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# Catastrophic costs of care at home for self-funders

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# Summary

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Older people who pay for care in their own home are almost invisible in policy and practice. Little is known about the ways in which older self-funders navigate the care market and negotiate buying care in a complex and fragmented care system.

Our research found that many older people pay thousands, sometimes hundreds of thousands of pounds in total, for care provided in their own homes. Many of those whose care needs were not eligible for state-funded support were struggling to pay for the care they needed.

- The costs for care at home can be catastrophic in terms of the burden they place on self-funders.
- Not all self-funders are well-off; some older people struggle to afford the care they need.
- The amount people pay for care is likely to rise as care costs increase and/or the need for care increases as their health and abilities decline.
- Many older people did not fully appreciate the implications that running out of money would have for their care.
- Some people have to make decisions about care based on pragmatic calculations about how long they, or their relative, will live.

## Introduction

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This briefing draws on research findings from the project Ethical Issues in Self-funded Social Care: Co-producing knowledge with older people. 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, further research briefings, booklets for older people and their families and more information about the project please visit: <http://www.olderpeopleselffundingcare.com/>

We usually think about the ‘catastrophic costs’ of care in relation to older people who live in residential care and nursing homes, but costs can also be ‘catastrophic’ for older people who have limited means and are receiving care at home. By engaging closely with the lived experiences of older people who pay for their own domiciliary and live-in care, this research briefing highlights their financial concerns and their position within the care market, and reveals the excessive financial burden that older people may have to bear when they are paying for care in their own homes.

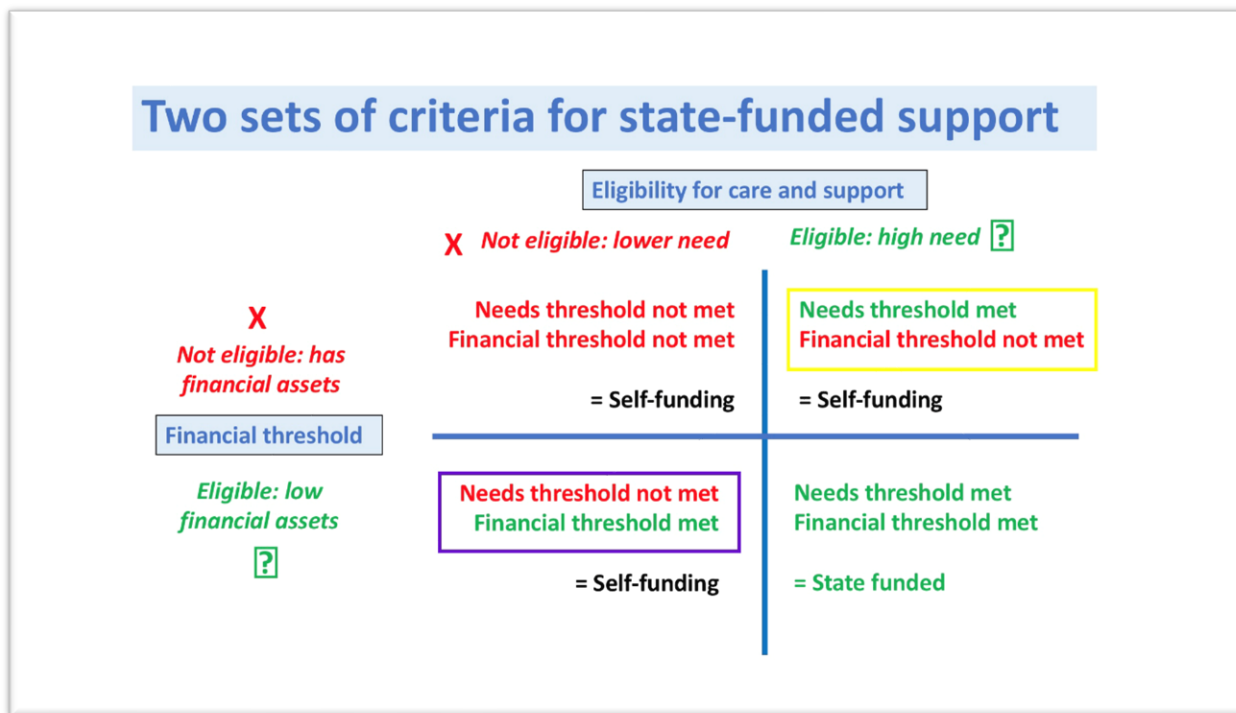
All names are anonymised.

## Not all self-funders are well-off

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There are two sets of criteria that older people must meet to become eligible for state-funded support with care costs. Self-funders are those people who fall outside the two criteria set for state-funded support with care costs.

One of the reasons people have to pay for their care is that they have assets above the financial threshold set by central government. Some older people have financial resources only just above this limit and may not view themselves as by any means well off, especially when their assets are set against the high costs of personal care.



Another reason for someone being a self-funder is that their assessed care and support needs fall below the eligibility threshold. There are startling inconsistencies within the system that mean people living with dementia, for example, who may need a good deal of care, may not meet the needs threshold for state-funded support. Older people who pay for their own care because their needs do not meet the eligibility criteria may well have assets below the financial threshold and struggle to meet the costs of the care they need.

*Well it was my choice, and I suppose I'm quite happy to pay for this, as long as I've got enough money, because it does worry me now we've taken on these night carers and Social Services at the moment won't help. I mean we really, when we've worked out all the finances, we're short of up to £200 a month, so I've got to find that from somewhere, and that is worrying. But, because we can't really cut down their hours... i(Adele)*

## Affordability and paying for care

The high costs of care came as a shock to many older people and their supporters, as did the fact that social care is means-tested and not free at the point of delivery like NHS healthcare. Marilyn, for instance, did not expect her mother Annie, would have to pay for care after a diagnosis of Alzheimer's disease.

*'I have to say I have been shocked at the cost of the care...I thought my mum could just go into a home like my grandmother did years ago... my grandmother was in a home for the blind and it was a beautiful home... So immediately when you think about it, that's what you think ...but you realise very quickly, no that's never going to happen because you have got a house, you have got money in the bank. So it's that, really, it's that awakening suddenly you go, wow I didn't know that.'* (Marilyn, daughter of Annie)

Older people themselves reflected a range of attitudes about having to pay for the care they needed. Some people accepted that they should contribute towards the costs but felt that there should be some limits on that contribution. People who were struggling to manage on their income tended to feel a sense of injustice and resentment, although others also voiced their concerns about the social care system.

*'I realised right, well you read so much about these things, you hear about so much on the TV about these things, it was pretty well obvious that, you know, caring has to be paid for... I'm okay with it.... But I'm only okay with it because I know that I have sufficient funds to be able to do so. I feel very, very sorry and very concerned for hundreds, thousands of people who can't afford it and find it a struggle to deal with it' (Douglas)*

Many of the older people we spoke to had to budget carefully to pay for their care, working out how much they could afford, against how much care they needed. Some people were trying to manage with insufficient care. Cutting back on care spending to economise may jeopardise older people's wellbeing and safety and have negative repercussions in future.

*'The evening is probably...when you could do with it, when you're tired but...I haven't got the money. I've only got pensions, you know I've got a small private pension, it's not that massive' (Brenda)*

Older people also spoke about the possibility of using up all their savings, that had been built up over a lifetime, sometimes through struggle.

*'I'll just have to go into my savings, one assumes... because I don't want to sell my home or do anything like that' (Adele)*

Even those with more substantial financial resources had to work out how long they could sustain paying for care and often had to cope with significant uncertainties, making it difficult to plan their finances. This was especially the case for people with the most complex needs who were paying for several care visits a day and/or overnight care or live-in care. This level of care provision could easily cost over £1000 per week.

*'So, you know, it's a lot of money. So, it's completely knocked awry what we had anticipated' (Isaac)*

## Catastrophic costs for care at home

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We often think of catastrophic care costs in terms of paying for residential care in a care-home, but older people often want to stay in their own homes and familiar surroundings. While care provided in your own home may be marginally less expensive than moving to a care home, the costs can still mount up and easily obliterate the value of savings and assets.

Trevor, 87, had a devastating stroke 10 years ago and now has very limited communication and mobility. His wife, Charlotte, has severe arthritis which causes her significant pain and limits her mobility. Charlotte and Trevor have had to pay for periods of live-in care when Trevor fell and his condition worsened, and when Charlotte was very unwell. Finding the right care at the right time and at the right price can be a challenging process, especially when you're on your own. Charlotte was lucky to have help from her family.

*'Well my daughter... she shopped around for a start and she got one or two well-known [agencies] in England and then of course I got this one which was a little bit cheaper, it was nearly £1,000 a week... They are very expensive these 24 hour carers' (Charlotte, wife of Trevor)*

Our research found that it is often impossible to 'shop around' for care services, especially in rural areas where there are fewer care providers and extra charges can be incurred to cover carers' travel and expenses. Self-funders living in rural areas often purchased more care time than they really needed to make it 'worthwhile' for carers who had to travel some distance to get to them.

Charles, 90, lives in a village outside a city. Charles is blind and susceptible to falls. After his wife died, and his health worsened, he tried living in residential care, which he did not enjoy at all. It was important to him to be able to stay in his own home and he now pays for 24/7 live-in care. Charles felt he had very little choice about who would provide the care he needed at home and he had to settle for the only agency with carers available.

He feels he has been somewhat exploited.

*'...at the private care home it was £2,000...[a] tremendous amount. The manager said to me "this is nothing to do with", or words to that effect, "to do with NHS, this", or "we're in the business, it's a business, we're in the business of making a profit" and they make a profit out of you, everybody' (Charles)*

Staying at home was important for many older couples too. Isaac is 95 and not as mobile as he used to be. His wife, Isabel, 88, lives with dementia and they pay for live-in care. Isaac arranged day and night care after becoming exhausted by his own efforts to look after his wife.

*'...by about October 2016, she was very much bedridden. It was a jolly tough year for me because I could get her out of bed, but I couldn't persuade her to go back to bed, so we'd spend half the night being up, and ... I had a certain amount of help where I had somebody coming in twice a week in our house, but I was doing the meals and doing the stairs and... I mean, not having much sleep at night, so in the end I gave up and decided I'd have to have some help... I lost a couple of stone' (Isaac)*

Like Charles, Isaac and Isabel have shared their home for several years with a variety of carers coming and going, who work in shifts. Isaac already pays more than £100,000 per year for care and was concerned about additional and highly unpredictable costs.

*'...me, or the client, as they call them, has to pay for, has to provide their accommodation and has to provide their board as well. What you don't expect to read on the contract, that if she's disturbed for more than half an hour twice a night, then you pay a premium of X pounds for each visit each time they're disturbed... And this applies, I've seen several prospectuses from different agencies' (Isaac)*

As well as paying an agency for the carer's hours, older self-funders incur additional costs for bank holidays, transport, food, fuel and for adapting their homes.

*'...stairlift we paid for, we have to pay to have the room altered to make it into a thing, all his electric equipment, chairs we bought... we have to keep buying things, I mean this is his second electric chair because the first one, after 11 years it'd packed up' (Charlotte, wife of Trevor)*

Financial challenges can also arise for self-funders after being discharged from hospital. Fred for example, has profound spinal injuries and paralysis, meaning his ongoing care needs are complex. After Fred came home from a stay in hospital, he and his wife, Leonora, received some support through NHS funding for a number of weeks, but later had to pick up the tab.

*'"And we're sending you home with eight carers a day." Yeah, one minute I was going to cope on my own, now I've got eight people coming... All this time nobody talked about money, nobody talked about how you were going to afford it ... and you think about it, you suddenly realise you're going to have eight people a day to look after him for a, how long, I mean he's 81 now... and you think I don't know, how long is a piece of string?' (Leonora, wife of Fred)*

## How long will my money last and what happens next?

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There was a lot of concern amongst some older self-funders about how they could continue to meet their care needs if or when their money ran out or if their care needs became more complex. Those who felt that they could currently afford to pay for care were conscious that the price of care was very likely to rise and they were drawing on a dwindling resource.

*'...but it's £1,000 a week, you know, it's not going to last long' (Charles)*

*'...at the moment I can manage without it being too hard but when I need more care...I've got a bit of equity release, but I probably have to take some more which I shouldn't really have to do' (Brenda)*

Many older people did not fully appreciate the implications that running out of money would have for their care, nor what their Local Authority's responsibilities would be with regard to funding their social care. Even if the older person's care needs qualify and their finances fall below the threshold, there may be no suitable care available in their area at the lower rates usually paid by Local Authorities. This is especially the case in rural areas, where any care is difficult to secure, or in wealthier areas where only higher-rate self-funded care is available.

This means older people who become state-funded are served by local authority care contracts and may suffer significant disruption to their care arrangements at home, or may have to move out of their area for residential care. If the older person was already in self-funded residential care, their family could be asked to 'top up' care home fees or the older person could be compelled to move to a less expensive care home. Such a move is usually an option of last resort because the adverse outcomes (deterioration and death) are recognised.

Our research suggested that self-funded care can easily become 'family-funded' care. Some families were 'topping up' care costs from their own resources in order to secure the type, amount, or quality of care that they felt the older person needed. Such arrangements had profound implications for family members' future financial status.

*'Mum and Dad have got X amount of money, which we've worked out will do two years, eight months if they both still live. If there's one of them left, and we've talked about this openly, it's not a problem. It's the two of them, [if] the money runs out, what happens? They put money into my brother's house. Would they expect him to sell up and release it? ...It's very difficult because it's such a delicate sensitive subject and I know from talking to other friends, that this is where we all seem to fall down. It becomes firefighting instead of actually facing something and making a plan. And at the very age where you don't really want to do it' (Deborah, daughter of Bev, and Walter)*

In Deborah's case and for others, the prospect of having to continue to pay for care forced older people and their families to make difficult and sensitive calculations, including about how long they could 'afford' to live.

*'I don't know, I don't know how many years Isabel has got... I mean it's knocked care plans a bit sideways, I mean it, with the cost of their food and keep and reasonable figures, must cost about £130,000 a year. So you know, it's a lot of money' (Isaac)*

It is clear that older people who have to pay for their own care can, and do, incur catastrophic costs that weigh heavily upon them and their families, consuming their savings and capital. These catastrophic costs can have ramifications through the generations, not just when older people have to sell their homes to pay for residential care, but when older people use equity release for instance - effectively part-selling a house - to meet the costs of care at home.

Importantly, there are inequities within the current social care system that mean some older people - those with ineligible needs and those who have built up even modest savings or assets - are left to fend for themselves in a difficult and dysfunctional marketplace for care services.

## Policy and practice implications

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- Older people may have to pay out a large proportion of their finances for the care they need, resulting in so-called, 'catastrophic' care costs. This applies as much to care provided in a person's own home as to care in residential and nursing homes. If the cost of care at home seems unaffordable, older people may cut back on care they really need.

- Older self-funders make a considerable contribution to the social care market. A review of the current system of care is urgently needed as it is not equitable, nor is it delivering choice, control or quality of care for many older people who pay for their care.
- Social care reform should ensure equity in the total amount of money anyone should be expected to pay for their care and make it absolutely clear what care an older person is expected to pay for or contribute towards and what is free at the point of delivery.
- Financial reform should consider raising the financial threshold for care which has remained at the same level for a decade.
- Social care policy needs to be founded on closer engagement with the lived experience of older people who pay for their care. This experience reveals that many of the assumptions made about self-funders are myths that prevent a more detailed understanding of the problems older people face.
- Much clearer and more accessible information is needed about the responsibilities that local authorities have towards self-funders. These include:
  - the duty to provide information about options for care
  - the duty to assess care and support needs for anyone who appears to have these needs
  - the duty to provide an option for self-funders to request, for a fee, that the local authority arranges to meet their care and support needs and manages that care
  - to make known the responsibilities and procedures that apply when people's financial assets dwindle.

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## Catastrophic care costs: Research Briefing