wellcome

UNIVERSITY OF LINCOLN

University of Brighton

UNIVERSITY OF BIRMINGHAM

CASE STUDY

Finding and accepting care - Jim and Holly

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 Jim and Holly. During their working lives they had each held senior management positions and had retired to a spacious flat within a housing development for retired people. Jim developed Alzheimer's Disease a few years ago. Holly, his partner, main carer and consultee, had several health issues of her own, including heart disease. They are both in their nineties. Their situation involves a slightly unusual transition from receiving care in a care home to care at home. Although Jim and Holly are relatively financially secure, they still had difficulty finding and arranging care that met their needs.

Jim is tall, well-built and physically fit. Holly is very attentive towards Jim, giving him constant care and patiently responding minute by minute to his repeated statements and questions. Their close relationship was evident in the interviews and Jim commented on how much he depended upon and valued Holly. But the strains of looking after someone with Alzheimer's on her own had previously proved too much for Holly, and she and the family had arranged for Jim to live in a care home. However, Holly thought that the combination of Jim having Alzheimer's but being physical active might have presented a challenge for the care home and Jim did not settle there.

> *He was very unhappy (in the care home) and he made the fact very well known. There was nothing outside the home in the sense that they didn't ever seem to take them out, they didn't have their own transport. It was a nice home and I'm sure they were good to him, but I think there was a lot of sitting about and long days and long nights. It was the nights he found, you know… 5 o'clock after they've eaten, that it was too long. So, he's definitely much happier at home and there were one or two things, so eventually he's been at home again now since November last year.*
>
> **Holly**

Holly's daughter insisted that if Jim were to return home, it had to be with domiciliary care support, for the sake of Holly's health. Holly agreed, with some reluctance:

> *It was agreed between everybody concerned that I would have carers, and so I have carers for four mornings a week. He was capable of doing a lot of things, (and while) we would always be there, I wanted a little help in the house…my daughter insisted that I have help in the house and for times when I don't feel that well.*
>
> **Holly**

Holly struggled to set up suitable care at home before Jim returned home. At first, she sought advice from the local authority:

> *I did actually in the beginning ring the council because I was bringing Jim out the care home and obviously, I'd heard of people coming out of the care home before and you know it really becomes an unsettling situation because they might just you know, not settle back down again and I asked for advice. I went to a carers group, and they said they had very little advice on it, and we had to go to the Council. So I rung them up and they said, well we've got a waiting list, we're waiting for people to interview or something and that was something like two months and I thought I'm definitely not keeping him in for two months, I need to have information now...*
>
> **Holly**

Holly did not have any experience of arranging care in her home and found it hard to get the kind of advice she wanted.

> *(Social Services) said they would send me some information through the post which they did. But I'd have liked to have heard somebody's experiences of what there is out there. You don't have to recommend the place but you can say some of the difficulties that you might experience and what you should be looking for, or (what) might be useful if you went along this kind of avenue. I realise that there are difficulties but you don't get a lot of information…you get a list of brochures or the little leaflets, (which) could have more information on them than they have. And of course, the person that comes is obviously selling that and will be open to whatever you suggest. So, you start by going to find out how it works…somebody comes to see you and asks you how many hours you need, what can you afford. Well it's a new land trying to get a suitable situation that will work for you. So, where do you go to find somewhere that someone will sit down to you and say to you 'well this is what the situation is with getting good help', because the quality is second rate?*
>
> **Holly**

Holly described the help she was looking for as "a little light housework and (to help) look after Jim," by which she meant some help with his personal care. She explained: "He thinks he can do everything himself still, but his memory is really really bad."

In the end she chose an agency that was based nearby, in part because it was local. She was very concerned to have continuity of care as this would help Jim to be as independent as possible.

> *They'll promise you anything, oh yeah there will be continuity and as far as I was concerned with Jim having Alzheimer's I would have thought he needed continuity, he didn't want a different person coming in every day and then a different one next week from the week before. A whole series of different people came, and sometimes it would be 11 o'clock in the morning which was totally useless to me because he was only going to stay in bed for a certain time and I don't want to encourage him to think that bed is the place where you lie, because he'd get ill. He needs to keep on doing things.*
>
> **Holly**

As well as Holly's dissatisfaction with some of the practical arrangements, the conflict between her need to keep her daughter happy and her own feelings about having help in the house also made the situation difficult.

> *The difficulty I had was that my daughter thought that if I was having carers, I should have a little bit extra time to help me to do some of the work to make it very easy for me to whatever. The first thing was that I don't particularly want people in the morning. I don't particularly want anybody to look after us anyway (laughs), but obviously I understood that that was the rules of the game.*
>
> **Holly**

Key to good care for Jim was the quality of care staff. Holly was sympathetic to the situations of many care workers and very aware of the effect that poor pay and the demands of the job had on the workforce:

> *The biggest problem is the level of staff … That's the one thing about the caring business, they have lots of problems, basically because of the level of staff. That doesn't mean to say that the staff aren't lovely, they are, but they have to have staff who will work for very little, who work shifts, who have families that they have to take care of. They get ill themselves or they have a baby; that kind of stuff is quite difficult because the pay is so low. I think that one of the biggest issues in the care situation is that the people are paid inadequately, and so you get a lot of fairly laid-back people or people who are doing it under some kind of situation because they need to work, whether they've got young children, or they've got other things that they have to deal with themselves. So, the level of staff is very below average if you like, they have a lot of sickness.*
>
> **Holly**

Cost of care was not a major present concern and care at home was less expensive than residential care.

> *The cost implications don't worry us too much, I mean in a sense it worries us that we're spending money but definitely not at the rate that we were paying for the care home. I mean the care home was £1000 a week. He didn't come out because we didn't want to pay it any longer, he came out because he was unhappy in the care home and I preferred him to come home again.*
>
> **Holly**

However, although Holly described their financial situation as “comfortable”, uncertainty about their future care needs and how they might pay for them caused her some anxiety.

> *We will probably go on for as long as we can, until such times that either I have something the matter or Jim does, or I’m just too old to cope with it. So, I don’t see any changes in the next few months, but you never can tell. Well you see I know at the end of life that’s what it’s about…If you’ve got money you should pay…we can afford to pay for care…but I don’t want to be paying it until my money runs out. You can’t cover that one because you don’t know how long you’ll live.*
>
> **Holly**

SUMMARY

Jim and Holly’s experience highlights the difficulty of finding appropriate care for someone who has dementia but is physically quite mobile. In Jim’s case, finding the right care, both in a care home and in his own home, proved difficult. Holly remarked that it had been easier to choose a residential service because you could at least visit a care home in advance, whereas with care at home “all you can see is if the management system works”. Holly’s experience also shows that it can be hard to reconcile oneself to having help in the home, even when there is a need for support. The lack of continuity of carers not only prevented Jim from getting familiar and comfortable with the carers, and they with him; it also made the process of building trust and confidence in the carers more difficult for Holly.

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/

Case study: Finding and accepting care - Jim and Holly

Designed by Nifty Fox Creative, 2020