't get in
681 touch with you and we couldn't get into the house' and he says 'oh, I haven't been well, I've
682 got the flu' and I said 'when were you last out the house' and he couldn't remember so that
683 was days and it meant if he was in the house for days and he doesn't keep food in the house,
684 then he'll have had water to drink, that's it. So he was very weak and disorientated and you

685 know, even normal flu, hopefully if you've got useful people living with you they're at least
686 making you cups of tea or at least giving you a bowl of soup or something but that's the
687 worry, without my dad being able to pick up the phone when I do phone, to keep that
688 connection going and I suppose technology you could get cameras put into the house and
689 you could monitor to see if he's in his bed or whether he's in the living room, or make sure
690 the stairway's clear and he hasn't fallen or whatever. And that might be something that we
691 would consider if he was really keen to stay in his house later on and if we had carers going
692 into the house, I'd probably want to do something like that as well (aha) just make sure that
693 you know the, that relationship was working. But again, we're not quite there yet, but I
694 know that, I mean I've read that that's what some people do you know, they've put camera
695 type things in (mm, yeah). I dunno how dad would feel about that (laughs) but I suppose, it's
696 just being aware of other technology there (yeah) and I would probably look at the [place]
697 Carers' Society probably as a starting point. Because dad's had his formal diagnosis, then
698 we're supposed to be entitled to this year, in Scotland of support to put plans in place, so I
699 don't know if once that kicks off, I haven't heard from anybody yet and that's already a
700 month into twelve months. So um, actually that's unfair, it's three weeks, it was 15th of
701 March. So, I don't know if they will maybe come with information that 'here's things you
702 could do to tailor in the house and also stay more connected as well' I don't know if that will
703 be somethings they'll suggest or if they know of firms that do that kind of work, that kind of
704 stuff, I don't know. How does that compare with other responses?

705 I: I mean you have given me a lot of things to think about (oh right) in terms of technology, so
706 thank you very much for that (ok). So just to sum basically, to sum up what we have been
707 talking about, what would you say for you personally are the most negative aspects of
708 combining work and care, and the most positive aspects?

709 P: The negative, right, negative and positive aspects of combining work and caring- so
710 obviously the negative aspects of it are that both demand mental and physical energy and
711 obviously if you're working full time and you're also putting hours in during that time and in
712 evenings or at weekends, there's a lot less time to recharge (mm). So you can be constantly
713 in a state of feeling tired you know and there's, because we've kind of chosen to get in to a
714 routine, that we leave the Saturday to try and do things around the house, spend a bit of
715 time with our son; get things done and we do the Sunday, it means that we go from having
716 that day with mum and day and doing house stuff as well as, we run straight into the
717 working week again. So, I would say the combining it is, is you know the risk that you, you
718 put too much demands on yourself mentally and physically and you end up running yourself
719 down (yeah). I suppose you're talking of priorities, you know you could have meetings that
720 you just you know, you have to attend or you really need to attend and preparation for
721 these meetings against you know, something that's just happened that morning and you're
722 in this kind of torn you know, where your priorities lie and obviously if it was, if it was a
723 health thing but with immediacy with my dad, it's often somebody's waiting on the line
724 wanting to know if dad's getting picked up for an appointment or something like that and
725 there's been one or two days when it's felt really stressful and I'm in this juggling, doing my
726 PA thing for my dad but things after, that was more when he came out of hospital and you
727 know, when he was in hospital he'd lost, the cleaners had lifted his hearing aid off his table
728 over the bed, er no it wasn't his hearing aid, it was his upper teeth, his dentures, so as well
729 as getting him into the house we then had to figure out getting dad a dentist because he
730 hadn't been to a dentist for -laughs- god knows how many years! (mm) and the dentist I
731 think he thought he went to was long gone and the house had been converted, the clinic
732 had been converted into a house, so we had to get him a dentist and then take him to
733 appointments to get teeth made and stuff on top of everything else. So there were all sorts

of appointments and these have drifted off now so you know, from September to Christmas was probably an awful lot more challenging than January to now, as a three month period he's got into a routine and once you're in that kind of routine, that helps you plan your work and your caring; regular commitments if you like (aha) and so the diary- I know what I need to do to call up for a transport if that's the case and as I said it was busy, it was busy earlier on but now it's getting an awful lot simpler, at the moment anyway. So that's quite good. So yes, I think the negative thing is just that it can be, it can drain your energy. On the positive side I think it's really important you know, for me I'm only 54 so I enjoy working, I enjoy the mental stimulation of working, I enjoy earning more money and I'm not at a stage that I could retire; I've still got a 21-year-old son who needs to move on into his own career yet. So financially I think I still need to work and I want to work and be involved with the world of work and I think that's good because that keeps your sense of your own identity (mm) but also tips that I pick up from work and communities like the Families' network give me insight into how other people have managed this, you know I've picked up tips and stuff along the way, or there's just that, I suppose it's energising that you know from the Families' Network that other people are in the same boat, you know you don't need to take this a kind of 'oh my god, this is us out there' there's lots of other things that people have got to struggle with as work plus something else and that it's a kind of cycle of life thing. You've moved from looking after young family into I can't remember what they call it- it's the stretched age or whatever where you might still be looking after older children and you've got your older parents too and you're still trying to do things by yourself. But I think working helps remind you that most people in your age range will be going through the same thing, unless they have a unfortunately lost their parents through sudden death, heart attacks, cancer, when their parents have been in their 50s and I've got a lot of friends who have lost one or both parents. I'm in my 50s and they've lost their parents in their late 30s or 40s, so in a way I, whilst this is challenging, I do feel blessed that I've had my parents for all this time and they've been able to part of you know, my son's life and be a support to me when I was a parent of a much younger child. I mean my mum used to live with us during the week to be there for my son so that I could just go out to work. My dad wasn't because he was always so busy but that was fine you know, he was busy so when I was younger I didn't feel guilty about not spending time with my dad because I knew that he had a busy social life. My mum, she was quieter so she needed to be involved with us a lot more and it wouldn't have worked if we'd had to split any more time out for dad -laughs- but that was that but um, yeah being involved with work and particularly in the Bank when they, they have the Families' Network it makes me think about things. I mean I suppose it's through the Carers' Network, it made me think where I'd read articles or become aware of workshops. I think there's a Families' Network in [place] of workshops, unfortunately they're mostly during the working day so I would have to take time off to go there and maybe I will now and again, but they're more involved in supporting the carer, I suppose manage stress or if they feel they need something else to be looking at like yoga and all the rest of it or outings for carers and I'm thinking 'when do we have any time! [both laugh] you know, to go on an outing or a whole trip or whatever and maybe it is about you know for some people maybe that gets so wrapped up in work and care that they're actually not doing anything else and that can become just whole and compos, and the Carers' Network can be an outlet to go and away and do things with people that are in the same boat and I think that's, that's a positive thing, is being aware that there are communities out there you can go and talk to other people. I mean as I say, my husband and I, we do dancing, we do ceroc dancing and whilst it spans quite an age group, you know, younger people your age and my age and there's people I dance with who are in their 70s that have had cancer and are still dancing. Older gentlemen may have done ballroom dancing in the past, and they've got brilliant moves (laughs) you know, to add to the dancing. But you know what you find is because in the club it's people

785 either my age or a bit older, there's at least a handful of people that are either in the same
786 situation or have been in the same situation but maybe their parents have now died, who
787 have had to cope with you know, being in a caring role or having to make decisions about
788 transitioning to care facilities or whatever. So, I don't feel I need to go down into any
789 networks at the moment, I feel there's people that I can talk to but I think that's an
790 important part of it as well (mm), is doing that. But I mean you know part of me wonders
791 what if I would want at some point to, not give up working entirely to look after parents but
792 perhaps drop hours and spend more time at a time when you could still do quality things
793 rather than have to leave that to the stage when it is latterly about provide, you know just
794 being there to provide a space of care, so that's something that I'm starting to think about,
795 yeah.

796 I: Thank you very, very much! That basically-

797 P: The joys of living older these days -laughs.

798 I: Yeah, so basically that completes the interview. I just have two questions left to provide a bit
799 of context because all of the other questions, we have already addressed throughout the
800 interviews. So, one of the questions would be the level of education that you have achieved,
801 the highest level of education?

802 P: Ok, I've got a Masters in Records Management, from [place] University ([place], ok, thank
803 you). I had an Honours Degree in Interior Design (oh, ok) so I did that, I did Interior Design in
804 my 20s and ended up after working in [place] for a few years I joined a Financial Services
805 firm in [place] that had an in house facilities department and they recruited me, interior
806 designer when they had a programme of expansion, so that's how I came to marry interior
807 design and financial services (that's really interesting) yeah and then from being in the
808 facilities department at that time of life, when the big issue came out about the Pensions'
809 crisis and that would be the 2000s. I then decided to move into records' management where
810 the facilities people managed the documentation and I was looking for a career move and
811 looking at how I could use my project management skills more in the company because it
812 was a good company to work for, when this role came up and they said they would be
813 willing to sponsor me to do my Masters if I was willing to put the work in. So, I suppose that
814 was a precursor to balancing full time work and care as actually fulltime work and study
815 (aha) because that was a tough order (yeah); that was really tough. I would say that's
816 actually a tougher order than the, than the fulltime work and caring, yeah. I don't know if I
817 would have done it if knew just how challenging it was, but yeah I really enjoyed what I did
818 with my work so gave all at work and then relished the thought of I suppose doing a more
819 grown up degree I suppose as I called it (mm), I was really interested in my records'
820 management degree and at the same time that was when my aunt was going through I think
821 her first cancer, so I had a young son as well so I would get home from work, be feeding my
822 young son, checking on his homework, doing all of that, leaving him with his dad to put him
823 to bed while I went off to hospital to see my aunt (wow) and then come back and then start
824 on an assignment (wow, sounds extremely stressful) it's, it's yeah, I mean looking back it
825 probably wreaked havoc with sleep. I'm still not fully recovered from it, you know I used to
826 work, because I was really enjoying the records manage-, the studying, I don't know if you
827 find that doing your research but you know when the house was quiet at night, there's no
828 televisions, there's none of that, I felt it was quite indulgent to be doing my studying (mm)
829 so the hours would just pass but of course as I said to you my mum was here as well during
830 the week and of course I would have her coming down in the middle of the night going 'oh
831 for goodness sake, you shouldn't be doing this' I'm going 'mum I have to get this finished,

832 away back up to bed' and she wouldn't be sleeping because I wasn't sleeping [both laugh]
833 and all that tension, but now I really worry about the lack of sleep I got because I never fully
834 caught up with that again (mm) and so after I got my Masters I went really downhill -laughs-
835 mentally myself, probably because my sleep pattern was so broken. It's only now I suppose I
836 truly appreciate the value of a good night's sleep and I don't get it; I'm conditioned not to
837 now, so I'm busy trying to backtrack like mad before it has a detrimental impact -laughs- it
838 probably has already, yeah.

839 I: I hope you do catch up on it (it is). The final question that I have is just on average, if you can
840 put them, how many hours a week would you say do you spend on caring for your dad on all
841 these tasks that you do?

842 P: Um, so, so it's a full Sunday, so probably you know we'll leave here maybe about ten and
843 we'll get back here maybe about nine at night (aha) so you know, I would say it's what nine
844 hours, maybe about eleven hours? Oh, that's travelling time as well so maybe it's about
845 seven hours or so on a Sunday and then during the week, because I have like I mean it was
846 quite all consuming before I set things up, but once regular things are set up, it might just be
847 a quick phone call every night to dad. Conversation is really limited because a) he doesn't
848 really want to have a conversation and I think that's partly the dementia but that's ok you
849 know, if he wants to just get back, hint that he wants to get back to his programme -laughs-
850 but I just use that call to act as a prompt you know on whether he's taken his medication. So
851 that's negligible time that'd maybe be two hours a week for that. It's, it's, I think it's gonna
852 be the caring commitment could maybe come in waves and go and up and down. So as I
853 said, he went through, we went through a massive intensive period four years ago when I
854 realised my dad just wasn't coping at all with the dementia specific thing and you know, loss
855 of his ability to drive having a very sudden cliff edge impact onto his ability to organise
856 himself and be able to go and get things done, so from that period, there was a big period of
857 intensity, supporting appointments and stuff like that and it could, I would say it would take
858 two days out of the working week you know, I was really suffering with work and my boss
859 gave me a really long piece of string to hang myself -laughs- because you know, she
860 understood that if you're stuck between a rock and hard place, I wasn't going to be able to
861 concentrate on work if I didn't get these things sorted out; so they were really good about
862 that and as I say once, and that was responding to him coming out of hospital and a change
863 of circumstances and now these things are in place it's really, there's minimal impact during
864 the week now. As I say, if he has an appointment- the next appointment when I would be
865 phoning him is May (mm), you know that's the next appointment he's got whereas over
866 September, October, November he sometimes had three appointments during the week
867 (aha), in which case there was a lot of juggling my lunches and transport and stuff but it's
868 evened off at the moment so you know, that's a hospital appointment, I've already
869 organised that. So, his patient transfer is already organised and all I need to do on that
870 Tuesday morning is prompt him and nearer the time, cancel his lunch. So that's you know a
871 lot less administration time eaten into my working day (aha). What I don't know is, now he's
872 been formally diagnosed with dementia and the support team, what impact that might have
873 if they want to do assessments and stuff and obviously, I need to be there because it's no
874 good asking my dad for a summary of what happened because you don't get any
875 information. If they leave information with him, it's not necessarily gonna get passed on
876 unless I go look for it or ask for it, so it's just easier to be there and to support that
877 assessment process or whatever. I don't know in the short-term what change that might
878 have to my diary but at the moment, you know, over the last month it has calmed down
879 quite a bit, almost to the point where I've thought is there something I'm missing, but it's
880 not, I mean it felt back in October- when they were dealing with my dad coming out it just, it

was all consuming and probably that, yeah, probably between October to November because as well as trying to set things up, it was then when things were going wrong because my dad wasn't remembering or whatever, so we were always having to back track on things that had, plans that had been put in place because something had been forgotten or, it only takes for the lunch club to be a new bus driver that forgets to pick you up, then my dad will phone to say 'nobody's come today' and you have to phone on his behalf because he's not thinking to phone them himself or whatever. Or the fact that the occasion when the patient transfer came to take him to the hospital appointment and dad had phoned me and said 'they're not here yet' because I had told him they would be there at 12 for this appointment at half past one and I said to him 'that's alright, give it another fifteen minutes, it's still fine' so then he phoned me about half an hour, half past 12 and then I phoned the hospital and asked them and they said 'oh well, the transport's on its way' so I thought fine, so really if it had arrived at one o'clock, it only takes 20 minutes and then they would have had to wheel him with a wheel chair and he'd have still got there for his appointment, but after one o'clock we said 'look it's not there, if it's gonna arrive later they won't be enough time now to drive him to the hospital and navigate through the hospital to get to clinic' so I says 'we're gonna have to cancel and get, I'm gonna have to speak to the clinic and get a new appointment' and so then I phoned the clinic to organise a new appointment and then I phoned my dad to say 'right I've set you up an app' and he says 'oh it's ok, I'm on the bus' (laughs) you know and at that point it was twenty past one and I said 'what do you mean you're on the bus?' and he goes 'well the bus just arrived, so that's me' I goes 'but I says it's twenty past one, you won't get there, the clinic will be closed, they'll all go away. You'll have to tell the bus driver' 'oh I can't speak to the bus driver while they're driving', I goes 'well you can't have them take you to hospital because there's nobody there for them to leave you with, then it could be hours before you get back, it's completely a waste' so then I had to phone the company that organises the transport, to officially tell them that 'look he arrived just ten minutes before the appointment, you are going to have to buzz him because the people are belted into their seat on the bus, they can't do it'. So and all that while I really should have been on a call at work, I should've been on a team meeting call but I'd, again with technology I was able to use skype, which is an instant messenger and I said, because the team meeting's- nobody's sitting in a room, everybody's sitting in front of their screen, then my manager was able to see my message, I said 'look I'm sorry, I've got something I need to deal with for my dad. I'll pick up after the call's finished' and she said that was fine. So that was great because as well as having the facility to work from home, the instant message, the skype technology that we have for doing quick messages meant I was able to tell someone in the meeting I was going to have to drop off the call, needing to make some calls for my dad (mm) and they were able to know why I wasn't contributing -laughs- to the conversation on the phone! So the technology's really good for that, it really is but as i say because it's, it's not, that technology's been there to, it's been implemented anyway to make the business operations more flexible in how people work and as I say it, it allows work/life balance for all sorts of reasons but also it helps to reduce the costs of maintaining the footprint of the state, the managed estate. So that's great and then it's about you know, people recognising how they can use that technology to then benefit (yep) yeah-

I: Yeah, absolutely. Thank you very, very much (you're welcome).

END