

Behind the headlines: the ‘top up’ stealth tax on older people in state-funded residential care

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1) Introduction – about the care system and ‘top up fees’

How the care system works in brief

Most older people with long term care and support needs want and are able to remain in their own homes. However, those with the most complex needs, such as a long term neurological condition or advanced dementia, often have to move into residential care homes. Over 400,000 older people now live in such settings in England.

Many are dismayed to find out that if they have to move into a residential care home their care will not usually be paid for by the NHS. Even if they require the substantial degree of support provided by residential care they are more likely to fall within the council funded social care system. (The councils in question are upper-tier local authorities such as county councils, not the smaller District Councils.)

At this point many of those affected experience another shock, when they discover that council funded care is by no means available to all. It is accessed only via strict eligibility criteria and an extremely ungenerous means test, so to obtain support older people have to clear two tough hurdles. First, they must show they fulfil the stringent conditions that councils use to decide whether someone needs care – essentially, these days they have to be experiencing substantial difficulties in managing the normal activities of daily living. Secondly, they must show that their income and wealth are sufficiently modest so as not to disqualify them, with tapering financial help on offer only for those with assets worth up to £23,250.

An older person whose needs have developed to the extent that they require residential care should be able to qualify for council funded care on the basis of their needs but, with the means-test so wretchedly ‘mean’, significant numbers of older people fall foul of it, disqualifying them from financial help until they have run down their assets to £23,250. It should be noted that when it comes to funding residential care, this £23,250 threshold includes the value of any home that the older person may own, unless their partner or dependent relative is still living in it.

Top ups

But even that’s not all, because even if an older person meets both requirements and qualifies for council funding, bizarrely it turns out that their relatives may still end up having to pay towards their care. This is because of ‘top ups’, which are now paid by the families of 1 in 4 care home residents whose care is supposed to be free – representing 1 in 10 of all care home residentsⁱ. Age UK is worried that these payments represent a ‘stealth tax’ on older people and their families in a care system that seems to be riddled with hidden unfairness.

In theory, top ups are a very good idea. They are intended to provide some flexibility in the system, enabling older people to choose a more expensive care home than

their council would pay for, provided that they can find someone to pay the difference - the top up must usually be paid by a third party (typically a relative or friend).

This provision was designed to allow older people who want a little extra comfort or convenience to have it, through them adding to their council funding with a financial contribution from someone else who is willing and able to pay the additional amount.

What the law says

The law, reaffirmed by Parliament only three years ago, is clear about what top up fees are and when they can come into play – essentially at the express request of the older person and their family or friend. The Care Act 2014 says:

‘The local authority **must** ensure that the person has a genuine choice of accommodation. It must ensure that at least one accommodation option is available and affordable within the person’s personal budget and it should ensure that there is more than one of those options. However, a person must also be able to choose alternative options, including a more expensive setting, where a third party or in certain circumstances the resident is willing and able to pay the additional cost (‘top up’). However, an additional payment must always be optional and never as a result of commissioning failures leading to a lack of choiceⁱⁱ.

So, according to the law, top ups should only be paid voluntarily and with the informed consent of families, and older people have the right to be offered at least one residential care placement which is available and affordable within the funding the council has allotted to them.

However, unfortunately, for years at Age UK we have heard examples of relatives being asked to pay a top up even when they don’t think their loved one has opted for anything particularly special. And with the care system in the state it is now it is not surprising that more such cases are being brought to our attention, and that some of the amounts relatives say they are being asked for are really significant.

The law is also clear that top ups are essentially an arrangement between the council and the older person and their family. If an older person and their family choose a care home that requires a top up payment the idea is that this is agreed with and paid to the council, which then passes the extra amount to the care home.

Over the last year Age UK’s national information line has dealt with more than 250 cases involving top ups, some of which are sketched out in this report. We have changed names in order to protect confidentiality. These cases illustrate different aspects of the current problems with top ups, so we have presented them around these various themes below.

1) An inadequate choice of care homes at the council rate means families feel faced with no option but to pay a top up

The largest volume of inquiries about top ups that Age UK has received over the last year involve situations where the choice of care home placement at the rate offered by a council is so grossly poor that families feel that they have no real option but to pay a top up to secure a care home place for their loved one that they feel is acceptable.

In some cases the problem may be a perceived lack of quality or suitability, but often the issue that arises is distance: it is quite common for a council to offer a 'choice' of care home place that is not terribly near where the older person used to live, or where their family or friends live – because it is often so hard to find one 'cheap enough' for the council to afford, or because there is a shortage of local affordable care home places more generally. This poses big problems for relatives and friends who know that the health and wellbeing of the older person they love depends to a significant degree on them being able to visit them frequently.

In some circumstances it may be possible for a family to persuade a council to change its mind about what is acceptable, in favour of a care home that is nearer and which makes visiting the older person easier. But in order to do this a family needs to understand the older person's rights – often requiring specialist advice, for example from a charity like Age UK.

Joan

The council has sent Joan an email, saying a top up needs to be paid or her mother-in-law must move to a care home 35 miles away. Joan is clear she cannot pay a top up. Joan feels a move will affect her mother-in-law's wellbeing, as Joan, and her mother-in-law's friends will not be able to visit, so she will be left abandoned. Joan will explore whether her mother-in-law's former GP and her current care home can give evidence about the effect of not having any visits on her mother-in-law's wellbeing.

Kathleen

Kathleen's mother needed to move into a care home with nursing care. Her family wanted to visit her every day. The council suggested a care home a considerable distance away, which would have made this impossible. Care homes in the immediate locality were either not available or cost more than the personal budget which the council said was sufficient to meet her care needs. Kathleen called at a later date to say that she had found a care home that she felt was suitable for her mother, and close enough to the family to enable daily visits. Her mother moved in last week and is settling in. The council has agreed to fund the placement and no top

up has been requested. Kathleen felt that because she had rung Age UK she had the information required to know what to raise with the council and was able to argue that the personal budget should be increased to pay for a home that would meet her mother's needs, including her social and psychological needs.

Edna

Edna's mother is in permanent residential care and is currently self-funding. She will soon reach the capital threshold to be entitled to council funding support. The council are involved and have advised that she will have to pay a top-up because every available care home in the local area that they might place her in requires this.

2) Care homes improperly demanding top ups directly from families

In some cases the care home asks relatives for a top up – a complete reversal of how the process ought to work.

Caroline

Caroline's mother-in-law has Alzheimer's Disease and has moved into a care home. Before she moved her social worker told Caroline that she would have to pay a top up of about £40 per week. However the care home has now asked Caroline to sign a separate, additional contract, which means the top up has now gone up to £90.

Hassan, and his daughter Suliha

Hassan has been in a residential care home for 12 months, with a top up payment agreed with the council of £100 a week. This is paid by his daughter, Suliha. Suliha says her father has now been given a letter from the care home telling him he must now pay a £300 top up a week to them or he will be evicted. Hassan's social worker has told Suliha that they need to sort things out amongst themselves with the care home.

The law says that once a council has accepted that an older person qualifies for council arranged care, it must pay the full cost of meeting their needs. The Care Act 2014 makes it plain that the council must pay the full care fee. Guidance issued under the Care Act states that 'Where a council is meeting needs by arranging a care home, it is responsible for contracting with the provider. The council is also responsible for paying the full amount, including where a 'top up' fee is being paid'ⁱⁱⁱ. The person paying the third party top up must have a written agreement with the council. Only if all three parties (resident, care home and council) agree can the third party top up be paid directly to the home^{iv}.

In other words, the law says a care home cannot approach the resident directly for a top up. The council is supposed to pay the full cost of the care placement and if a top

up is required it is paid to the council, unless everyone, including the family, agrees otherwise in writing.

Yet in these cash-strapped times for social care the reality is often totally different: a freedom of information request by Independent Age in autumn 2015^v found that over a quarter of councils were aware of the existence of third party top ups that they had not agreed, and over a third had not complied with the requirement to have written agreements.

This year we have heard of some councils that are clamping down on this bad practice, which leads us to hope that the Care Act may now be starting to have an effect;

Barry and his mother

Barry's mother is moving to another care home and is receiving council funding. The council arranged an £18.00 a week top up with Barry which he was happy with. However, the new care home asked Barry for a separate £300.00 a week top up and told him not to tell the council. Luckily Barry did tell the council and the council contacted the home. When the council asked them about it the care home said that Barry had 'misunderstood'.

3) Hospital discharges held up by requirements for top ups that families cannot fund

The issue of unexpected requests for top-up fees is not only creating stress among families, it is also impacting on our already stretched NHS hospitals. We have encountered several examples of older people being unable to leave hospital due to demands for top up fees that simply cannot be met;

Jo's father-in-law

Jo's father-in-law has been in hospital for 12 weeks, having been medically fit to leave for a while. Social services have not yet managed to offer him a care home place and now say there is no suitable care home in the area. The family have identified a care home outside the area which they think is appropriate but social services say they will not pay the full fee rate, meaning that a top-up payment is required. Jo is going to have to make a contribution, which will leave her with very little money to live on. She says that the council has told her that her father-in-law cannot be discharged from hospital until the family agree to sign a top-up agreement. This is placing her in an extremely difficult and stressful position.

Christine's mother, 85

Christine's 85 year old mother is in hospital due to poor health and the onset of dementia. She is no longer able to look after herself - this is also the opinion of hospital staff and occupational therapy. She has been assessed as needing 24/7

care, and the family have met with hospital social services to try and get this in place. Her finances are very modest and her assets below the threshold for council funding. However, there are no places available at rates which the council will pay. Christine has been told that she will have to pay a top up. Her mother does not have funds to pay this and Christine has been told the family will have to pay, but no one in the family can afford it.

David's grandmother

David's grandmother needs to be discharged from hospital into a care home suitable for people with dementia. The council have stated they will only fund a home up to £657 a week. There are three local suitable care homes but they all cost more than this and would require him to pay a top up, which he can't afford. There is one home that does not require top up, but it is a long way from where the family lives, which would make visiting their grandmother difficult as well as expensive.

One of the main causes of delays in discharging people from hospital is referred to by NHS England as 'patient choice'. But, as our recent *Behind the Headlines* report on delayed discharges^{vi} demonstrated, this broad category includes a variety of situations which explain why patients and their families might feel that the service that has been offered to them after they move out of hospital is unsuitable or inadequate. In some cases the reason is because councils have only offered a choice of care home placement that requires a top up and the family cannot afford it.

These examples show that the problems caused by top up fees are not confined to people who have to pay the fees. There is also a knock-on effect on the wider health and care system.

4) Care home fees go up so it's 'pay a top up or move out'

In some cases older people move into a care home where no top up is required, or the top up is set at an affordable level, but the home then increases its fees. Care home contracts rarely state how, when or by how much fees can be increased. If the council refuses to pay the increased rate relatives can be asked to make up the difference:

Linda and her mother

Linda's mother went into a care home in 2015. She is funded by her council. The council helped Linda to find a care home that did not require a top up. However, 4 weeks later, by which time her mother was settling in, Linda was told her mother could only remain if a top up of £120 a month was paid and now she has been told

the top up has increased to £160 a month. The council says that if Linda can't pay the top up then she should look for a home that doesn't require one.

Karen and her mother-in-law

Karen's mother-in-law moved to her current care home two and a half years ago. Her mother-in-law only has £4,000 savings, no property and a small pension income. Social services fund her care. Relatives have now received a letter from the care home saying that their fees have gone up and they must pay £33 a week towards her care.

5) Top ups demanded when self-funders run out of money

An issue that Age UK frequently encounters is what happens to older people who have been paying for their own care, once their assets have been run down to the point that they qualify for council funding – the £23,250 threshold referred to earlier.

The older person is likely to be occupying a place that is more expensive than the council usually pays. This might be by choice, but more often now it will be because private funders cannot purchase places at the lower rates that councils pay. Families are therefore likely to face demands for top ups, and if they cannot pay their loved one is at risk of being evicted. For some very unwell and vulnerable older people an unwanted move will constitute a risk to their health and for all it will be an enormous upheaval they would be better off without;

Vanessa's mother, 92

Vanessa's Mother, aged 92, has been in a care home for 2 years. Her health has deteriorated over this time. Her mother is blind, deaf, and completely immobile and her skin has become very thin so it breaks easily. She has been a self-funder but is now eligible for council funding. The care home costs £675 per week but the council will only pay £473. The care home has said that they will reduce the cost slightly but Vanessa cannot afford to pay a top up payment.

Maureen and her father

Maureen's father is in a care home with nursing provision. Her father wants to move closer to her. She has found a place and the council has finally agreed to pay the full cost, minus her father's contribution. They initially asked for a top up, but a care assessment was carried out to establish his needs and the council has agreed this is the cheapest one that meet his needs. Maureen has now been asked to sign an agreement that any future increases will be paid by her. Maureen does not know how much an increase might be, is worried about effectively signing a blank cheque, and asks 'do I have to sign this?'

Rupinder and his father

Rupinder's father is a self-funder in a care home and his assets are running down towards the £23,250 upper capital limit. He has had an assessment by the council who have indicated they support his need for residential care. The nearest care homes costs £550 a week, with most local ones quoting between £700 to £900 a week. Rupinder has been told that when her father is eligible for council funding support there will be a top up required of £600 a month because they only pay £400 a week. Rupinder says their figure does not reflect the cost of care homes in the area.

Junior

Junior's father has dementia and has been self-funding in a care home for five years. It was chosen for its familiarity as some residents are his friends and it is also close to his family. He is now bed bound and his capital has reached the capital limit and he needs council funding support. The care home has approached the family to pay a significant top-up so he can remain in his present accommodation.

As another previous Age UK 'Behind the Headlines' report^{vii} showed, some care homes are asking for assurances that when people qualify for council funding they will continue to pay fees at the higher rates that self-funders pay, so quite improperly families and friends are sometimes being asked to guarantee top ups in advance.

6) How much do families pay and how many are affected?

Across the UK 48,000 people, amounting to 24 per cent of council funded care home residents, are currently paying top ups. Market analysts Laing and Buisson estimate that the size of top-ups varies from about £25 a week to over £100 a week^{viii}.

There are no statistics that are directly comparable over time showing definitively that more people are paying top ups, but such is the state of social care as a result of central Government funding cuts that we know that all kinds of creativity is being used by commissioners and providers to try to extract 'a quart from a pint pot' – unfortunately sometimes through passing on more of the burden of cost onto older people and their families. Our concern is therefore that the financial realities facing the care system will sometimes continue to thwart the expectations set out in legislation.

Research by Laing and Buisson shows that much of the variation in the frequency and size of top ups is due to regional factors. For example, in the north east of England only 18% of residents have to find top ups, but in the south east this rises to 54%^{ix}.

This variation is because in more affluent areas like the south east, where many people do not qualify for council funding, more care homes are targeting self-funders

and are unwilling to take clients at council rates. This means that it is difficult, or sometimes impossible, to find a care home in a better off area that does not require a top up. But things are not necessarily rosy in poorer areas either; here care home proprietors can't rely on self-funders and are dependent on council rates: if they consider these to be too low to keep their business going they may feel that it is not worth continuing. This is one of the factors which makes us worry that 'care deserts' could develop in some places.

We sincerely hope that the additional funding announced by the Government for social care at the last Budget will halt this worrying trend of 'provider flight', especially in less affluent areas, but it will be important for the Government to monitor the position carefully and be prepared to intervene with additional investment if the evidence suggests otherwise.

7) Conclusion

Top ups offer welcome flexibility when they are operating in a care system that is functioning well, where the market is buoyant and responsive to older people's needs so that a genuine 'choice' of decent, affordable care home places is available for those who require this level of support.

However, against the context of a care system that is woefully underfunded, in which councils are struggling to fulfil their legal duties and many care homes find it tremendously hard to provide decent care for older people on council rates, top ups are at risk of being unfairly exploited, with families the biggest losers: the cases we have heard about at Age UK suggest that sometimes they are being used to 'milk' families and friends in order to fill funding gaps for which there is no other apparent solution.

The Care Act 2014 outlaws such practices but unfortunately this is apparently not enough to stop them everywhere. The system is complicated, most people are unaware of their legal rights, and decisions about moving to a care home are usually taken at a time of great turmoil and stress: all these things help explain why the unacceptable carries on.

The truth is this is just another miserable manifestation of how badly served our older population is by social care as it currently operates, and the horrible resulting impact on those closest to them. It is time to be honest about how shabby and dysfunctional the 'system' has now become, despite the best intentions of the people working in it. The Government needs to drive through a process of urgent, thorough-going reform, and change social care for the better, once and for all.

There are also a number of steps that could be taken to make care home residents and their families and friends more aware of when top ups could come into play and when they should not.

- People are often unaware of the legislation governing top ups – councils should refer people to relevant independent information, for example Age UK, at the time that they request top ups.
- People are rarely aware of what the council's contract with the care home covers. They should receive a statement setting out what the council has paid for, including care and support, accommodation and 'hotel costs'. They should also be informed of the nursing care contribution (£155.05 per week) paid by the NHS to each nursing home if they require on-site nursing support.
- Even where people are fully aware of their entitlements they may be reluctant to complain for fear that their loved one will face retribution. In particular, because care home residents disgracefully have no security of tenure, making them vulnerable to eviction, they and their relatives can be reluctant to speak out even if they think they should not be paying a top up. Care home contracts should give residents much greater protection against eviction and should clearly set out the circumstances – which should be limited – in which care homes can give them notice.

Age UK publishes Factsheets which set out the rights of care home residents. Factsheet 48, 'Paying for Permanent Residential Care', explains these rights in detail.

http://www.ageuk.org.uk/Documents/EN-GB/Factsheets/FS10_Paying_for_permanent_residential_care_fcs.pdf?epslanguage=en-GB?dtrk=true

This Factsheet only covers England but Age Cymru, Scotland and Northern Ireland produce their own versions.

ⁱ Laing & Buisson – UK Healthcare Market Review – Twenty-Ninth Edition

ⁱⁱ Care and Support Statutory Guidance updated 27.10.16 Section 8.37

ⁱⁱⁱ Care and Support Statutory Guidance updated 27.10.16 section 8.33

<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#charging-and-financial-assessment>

^{iv} Ibid. Annex A

^v Independent Age p12 *Year One of the Care Act – Taking its First Steps*

2016 https://www.independentage.org/sites/default/files/2016-05/Care%20Act%20Report%20-%20Final_spreads.pdf

^{vi} Age UK *Behind the Headlines: are older people and their families really to blame when their hospital discharges are delayed?* – Age UK 2016

^{vii} Age UK *Behind the Headlines – stuck in the middle – self funders in care homes* – Age UK 2016

^{viii} Laing and Buisson *County Care Markets Market Sustainability & the Care Act 1st edition 2016*

^{ix} Laing and Buisson p212 *Care of Older People Market Survey 2015*