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BRIEFING

**The impact of self-funding
on unpaid carers: lightening
the load or adding to it?**

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SUMMARY

Tight needs-based eligibility criteria and a fixed financial threshold for local authority care mean that an increasing number of older people have to pay for their own social care. The bulk of personal care is received by older people with high level needs and multiple conditions, including dementia. Navigating the self-funded care market and managing private care arrangements are complicated processes. For many older people who are paying for their care, it is their family or close friends ('unpaid carers') who take a main role in finding, arranging and overseeing the care arrangements. This can place heavy responsibilities on unpaid carers, over and above their other caring tasks. Responsibilities for self-funded care are not only practical, such as finding suitable care, agreeing the terms and managing and monitoring payments, but also emotional, bound up in the dynamics of relationships between people. We need to recognise the demands of this unseen dimension of caring and the impact that giving support with self-funding has on the lives of unpaid carers. Otherwise, instead of lightening the load, the purchase of self-funded care adds another layer of responsibility, anxiety and stress for unpaid carers.

INTRODUCTION

This briefing 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.olderpeoplesselffundingcare.com/>

Austerity and the extreme pressures on social care resources have made it harder to access care and support from the state, with more older people falling below the eligibility threshold for care and support needs to be met by the state. At the same time, even those with high level needs that meet the eligibility criteria may have to self-fund their own care if their assets fall above the financial threshold. Taken together, these factors mean that there has been significant growth in recent years in the self-funded care market; more older people are having to purchase their own care from the independent sector. Having to find and manage care can be difficult and the older people who are most likely to need high levels of personal care are those least likely to be able to navigate the care market. It often falls to unpaid carers to take on responsibilities for self-funded care. We interviewed 46 unpaid carers who were providing support to older people who were paying for all or some of their personal care. Our research highlights the strains that self-funded care can generate for unpaid carers.

GETTING PULLED IN

As with other aspects of caring, some unpaid carers did not feel they had a choice about whether to care themselves, or whether to provide support with self-funded care. In the absence of other sources of support, they got drawn - whether they wanted to or not - into finding and choosing care, making the arrangements and then maintaining ongoing liaison with the care agency. It was simply assumed by some care providers that they would take on this role.

That's when I stepped in a lot because that's what happens, the family steps in instead of the state stepping in

Ava

Many unpaid carers also assumed responsibility for making and monitoring the payments. In some cases, particularly when older people were in care homes, unpaid carers were 'topping up' care fees from their own financial resources.

Whilst many unpaid carers undertook these responsibilities willingly for their loved ones, a few felt that they had been coerced into it by the lack of alternative sources of support.

I don't want to be caring all the time, but I seemed to have got pulled in. ... Why should it be up to us, making phone calls, trying to get all this sorted... They keep saying to me, "Are you her daughter?" I say, "No, I'm her niece"... I feel sometimes that everything is on me.... They've got to have somebody to contact.. I do what I can, but I don't want to be a carer.

Nancy

BEING LEFT TO YOUR OWN DEVICES

When unpaid carers were in the position of having to find and negotiate private care, they quickly became aware of how complicated this is and how difficult it can be to find the information needed to make decisions about care. This was especially the case if care had to be found in a hurry because of a crisis. They did not know what it was reasonable to expect from care providers, what was a fair rate of pay, what the fees included, or how to judge 'good' care. One carer described it as "like trying to pick the winner in the Grand National", without having the knowledge needed to guide the decision.

You know, I understand that they have to set a threshold somewhere, and I understand that there isn't a bottomless pit of money, but it's this thing that it's like a sharp cut off. You're either below that threshold or you're above it. If you're above it, you just drop off into the void, absolutely on your own.

Frank

There is a need for clear information and a detailed understanding of the care system to find, assess and secure the 'right' care. Many unpaid carers did not possess the knowledge and skills needed and only a few knew where to go to obtain this information. The rules about who can get financial help with care fees, how much, in what circumstances and from what source are complicated and most unpaid carers we spoke to did not have access to the financial information they needed. Moreover, even those with an administrative or business background, found the invoicing systems used by care providers hard to understand. They felt responsible for managing their loved one's money but did not have information they needed to ensure they were doing this accurately.

I think we need someone who'll come and sit down, sort out a good care package which will suit all the needs, be reliable and we want bills we can understand. I mean these are put in such a way, I've had four people look at them and no one can understand them for a start. But they're done, I think, like that so you can't understand them.

Ruby

OILING THE WHEELS

It often fell to unpaid carers to 'oil the wheels' of self-funded care, to make sure that everything ran smoothly. For example, the unpaid carer would need to make sure that the paid carers had access to the home and everything they needed to deliver the care. Sometimes, particularly for spousal carers, they saw it as a necessary part of their role to get everything ready in preparation for the paid carers, such as laying out clothes or putting food items ready, as this was the only way the tasks could be completed in the allotted time. Unpaid carers were likely to be contacted if the paid care arrangement broke down for any reason and would then have to plug the gap themselves.

A different type of responsibility was towards paid carers themselves. The demands on the care sector meant that unpaid carers were very aware of the pressures placed on paid carers and felt a sense of obligation to 'look after them'. This seems a powerful indictment of the care sector if the people care agencies are paid to support are concerned about the wellbeing of the care workers.

...but because some of them (the care workers) are nice and in such a state when they get here, I almost feel I should make them a cup of tea rather than them making the tea for my mum.

Tammy



MORE TROUBLE THAN IT'S WORTH

When the care arrangements did not work out well, having paid care could end up causing more problems than it solved. On the one hand, it could make life very difficult for unpaid carers if the carer did not turn up on time, causing them to be late for work or miss appointments. On the other hand, the need for fixed pre-arranged care proved difficult for unpaid carers who were working in jobs that required a measure of flexibility.

....the domiciliary care was just not, it was so disruptive ... always waiting for the doorbell to go, always waiting to see who would turn up and the times they turned up was unpredictable and that became more upsetting than actually just getting on with it yourself.

Jo

When one partner in a couple was the unpaid carer for the other, they had to get used to having different carers coming in and out of their home. If their partner had regular necessary or preferred routines and the paid carer was late, they could end up having to do the tasks themselves anyway. Given that spousal carers were usually older people in poor health themselves, this could jeopardise their own wellbeing.

I found it really, really intrusive...the guy that came said that he had half an hour (for each call) and there was no allowing for the time in between. And so they were either early or late or didn't show. I had appointments, I was getting stressed, and the stress was passing onto him (husband). It was just a nightmare.

Margot



THE NEED FOR A WATCHFUL EYE

Public scandals about poor quality care and abuse had undermined the trust that some unpaid carers felt in care services. They felt that they needed to monitor the quality and safety of care that was being provided, especially if they lacked confidence in the care agency management.

I am here every single day, I do watch things very carefully, I do really keep an eye on what's going on and if any, you know, where she has bruises I take photographs of them and whatever, and ... I do like to keep an eye on things and with the bills, you know, when they were doing the extra three seconds so you get, my bills, £250, £300 a month more, you know, just by something as silly as that.

Tammy

However, as with some of the older people who were the direct recipients of care, some unpaid carers were reluctant to complain or take action even if they felt that the quality of care was lacking. There was a fear that care might be withdrawn if they complained or that they would end up with even worse care if they changed agencies. One unpaid carer described the lack of sense of entitlement to good quality care, despite paying in full for the service.

You're paying for something; if you're going into a restaurant and order a plate of food and you're paying for it and you don't get what you, you know, you've ordered fish and chips and you get sausage and mash, you know, you're going to say, "Hang on a minute," or it's quality's rubbish...you know. But nobody kind of seems to get that within the care system, you know, that whole thing about, you know... 'We're still doing you a favour, you might be paying for it but we're still doing you a favour'.

Philip



FEAR OF GETTING IT WRONG

Taking on responsibility for a loved one's care brought with it a desire to secure the best possible care arrangements. Making decisions for the person and trying to 'do the right thing' is highly complex in emotional, moral and practical terms.

It's quite stressful, very stressful to get, ... you know... you want to get the best solution and you're never convinced that that's what you've got. Could we have done better, could we have managed it better, could we have done things differently, you know?

Philip

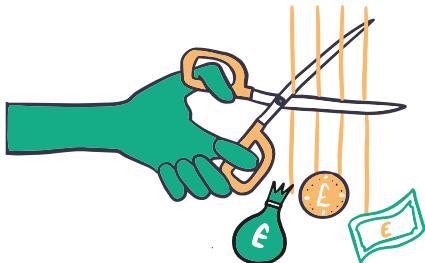
If an unpaid carer was in the position of having to make decisions on behalf of the older person, this generated irresolvable questions: How much care do they need? How do I know whether the care is good quality or value for money? How much can they afford to pay when we don't know how long the care will be needed for? How far into the future should we plan? And, ultimately, how long are they likely to live?

Many of the unpaid carers we spoke to felt a high level of anxiety about what was going to happen in the future. This included uncertainty about what would happen when the money that was currently being used to pay for care ran out. Very few understood the rules about when social services would step in or what would happen at this point.

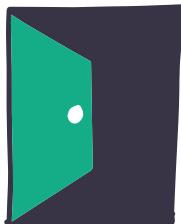
You're in this awful kind of roulette situation where you think, well, she might die, well she will die, we all die, but, you know, and you're thinking, well, will she die before the money runs out? That's an awful situation to be in.

Victoria

POLICY & PRACTICE IMPLICATIONS



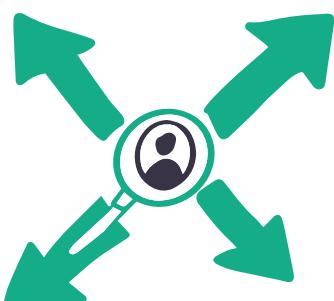
It should not be assumed that once self-funded care is set up, the need for unpaid care will reduce. Older people who have personal care needs often have an array of other needs as well, including financial management. The need to manage and monitor self-funded care can bring new ongoing tasks and responsibilities for unpaid carers.



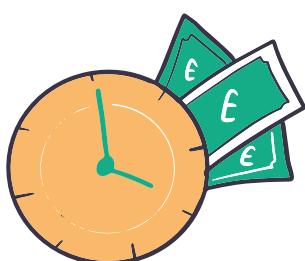
The work that unpaid carers do in supporting older people who self-fund their care is often hidden. Carers' assessments should include asking them about what they do to support self-funded care, how they feel about this and what impact this has on their lives.



Unpaid carers need good sources of information, guidance and support with issues to do with self-funded care, including financial advice, so that they are not 'in the dark' or 'left to their own devices'. This needs to include planning for the future so they know what to expect in given scenarios that may arise.



There need to be well-publicised and accessible avenues for managing self-funded care for situations where unpaid carers are unwilling or unable to take on this responsibility. Although local authorities can arrange to meet the care and support needs of self-funders (charging a fee for making the arrangement), we found that very few unpaid carers were aware of this option.



If paid care is to be helpful and supportive to unpaid carers, it must be timely, consistent, reliable and trustworthy. Unless this is the case, it can compound the difficulties faced by unpaid carers, rather than relieving them.



People who are receiving care from care agencies and their unpaid carers should be able to feel confident in the quality of care that is being provided and not obliged to worry about either the standard of care being received by their loved ones or the health and wellbeing of care staff. The training, pay, conditions and support for care staff is a vital issue to be addressed by the sector.

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