



UNIVERSITY OF
BIRMINGHAM



CASE STUDY

Self-funded care and
unpaid carers: Louise caring
for her mother, Agnes

INTRODUCTION

This case study draws on research findings from the Ethical Issues in Self-funded Social Care: Co-producing knowledge with older people project. Conducted over 3 years and funded by the Wellcome Trust, this participatory research project explored how older people experience the process of finding and paying for personal care from their own resources in three local authority areas in England. For the full research report and further information about the project please visit <http://www.olderpeopleselffundingcare.com/>

The case studies show, through the lived experiences of older people and carers, that paying for care brings its own challenges and does not necessarily mean you get the care you want or need. This case study was developed from the transcript of the interview with the participant. All names are fictitious and details that could identify the person have been changed or removed.

CASE STUDY

This case study looks at the experiences of Louise who is an unpaid carer for her mother, Agnes, who has dementia, and shows how self-funded care fits into a much bigger and complex picture of their lives.

Agnes is 86 and, until a few years ago, lived in the north of England. She was married and has one daughter, Louise. Louise is 54 and single. She had a senior professional full-time role that she reduced to part-time in order to in order to care for her mother who had developed increased care needs. Agnes now lives with Louise.

I think I was lucky because I've lived here a long time so I didn't have big bills and I didn't have big mortgages on it or anything, I guess, and I was also getting old then so, you know, I'd been up the ladder and come down again sort of thing, so, whereas I guess if I'd have been twenty years younger and still trying to work my way up I wouldn't have been able to say no and set those limits either because I wouldn't have felt able to or would have thought it, this might damage things.

Louise

Louise and Agnes do not have extended or local family to provide support. Louise lives in a one-bedroom flat that she bought around 30 years ago. Agnes has a hospital bed in the living room where she has lived for the last three and a half years.

I mean my house is complete chaos because obviously you've got all this stuff, I can't have new carpets because orange juice goes everywhere and you wouldn't believe where tomato sauce can get to when the need arises, so, and what gets spat out, you know. But, I think you reset your brain and that's what I've done and I know I've done it and it's sort of been a conscious thing over time, but she's not unhappy and I'm not unhappy with this.

Louise

Louise explained how Agnes came to be living with her (250 miles away from where she had lived all her married life). Agnes became unwell whilst she was staying with Louise and this resulted in Agnes being admitted to Louise's local hospital.

About three and a half years ago, almost overnight, she just lost the use of her legs and, and it was a urine infection that triggered quite a big illness. She was in hospital for eight weeks, they didn't know if she was going to come out. They thought it had really accelerated the dementia to a bad state, and that's where I just thought I can't go to work and do all these things. I was in a senior position at work so I resigned all my responsibilities and went part-time, because I do still need to work, I have got bills to pay.

Louise

Within this process Louise says she was told that as her mother was not a local resident, she would not be entitled to local authority provided care. It seems that the social worker helped set up Agnes's care and that a brokerage scheme was put in place, however, it wasn't clear exactly what this covered. Louise's understanding was that if she arranged (or re-arranged) care outside of this original agreement it may not be at the local authority rate and she would therefore be charged at a higher rate:

So for the last three and a bit years we've had carers, I've paid, obviously I have to pay for it, we have people coming from the Care Agency depending on what hours I work during the day. This year we have them Tuesday to Friday and for a morning call and a lunchtime call. When she first came out of hospital I was having them seven days a week, four calls a day, but I couldn't sustain that,. It already takes more than most of my wages and also I suppose I got better at doing things so I didn't need them when I was here. If I'd have carried on at that level I don't think I would have had the money to keep doing it.. It has gone into my savings, I'm not going to kid you, it's, you know, my savings are reducing but, but they'll go back up again at some point, you know, and it will be alright and I don't need them now and I've got a plan in my head, we're alright and, you know, the sun's shining so it's all alright.

Louise

Louise has seen a deterioration in the running of the care agency. To begin with they had the same team of carers – always one of six. Some she liked better than others, but she knew them all. Louise explained that within the six weeks prior to the interview there had been 26 different carers to cover 2 calls a day, 4 days a week (48 visits). Louise described the impact of having unknown carers on her mother's well-being:

Sometimes I come home from work, because I only work part days, it's never a major trauma, but she'll just look at me, she'll say 'it's you', and it's heart-breaking in some ways. I know that she's not using words during the day because she won't talk to them if she doesn't know them, I think it's going to affect her language use longer term. But the agency have had an immense amount of resignations ... I understand their difficulties but it's a balance isn't it, you know, I do pay a lot of money.

Louise

Louise carefully audits the invoices from the care agency as they are not always correct:

I try to be good, do you know what I mean, I don't like being awkward, I don't like causing whatever, but one day I've had three people come, so they're just like add extra people on and I'm sorry but I'm so cautious with them now. And if they're adding £17.83 per hour on for people that don't exist, I'd rather go and buy my mum Jelly Babies or whatever the current fixation is, if I've got that spare twenty quid it goes on her, it doesn't go on them.

Louise

Louise arranges the care to cover whilst she is at work but she prefers to care for her mother herself whenever possible:

they won't get my mum up, they say their job isn't to take her to the toilet, they'll change her pad but they won't take her, you know, they don't do things like that and I think, well OK, that's OK because I am here, I will come home and I do it...which is why like today when I'm on holiday I cancelled them because it's much easier and much nicer when it's just us."

Louise

Although Louise expressed a lot of challenges in caring for her mother, she is clear that, for her, it is the right thing to do:

You know, she's 86, as I say, I'm not naive about it, I know that to have dementia for twelve years is going it a bit, really, so I'm not naive that things are going to get better, you know, and I can see the decline, but on the other hand, you've got to be able to sleep at night and you've got to feel you've done the right thing.

Louise

Louise is clear that her motivations for caring for her mother are based on a sense of reciprocity:

I sort of see it as payback, we come from a very Northern working-class background and my mum and dad let me do A Levels when the rest of the family were saying 'no, don't because she should go out to work', and then they let me go to do my degree and everybody else was then working, and in my head I just think, oh you know, they gave me a really, really nice life, they let me have loads and loads and loads of opportunities and I wouldn't have got that if they hadn't and therefore this is just...you know, it's payback, as I say, it's, I'm quite at ease with it all.

Louise

This emotional aspect is more important to Louise than financial decisions and echoes the experiences of others who care for their relatives:

Sometimes I think my boss at work really quite like me to do more and I say 'no, I'm sorry, I've got to go home now, I've got to go see to my mum', he doesn't always like it quite so much. But, it is my own time, you know, I don't have days off work for anything, it's not affected anything like that. I think it probably would if I was still full-time but because I went part-time, everything becomes doable."

Louise

Whilst paying for care adds an extra level of complexity for self-funders, money is not the only, nor the most important consideration:

...you've just got to put the jigsaw bits of your life together in whatever way they fit at that time.

Louise

QUESTIONS FOR DISCUSSION



Care and self-funding:

- What do you find troubling about the experiences of self-funded care described in this case study?
- What aspects of self-funded care work well?
- Looking forward, what might improve this person's experiences of self-funded care?



Broader issues you may want to consider:

- What seem to be the most important factors for this person's sense of wellbeing?
- What could be done to promote their wellbeing, aside from the issues related to self-funded care?

LINKS TO OUR BRIEFINGS

Some of the issues raised in the case study are discussed in our briefings:

Six Myths about paying for care

<http://www.olderpeopleselffundingcare.com/publications/briefing-3-six-myths/>

Impact of self-funding on unpaid carers

<http://www.olderpeopleselffundingcare.com/publications/impact-of-self-funding-on-unpaid-carers/>

Self-funders: the invisible lynchpin of the social care system

<http://www.olderpeopleselffundingcare.com/publications/briefing-1-self-funders-as-lynchpin/>



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Designed by Nifty Fox Creative, 2020