Taking greater care

Why we need stronger consumer protections in the care home market





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Contents

Summary	3
Background	5
Research method	8
1. A (consumer) choice like no other	9
2. Charging practices can be confusing and unexpected	17
3. Families lack options, even when they have concerns	24
Conclusion	29
Appendix	32

Summary

The decision to move an elderly relative or loved one into residential care is one of the most difficult to take, fraught with anxiety, guilt, uncertainty and loss for individuals and families. But often the stress doesn't stop there. Many families - already dealing with a challenging situation - then find themselves navigating a complex market, without the signposting or support they need.

Citizens Advice helped over 20,000 people with 27,000 social care issues last year, over a third of which related specifically to care homes. We see firsthand how people struggle to navigate the care home market. This report provides further insight into people's experiences of arranging and paying for care. The research looks at whether people are able to make an informed choice about a care home that is right for them, understand their rights and receive fair treatment from the provider, and speak up if they have concerns.

In recent months, there has been an important focus on the challenging market care providers face, as well as the ways the sector is letting down care workers. The report identifies signs that the care home market is also not working well for older people and their families. Building on previous Citizens Advice research, which highlighted a number of consumer protection concerns, this research takes a broader look at the care home market. The findings are based on 15 in-depth interviews and a survey of 510 adults who helped an older person arrange and pay for a care home place in England in the past 3 years. They highlight concerns at each key stage of people's engagement with the market.

First, people are often under extreme time pressure when deciding on a care home and are bewildered by their context. Over half (55%) of the respondents to this research said that the entire process of arranging a care home place took under a month, and nearly 1 in 10 (8%) said it took less than a week. Just under half (49%) said they found the process of arranging a care home place distressing.

Second, older people and their families are both underwhelmed and overloaded by choice in the care home market. Families were overwhelmed by the number of variables to consider when choosing a care home and the lack of accessible information. Only 7% were provided with information about care home fees, for example through marketing materials or the website, prior to making direct contact. But they were also underwhelmed by the range of care homes. Almost 4 in 10 respondents (39%) said they did not have enough choice.

Third, charging practices in care homes can be confusing and unexpected.

Over a third (36%) of respondents to this research were either not given a copy of the care home contract until after the resident had moved in, or not given a contract at all. Looking at billing practices specifically, this report finds that 1 in 5 (20%) people have experienced an unexpected additional charge, such as a back-bill or unexpected top-up fee, and over a third (37%) have put down a deposit for their room, despite the fact that care home residents lack the protections typically associated with this practice in the private rented sector.

Fourth, people lack options to make their views known to care homes, even when they have concerns. Over a quarter (26%) of respondents to this research have had concerns about a care home provider, but only 1 in 5 (21%) of those who had concerns subsequently made a complaint. The most common reason for not complaining (highlighted by 37% of respondents) was the worry that this would result in negative treatment from the care home. But moving care homes is also not a realistic option for many - fewer than 1 in 10 (9%) moved care home as a result of their concern.

Recommendations

- 1. Local Authorities, health professionals and civil society organisations should encourage people to consider care plans, including arranging a power of attorney, at appropriate moments in their lives.
- 2. Older people and their families should have access to advocacy throughout the care journey. Local Authorities need to assess whether all those who need advocacy support are receiving it.
- 3. NHS Digital, local authorities and care providers should work together to agree a common set of standards for online care content so people can better compare and contrast their options.
- 4. Care home providers should improve information to help older people and their families better understand their rights and options in the care home market.
- 5. The Competition and Markets Authority (CMA) should carry out a wider study of the care home market to examine whether it is working well for older people and their families. The CMA should also take enforcement action against care home providers with unfair terms.
- 6. Consumer protections in the care home market should be strengthened so they are in line with practices in other consumer markets.
- 7. The Care Quality Commission (CQC) should explore how it can help promote consumer protection within the care home industry.

Background

The number of people aged over 85 is set to more than double in the next 20 years. Chart 1 below shows the projected increase in the number of older people in England. As our population ages, demand for social care is increasing. 1 in 6 people aged over 85 currently live in care homes and research published last year predicted a 15% increase in demand for residential care from 2015-16 to 2020-21.1

14,000,000
12,000,000
10,000,000
8,000,000
4,000,000
2,000,000
2,000,000

Chart 1: The number of people aged 65+ in England is set to increase significantly

Source: ONS population data combined with ONS population projections for England

Unlike our healthcare system, most people pay something towards their social care in England. And the proportion is increasing - there are now 26% fewer people on local authority funded places compared with 5 years ago.² Nearly half of older people's care home places (44%) are fully self-funded and a further 30% of care home places are paid through top-up fees.³ Looking ahead, it seems likely that the individual will increasingly be responsible for funding their social care.⁴

¹ Respublica, <u>The Care Collapse</u>, 2015

² King's Fund, <u>Social care for older people: Home Truths</u>, 2016

³ LaingBuisson, The Care Market for Older People, 2015

⁴ See, for example, a <u>recent Guardian article</u> which shows that the government has been examining ways to incentivise people to save for their social care costs.

The reduction in local authority funding has not only impacted upon older people. There is also a growing recognition of the huge financial pressures care home providers are under because of the reduced fee levels local authorities are willing to pay.⁵ Despite the pressures created by our ageing population and the introduction of the National Living Wage, only 18% of councils have increased or maintained expenditure over the last 5 years.⁶ The CQC has issued a warning about the fragility of the adult social care market.⁷

Regulation of the care home sector

Our previous research identified potential ambiguities about which organisation should take the lead on updating and strengthening consumer protections within the English care home market. In part, this is because a number of organisations have responsibilities, creating the potential for both duplication as well as gaps in oversight.⁸

The **Care Quality Commission** (the CQC) regulates the English care home market. Its core role is to monitor the quality and safety of care provided. The CQC does this through monitoring care homes, including through regular inspections. It also considers a care home's financial arrangements with residents. The CQC has a wide set of enforcement powers which it can employ when it believes standards are being breached. As part of its regulatory role, the CQC also assesses the financial sustainability of care organisations that local authorities would struggle to replace if they failed.

Local authorities also play a role in shaping the local care market. The 2014 Care Act places new responsibilities on local councils to ensure a diverse and sustainable market.

General consumer protection law also applies to the industry. The **Competition** and **Markets Authority** (CMA) has a range of consumer powers and tools to tackle systemic market-wide consumer problems or issues which affect consumers' ability to make informed choices. The CMA's remit applies to many different markets across the economy, including the care home market. It has adopted guidance published by its predecessor the Office of Fair Trading (OFT)

⁷ CQC, Adult social care 'approaching tipping point', warns quality regulator, 2016

⁵ CQC, The state of health care and adult social care in England 2015/16, 2016

⁶ King's Fund, Social care for older people: Home Truths, 2016

⁸ The confusing regulatory landscape for the care market was highlighted in the Government paper, <u>Cutting Red Tape: Review of adult social care - residential and nursing home sector</u>

⁹ Regulation 19 in the 2009 CQC (Registration) Regulations requires that: '[P]roviders must make written information available about any fees, contracts and terms and conditions, where people are paying either in full or in part for the cost of their care, treatment and support.'

in 2003 outlining unfair terms in care home contracts.

Trading Standards officials are responsible for most of the day-to-day enforcement of consumer protection law and can carry out investigations in cases where they think relevant legal provisions are being breached. This includes misleading care home marketing materials, websites, and cases of unfair practice.

Since publishing our earlier research, we have been working with relevant regulators to address some of the consumer protection concerns identified. We hope that our new research offers further insight.

Research method

All data in this report are from 2 sources unless otherwise referenced. The first is a series of qualitative in-depth interviews with 15 people who helped an older person arrange and pay for a care home place in the past 3 years. 14 of the interviews were conducted with people recruited through the Citizens Advice website and social media accounts. One interviewee was recruited through ComRes to help meet the criteria outlined in our sample. Citizens Advice research staff conducted these interviews from July - September 2016.

The second is an online survey by ComRes of 510 adults who helped an older person arrange and pay for a residential or nursing home place in England through self-funding or top-up fees in the last 3 years. Fieldwork was conducted online from 4 August to 7 September 2016. Data were weighted to be representative of this audience according to funding type and type of care home. The survey reached a good mix of respondents by variables including age, gender and region of care home. ComRes is a member of the British polling council and abides by its rules.

It is worth noting the limitations of the research methods used. Both methods relied upon online recruitment methods and only offer insight into the experiences of older people who had access to support from family or friends.

A full breakdown of both the sample for the quantitative and qualitative research is included in the appendix.

1. A (consumer) choice like no other

"The whole thing was difficult because you are having to acknowledge the fact that your mother is no longer able to care for herself; because your mother looks the same as she did three months before but she is not the same person... You're having to confront the fact that she may well only ever live in that care home. That might be where she spends the rest of her days, weeks, months, years. That's one of the hardest things."

Citizens Advice client

This chapter explores people's experiences of choosing a care home.¹⁰ Selecting a care home is no ordinary decision. It involves determining how someone will be looked after when they are potentially at their most vulnerable. This chapter examines both the context in which people make the decision and the availability of information and support to inform their choice.

The context of decision-making is unfamiliar and bewildering

The context in which people decide on a care home is often overwhelming. Many families find themselves making the decision after an unexpected incident such as a hospital admission or a serious fall. But even longer-term deterioration of an older person's physical or mental health can crystallize in a moment of shock as families suddenly realise they are no longer able to support a family member. Chart 2 shows the wide variety of triggers for people moving into a care home.

Previous research by Citizens Advice shows that while consumers want to make the most of their good years, they often avoid planning for what will happen if their health deteriorates. Just 12% see not being able to fund future care costs as a key concern, even though over three quarters are likely to have a care need at some point in their retirement.

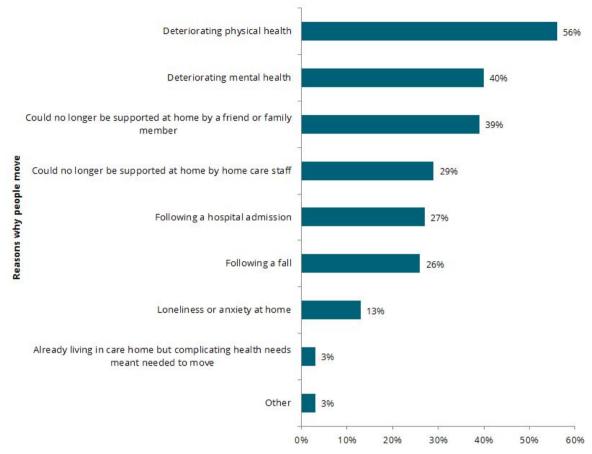


Chart 2: People move into a care home for a variety of reasons

Source: Citizens Advice analysis of ComRes data¹¹

Few older people have discussed care plans with their families in advance of them developing care needs.¹² People also tend to overestimate the quality of their health in later life and therefore often don't anticipate developing care needs.¹³ This provides some insight into why families are frequently caught by surprise. As one Citizens Advice client explained:

"Initially I thought there might have been an opportunity to have someone - in my case someone who'd given up their job - to care for her at home... But once it got to the point where you realise you would need realistically two people to look after her... you realise that this was not going to be a caring-at-home-type feasible situation. It's just not viable."

¹¹ Question: 'Which, if any, of the following reasons explain why your friend or relative decided or needed to move into a care home?' Base: All respondents (483).

¹² <u>Research by Partnership</u> shows that overall, just 14% of over-65s have had any general discussions around care with their families.

¹³ Citizens Advice, Approaching retirement, 2016

As a result, for many the decision is rushed and for some, the decision is so hurried and unexpected, they have little opportunity to exercise choice. Over half (55%) of survey respondents said the entire process - from the point at which they decided a family member or friend needed to move into a care home, to the point where the older person actually moved into the care home - took under a month. Nearly 1 in 10 people surveyed (8%) said the entire process took less than a week. Chart 3 below highlights the extreme time pressure some families and friends are under when making this crucial and complex decision. Only 4% of respondents said they spent 6 months or more planning and arranging the older person's move into a care home.

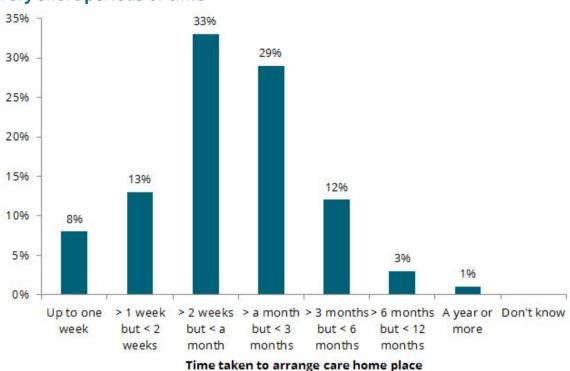


Chart 3: Older people and their families are arranging care home places in very short periods of time

Source: Citizens Advice analysis of ComRes data¹⁴

Interviewees described the range of overwhelming and sometimes conflicting emotions they experienced when helping an older person move into a care home, as well as the sometimes complex dynamics that emerged when making decisions involving other family members. Common emotions include a sense of guilt, anxiety about whether they are doing the right thing, and concern that they have failed their family member. But some interviewees also mentioned the

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¹⁴ Question: 'To your best estimate, how long in total did it take to arrange the care home place for your friend / relative?' Please provide your best estimate, thinking about the time it took from the decision to move your friend / relative into care until the point at which they moved into the care home. Base: All respondents (483).

sense of relief they experienced, knowing their family member would now be living in a safe and secure environment.

Underwhelmed and overloaded by choice

The research also explored what information and support is available to help people choose the right care home. Comparing and contrasting different care homes is very complex and requires a high level of effort and time to research and evaluate. People have to shop around to assess and compare the various features of an often unfamiliar product - from the friendliness of the staff and the familiarity of the surroundings, to the quality of care and the terms and conditions in the contract. Chart 4 highlights the wide range of factors families consider when making a decision.

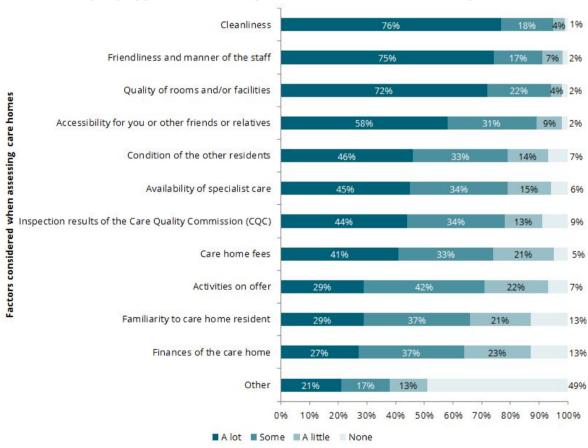


Chart 4: People juggle a wide range of factors when selecting a care home

Source: Citizens Advice analysis of ComRes data¹⁵

Juggling all these different features of the market can lead to a sense of bewilderment. As one Citizens Advice client described, "[you're] overwhelmed

¹⁵ Question: 'Please indicate how much consideration you gave to the following factors when you were assessing different care homes'. Base: All respondents (483).

with variables, really. You just had so much to consider." The sheer number of features that people are required to assess can lead to choice overload, impeding instead of enabling a good decision. 16

"There's a lot to take in. It is a very complicated package. You are looking at judging menus and stairs... It's a very complicated thing to buy... And a lot of responsibility: the effects of a good or a bad home could be really far reaching. Also, there is not enough time to get other people to go along with you to share the judging."

Furthermore, many of these features can be hard to assess which makes it difficult to compare different care homes across the market. Current processes can exacerbate this confusion. Nearly half (49%) of survey respondents said they found the process distressing and 45% reported that they found the process frustrating.

Figure 1: Older people and the families are arranging a care home place in a very short time period and many people find the process distressing



Furthermore, 37% said it was complicated to access the information they needed to make their decision. Only 7% of respondents were provided with information about care home fees, for example through marketing materials or the website, prior to making direct contact. Few other markets have such opaque pricing.

"It was only when visiting [the care home] I got the firm price. Everything else was a bit wishy-washy."

"If you notice, you go on their website, that [fees] is not on there at all! In fact, I had to go on for one of my friends today and I said 'hmm, that's

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¹⁶ Schwartz, B, The Tyranny of Choice, 2004

interesting'. And you know the reason for that is not everybody pays the same. Even private."

Several interviewees said they used digital comparison tools to look at care homes, but there have been concerns in the past about how these websites are managed and evidence that care home providers have removed poor reviews. There is currently no common standard regarding how information should be presented which makes it harder to draw comparisons.¹⁷

But alongside feeling overloaded by the number of variables to consider, survey respondents also felt underwhelmed by the range of options available. Nearly 4 out of 10 people (39%) said they did not have enough choice. As one interviewee responded when asked whether there was sufficient choice:

"Not really - I know that sounds daft because there's hundreds of homes in and around [Town A] but they mainly cater for the well-heeled independent person who just wants to live in the hotel... so the high-end residential mini hotels but when it comes to nursing care it was a bit hit and miss"

"[Choice is] very, very limited... For the type of care that dementia people suffer, where they need nursing, in this area it is very, very limited"

The poor process for searching and arranging a care home place can in turn have a substantial impact on people's lives. In some cases, interviewees said they quit their job, took early retirement or became ill from the anxiety and stress. At a time of huge distress, families described visiting or making enquiries with as many as 30 different care homes. But many of these care homes never had a chance of fitting the bill. This lack of information limits families' ability to make informed choices and also creates knock-on effects on other parts of the health system. Several interviewees expressed concern that their search for a suitable care home place delayed their family member's discharge from hospital.

Access to support when choosing a care home is patchy

Of course, many families want more than just information when navigating the care home sector. They also want access to advice and advocacy. The 2014 Care Act recognised this important need and introduced a statutory duty for all local authorities to provide information and advice, as well as advocacy support to

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¹⁷ Institute for Government, Making public service markets work, 2016

those with substantial needs. In some cases, interviewees described the positive role local authorities - and social workers in particular - played, supporting them to access the information they needed. One interviewee, for example, spoke positively about the information she was provided with by her local authority, including a list of local authority approved homes and a set of guestions to help guide her enquiries with care homes.

But several interviewees described the struggles they faced when trying to access the right support at key moments of the care journey. One Citizens Advice client remarked on "a lack of internal communication" between social workers, health professionals and others involved in the process of moving into a care home. Another interviewee expressed frustration that, when they asked for advice and guidance about which care home to pick, the social worker replied that they couldn't "possibly show any favouritism". Accessing support when choosing a care home may be especially challenging for self-funders or top-up fee payers. As one Citizens Advice client put it:

"As soon as [the local authority] know that you've got a property, they are not really interested [...] It's a vicious circle really. You're better off having no money sometimes."

Their experiences correlate with insights from recent research. Analysis shows that 70% of local authorities are failing to provide online information in all areas required of them as part of the Care Act. 18 Furthermore, there is evidence that referrals to advocacy under the Care Act are well below what was anticipated. 19

Not having power of attorney can further hold back decisions

A final theme that emerged when examining people's experiences of choosing a care home was the importance of having power of attorney. Families were frequently hindered when making decisions because they lacked this legal power. Family members can find themselves in a potential legal limbo, where their family member has lost capacity, but no one has been assigned it in place. ²⁰ Several interviewees described the impact this can have:

"Because we never had power of attorney, if you phone up the bank... and say I need to know what her current balance is, they say look online. She's 90, she doesn't have online banking and they say unless we actually speak

¹⁸ Independent Age, <u>Information and advice since the Care Act - how are councils performing?</u>, 2016

¹⁹ Community Care, <u>Care Act advocacy referrals 'way below' expected level</u>, 2015

²⁰ The National Centre for Post-Qualifying Social Work and Professional Practice (2016) Next of kin: Understanding legal decisions, Bournemouth University

to her, we can't give you any information... that was just hoops to jump through"

"When he ended up in hospital, I was really powerless... When it came to it we weren't allowed to make any choices at all about his care at all, despite the fact that he was old and frail. It was sad."

These findings correlate with insights from our network of local Citizens Advice. We supported people with 6,577 advice queries about the power of attorney in the past year.

2. Charging practices can be confusing and unexpected

"From being told it was going to be £700 a week, since then it's fluctuated to £1,100 a week so that was kind of like "ooohh". And we tot up - how long will the money from the sale of her property last? But things like inheritance - we just don't care, we just want our grandma to have great care."

Citizens Advice client

The next chapter looks at people's experiences of paying for care. Most people pay something towards their care and just under half (44%) of older people entirely self-fund in England.²¹ 1 in 10 people will spend over £100,000 on care home fees.²² Previous Citizens Advice research highlighted some concerns with how charges are applied. This research offers further insight into some of these issues.

Often costs are not people's primary consideration, but they do play a key role in shaping people's range of choice. Nearly three quarters of people (74%) gave care home fees 'some' or 'lots' of consideration and only 5% gave them no consideration at all. Perhaps unsurprisingly, a number of interviewees commented on the sheer expense of care home fees. But families who were self-funding through limited budgets seemed especially concerned by the prospect of running out of money and being forced to move care homes as a result.

"It was really - how long would he live and how long would his money last? No one could give an estimated time... with cancer [with my mother] they could take an educated guess, with Alzheimer's no one could help. So we didn't know, we had to think how long will this last, and will the poor man be shoved somewhere when his money runs out?"

"The thing about affordability was whether or not he would have to move. So we didn't want him to go somewhere that he could afford while he'd got the money and then have to move. We wanted this to be his last

²¹ LaingBuisson, The Care Market for Older People, 2015

²² Dilnot, A, <u>Fairer Care Funding - The Report of the Commission on Funding of Care and Support</u>, 2011

move. So it was to do with whether they would accept him with less money."

Previous research suggests this concern is valid - 25% of self-funders fall back on state funding.²³ The National Audit Office estimates this costs the state £0.5 billion.²⁴ Just over 1 in 5 respondents (22%) said they made a financial contribution to a friend or relative's self-funded care package and a further 8% said another friend or family member was contributing.

Contract terms can be confusing or unspecified

How easy do people find it to understand their rights and obligations as consumers in the care home market? Previous Citizens Advice research has shown that the importance that people themselves assign to a good or service does not necessarily correlate with the time they spent assessing it.²⁵ The findings of this research appear to confirm this. 1 in 5 people said they did not consider the care home's contract terms when selecting one.

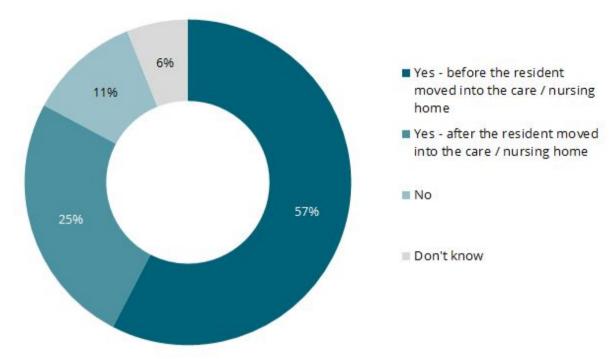
Furthermore, this research highlights that contract terms are not always clear and can be unfair. As Chart 5 shows, a quarter of people (25%) surveyed said they were only given a copy of the care home contract after the resident moved in and 11% said they have not been given one at all. Guidance published by the Office of Fair Trading (and subsequently adopted by the CMA) states that "the consumer should have the chance to read all the terms before agreeing to the contract, and it should be in format suitable for the consumer".

²³ LGiU, <u>Independent Ageing: Council support for self-funders</u>, 2011

²⁴National Audit Office, Oversight of user choice and provider competition in care markets, 2010

²⁵ GfK, Consumers' hierarchy of priorities: A research report for Citizens Advice, 2014

Chart 5: Over a third of people were only given a copy of the care home contract after the resident had moved in, or not at all



Source: Citizens Advice analysis of ComRes data²⁶

Several interviewees highlighted the potential ambiguities that can arise as a result of not having clear contractual rights:

"I never got one with [Care home 1]. With [Care home 2], I insisted on it and I had my Compliance Manager go through it because there were all these blanks on the contract [...] I said 'how long do I get if', like, for example, because I asked, you have so many days to clear the room out following a bereavement. And I said 'you can't expect me to sign this with all these blanks on', I said 'I'd be shot by my Compliance Manager'. 'Right', I said, 'how long do you get?'. Do you know, it's 48 hours? 48 hours. So literally, you're grieving, you've got your funeral to organise".

'What they have done, the social worker has sent me a contract to sign for this care home. Now I've read through it and there is some indication about me being responsible for my mum's finances, not being in charge of the finances but me having to... from it, and I won't sign it because I'm not accepting that. It's something that they have to sort out, not me'

But not all reported a negative experience. One interviewee described the

²⁶ Question: 'Were you given a copy of the contract setting out fees and charges?' Base: All respondents (483).

lengths the care home went to to ensure they fully understood the arrangement:

'[T]hey went through it with us. We had quite an extensive meeting, it must have been a 3 or 4 hour meeting going through all of the different things that they'd do... We took notebooks and everything but you can't always remember everything you put down, can you? Even when you are taking notes. But that's what they did. We did this meeting and we were quite happy then with it. It really then took a weight off your shoulders because we knew then she had somewhere to go.'

Billing practices are not always clear

The research also looked at billing practices. Just over 1 in 10 people (11%) have had concerns about the way in the care home charges and 15% of people say the breakdown of different charges in their care home bills is unclear. As one interviewee explained,

"I've not seen any breakdown, I don't know if it's in the brochure - it doesn't really say"

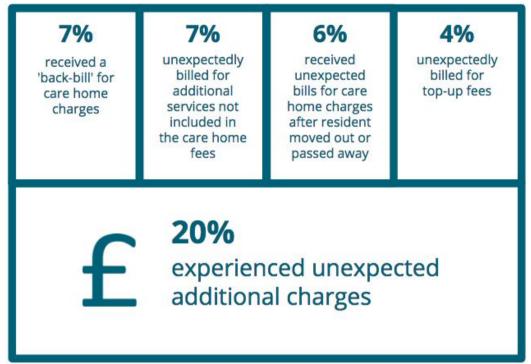
But most interview participants thought their care home bill was clear, pointing out that it is often a straightforward single number. It was only when probed that interviewees noted they had little understanding of the breakdown of different charges. Furthermore, only one of the interviewees involved in this research who had a family member living in a nursing home was aware of the Registered Nursing Care Contribution to the nursing homes.²⁷

Unexpected extra charges

Some people also encountered a range of possible unexpected additional charges. As Figure 2 shows, 1 in 5 (20%) people said they had been unexpectedly charged including backbilling, top up fees, additional charges and charges after the older person had passed away or moved out of the care home.

²⁷ The Registered Nursing Care Contribution is a tax-free, non-means-tested benefit, paid by the NHS to cover nursing or medical care. The contribution increased in June 2016.

Figure 2: 1 in 5 respondents have experienced unexpected additional charges



For each characteristic, only a minority of people (less than 10%) said they had experienced this form of poor practice. But when aggregated we see that 1 in 5 people have experienced some form of unexpected charge, suggesting that unclear charging practices are relatively common across the sector. Our previous research highlighted the range of different additional charges families can face for key services such as carer assistance and chiropody. In some cases, these can be very expensive. Citizens Advice has, for example, provided support to people who have incurred unexpected bills such as a £1,990 management fee and an £1,000 phone bill.²⁸

Short notice and arbitrary care home fee increases

7% of survey respondents told us they had experienced a short notice increase in care home fees.²⁹ We define a short notice fee increase as less than four weeks given that in other consumer markets, such as energy, protection against such increases exists. Previous Citizens Advice research highlighted that care

²⁸ Age UK <u>recently published evidence</u> from their information and adviceline which shows a similar story, warning that such practices are the result of financially squeezed providers cross-subsidising the shortfall in public funding.

²⁹ Our previous research showed that 11% of care homes gave less than 4 weeks notice for a fee increase.

home fees on average increased by £900 in 2014/15, but in some cases increases are much larger.³⁰

Several interviewees explained the sometimes arbitrary nature of the short notice fee increases they experienced and how they responded:

"I queried why it had gone up by so much - and he replied saying it was a change in my mother's care. So I wrote back saying I'd be really interested to know what the change in her care has been because I certainly haven't been notified... nothing had actually changed which might be why they agreed to reduce it slightly".

"So there wasn't enough notice given. I think if you are going to be increasing fees you need to be giving at least a month's notice. I was annoyed about it because I felt it was quite disrespectful and because I felt it was quite a substantial increase. I didn't do anything about it because obviously when you've got someone that's unwell there's always something bigger to think about. You feel like you don't really have an option. You feel like you just have to adhere to any pay increase because the alternative is moving somewhere that you know is going to cost the same... It felt inevitable... You do almost feel like the business knows you are going to pay it. So you feel a bit helpless."

Care home deposits

The research also explored whether people were asked to pay a deposit for a care home place. Over a third of people (37%) have put down a deposit and nearly 1 in 5 people (18%) put down a deposit of £1,000 or more. Given that care home residents do not have comparable rights to tenants in the private rented sector, the requirement for a deposit seems difficult to justify. As licensees, care home residents lack the protections from being evicted that tenants have when falling into arrears. Care home residents can simply have their contract terminated. Furthermore, there is currently no care home deposit protection scheme. And for some, this can prove a problem: 7% of those who put down a deposit said they did not get their deposit back. As a growing number of care home providers are at risk of insolvency, this risk may increase. 32

³⁰ Citizens Advice, <u>Hidden Charges in Care Homes</u>, 2016

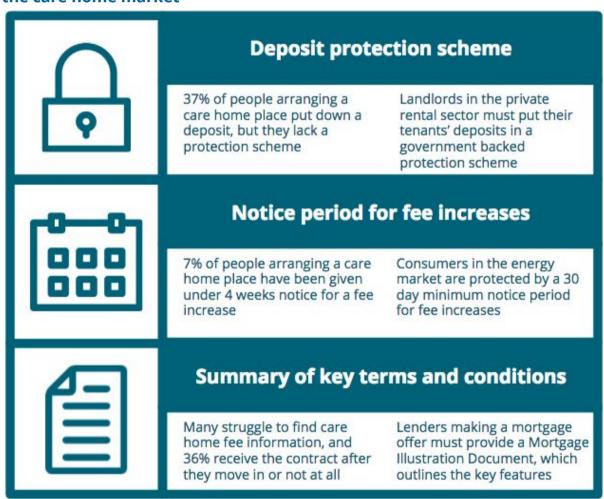
³¹ Age UK, Behind the headlines: stuck in the middle - self-funders in care homes, 2016

³² Previous <u>Citizens Advice research</u> has highlighted how consumers are 'last in line' when a retailer is declared insolvent.

How does the care home market compare to other markets?

As the consumer champion, Citizens Advice is able to look across a wide range of markets and compare how different markets are performing. We can evaluate consumer protections that have worked in one market and help other regulators apply a similar approach. This research highlights how many of the protections that are present in other sectors are lacking in the care home market. In the energy market, companies must notify consumers 30 days before a price increase, for example, and landlords in the private rental sector must put tenants' deposits in a government-backed protection scheme. Package holiday providers similarly have to ensure the security of deposits. This absence of protection is especially striking given the vulnerability of people in the care home market and importance of care as a service.

Figure 3: Consumer protections that exist in other sectors are lacking in the care home market



3. Families lack options, even when they have concerns

"Right at the beginning, when they [residential home] told us that he had to move, that was the hardest of all of them because we thought that he was there forever. We thought that this was the home that he had gone to live in and it was his home"

Citizens Advice client

The previous 2 chapters explored how older people and their families choose and pay for care. But helping to arrange care does not stop when you find a care home and pay the fees. Care home providers also need to hear from older people and their families on an ongoing basis in order to provide a service that responds to their needs.

This chapter examines whether people feel able to speak up when they have concerns.

People have concerns, but moving is not a desirable or viable option

In most consumer markets, a decision to choose and pay for an ongoing service will not be final. When someone chooses to purchase a service from a provider, other providers of the same or similar services continue to seek their attention and attempt to persuade them to switch to them instead. In fact, this competitive pressure should ideally ensure that suppliers of services remain responsive to the needs and concerns of their customers: those who are not will lose out to others in the market.

People involved in arranging and paying for a care home place in the past 3 years are certainly not free of concerns: over a quarter (26%) of survey respondents had them. But the possibility of switching provider is often not a desirable or viable option for older people in care homes. Fewer than 1 in 10 (9%) respondents who have had concerns have moved care home as a result.

Figure 4: Only 1 in 10 of these who have concerns about a care home move as a result



Nearly 1 in 10 (9%) respondents said they have thought about moving care homes but haven't. The most common explanation for not moving is that it would cause too much harm or distress. 68% of survey respondents selected this reason. There is some clinical evidence to support this belief - research suggests that moving care home can present health risks.³³

Those who do move do so for reasons outside their control and often have poor experiences

Nearly a quarter (24%) of respondents have moved care home. But even this comparatively low figure should not be seen as a sign of engagement or agency: over three quarters (76%) of those who did move did so for reasons outside of their control, such as the older person's care needs changing or the care home closing down.³⁴

³³ Holder, J. and Jolley, D. <u>Forced relocation between nursing homes: residents' health outcomes and potential moderators</u>, *Reviews in Clinical Gerontology*. 2012

³⁴ Moving for reasons 'outside of their control' is an aggregation of the following survey responses: moved because the older person's care needs changed (12%), moved because the care home closed down (4%), and care home fee increases meant the older person needed to move (4%). The figure of 76% is found by calculating all those who moved for reasons outside of their control as a proportion of all of those who moved.

Figure 5: Three-quarters of those who have moved care home did so for reasons outside of their control



Some of the experiences of the minority of people who have moved care home seem to support the negative impressions of those who don't. One Citizens Advice client interviewed as part of this research described how, after deciding to move her mother from one care home to another so that she could be closer, the manager of the care home her mum was leaving warned that "most patients usually die within three months of moving" and "if [she] got it wrong, it would be at the cost of [her mum]". The interviewee decided to move her mother anyway as she judged that her mother's quality of life would better. The manager's warning about her mother was fortunately not correct.

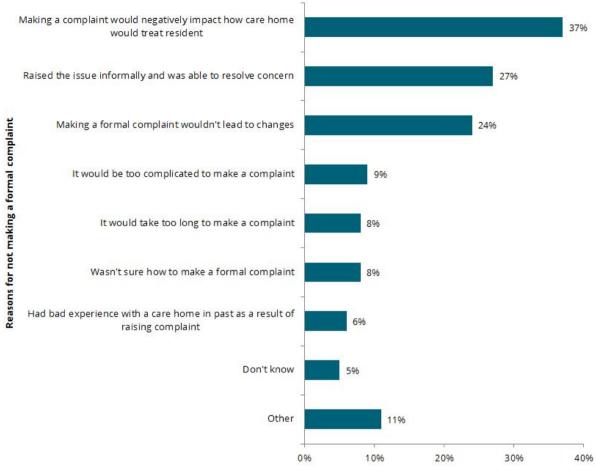
Complaints processes are not helping people to make their voices heard in the care home market

In a context where moving care home is not a viable option, it is important for alternative feedback routes to be suitably robust. Where people are not able to represent their interests to care home providers through the traditional market mechanism, complaints processes should act as a backstop.

But this research shows that complaints processes are not helping people to make their voices heard in the care home market, even when they have concerns. Just over 1 in 5 (22%) respondents who had concerns about a care home made a complaint, either to the home itself or to an industry regulator or ombudsman. When those who did not raise their concern formally were asked why they chose not to, around a quarter (27%) were able to resolve their concern informally. This is to be welcomed. Not all concerns need to result in complaints and it is positive if care home staff are able to satisfactorily address issues directly with residents and their families.

The most common reason for not complaining is far more concerning, however: over a third (37%) worried that complaining formally would result in negative treatment from the care home, as Chart 6 below shows.

Chart 6: Most people don't complain about care homes because they worry about negative treatment from care home



Source: Citizens Advice analysis of ComRes data³⁵

Those who do complain have a poor experience

Previous Citizens Advice research³⁶ suggests that those who don't make a complaint about social care because they anticipate a poor experience have evidence to support their belief. Almost half (45%) of social care complainants are extremely or quite dissatisfied with the outcome of their complaint, and nearly a fifth (18%) gave up altogether.

³⁵ Question: 'Which of the following statements, if any, best explain why you did not take any formal action regarding your concern about the care home?' Base: All respondents who have been concerned about the care home who have not taken formal action (97).

³⁶ Citizens Advice, Consumer experiences of complaints handling, 2016

Figure 6: Complaining about social care leaves almost half of people dissatisfied, and many give up altogether



Furthermore, while over half (52%) of social care complainants want an apology to result from their action, only 15% receive one. Previous Citizens Advice research also found that over a third (36%) of people who complain about social care are extremely dissatisfied with the speed with which their complaint was processed.³⁷

Interviewees offered insight into some of challenges older people and their families can face when complaining about care homes:

"I spoke to the social worker, who went downstairs and told them 'we've got a few problems' and they came up with these very poor excuses as to why, you know, my dad didn't have hot water, and didn't have this, and [the social worker] seemed fairly satisfied by the answers, I was not. But bear in mind, they'd put him in there, and they couldn't make too much of a fuss. But I went to the safeguarding team and I said 'I've got pictures. You want them, you know where I am'"

But some research participants highlighted good practice. One Citizens Advice client interviewed as part of this research reported that her mother's care home organised regular meetings between staff, residents and relatives which provided an opportunity to receive updates about what was going on in the care home and raise concerns.

³⁷ Citizens Advice, Consumer experiences of complaints handling, 2016

Conclusion

Many people who find themselves navigating the care home market never expected to be in a market at all. Few people discuss care plans in advance with their friends and family and an even smaller number put financial plans in place. But as people live longer and develop increasingly complex needs, it is clear that public funding for social care is not keeping pace and the individual will increasingly be held responsible for funding their own care.

As growing numbers of families find themselves navigating this market, it is vital that robust consumer protections are in place. This research suggests that, compared with other consumer markets, a number of important protections are lacking. This insight is all the more stark given the vulnerability of the older people concerned and the importance of care as a service. At each stage, there are opportunities to improve the support and signposting to older people and their families.

Our recommendations are:

1. Local Authorities, health professionals and civil society organisations should encourage people to consider care plans at appropriate moments in their lives.

Most people do not plan in advance for how they will pay for their care. This lack of preparation can contribute to the confusion and pressure people face when they are deciding and making arrangements. There are times in people's lives when they may be particularly receptive to prompts about planning for future care costs, such as during a Pension Wise appointment. There are also more pressing times where people would greatly benefit from an enhanced advice and support offer, for example, ahead of an older relative being discharged from hospital. Local authorities, GPs, hospitals, local Citizens Advice and others should explore how and when these interventions have the most impact.

Alongside planning for care costs, people should also be encouraged to set up a power of attorney.

2. NHS Digital, local authorities and care providers should work together to agree a common set of standards for online care content

Many people begin their journey looking for a care home online, but currently the information available online is highly fragmented and there is no common

standard for online content. NHS Digital, local authorities and care providers should work together to agree a common set of standards for online care content to improve people's online navigation of the care sector and allow more effective comparison tools to develop.

NHS Digital should also continue to develop its care home directory and expand the range of variables it records information on, including the care home fee range and any extra charges. As part of this, it will be crucial to examine ways to incorporate insights and feedback from families of current residents.

NHS Digital will also need to look at ways to extend online improvements so that those with low digital capacity can benefit. An assisted digital option is crucial to ensure the digitally excluded can also navigate the care market.

3. Older people and their families should have access to advocacy throughout the care journey. Local Authorities need to assess whether all those who need support are receiving it.

Access to independent advocacy support should be available throughout the care journey. Local Authorities have an obligation under the Care Act to provide an independent advocate to facilitate the involvement of those who have substantial difficulty being involved in the process, but this is not reaching all those who need help. Local authorities should examine whether there is a need to relax the 'substantial difficulty' condition so that all those who need support can access it.

Advocacy support should be offered to all those with concerns about care. The most common reason people said they did not raise a formal complaint was because they were worried about how the provider would subsequently treat either them or the older person concerned. Access to an independent advocate is crucial to enabling some people to speak up.

4. Care home providers should improve information to help older people and their families better understand their rights and options in the care home market.

Care home providers should include information about care home fee ranges online and in marketing materials to help families understand their options and narrow down their search more easily.

Care home providers should summarise the most important terms and conditions and include this on contracts and on care home webpages.

Providers should also offer a clear breakdown of costs in care home bills. As a minimum, this should include a breakdown of additional charges for services not included in weekly care home fees.

5. The CMA should take enforcement action against care home providers with unfair terms and carry out a wider study to examine how well the care home market is working for older people and their families

The CMA should work with Trading Standards to carry out enforcement action against providers who have unfair terms or are responsible for poor practice.

The CMA should also undertake a market study of the care home sector. As part of this, they should examine whether older people and their families and friends are able to exercise informed choice and speak up when they have concerns. They should also look at whether there are sufficient consumer protections in place.

6. Consumer protections in the care home market should be strengthened.

Unlike in other markets, such as energy, there is no minimum notice period for increases in care homes fees. At the very least, there is a case to extend this to 4 weeks because it is unrealistic to expect older people and their families to make alternative arrangements with less notice. And given that 45% of people surveyed said it took over a month to arrange a care home place, there is a case to explore a longer notice period.

There is currently no deposit protection scheme for care home residents. The research shows that over a third of care homes currently request a deposit. But the motives for this can be unclear and families can find it difficult to monitor whether or not they are entitled to their full deposit back. Just as there are deposit protection schemes in the private rented sector, comparable securities should be introduced for the care home market.

7. The CQC should explore how it can help promote consumer protection within the care home industry.

As part of its role monitoring the quality of care homes, the CQC should explore ways to further scrutinise the information care homes provide, as well as their complaints processes. The CQC should also look at ways to support greater scrutiny of consumer protections in the care home market, for example, by developing guidance on good practice.

Appendix

Data supplied by LaingBuisson on older people in care homes in England was used to inform the qualitative and quantitative sample frame. The samples reflect the proportion of older people in England living in nursing and residential care homes, and the split between those who pay top-up fees and those who self fund.

Qualitative research

Type of care home	
Nursing home	8
Residential care home	7

Funding method	
Self-funded	9
Top-up fees	6

We also collected data on interviewee's gender, age and relationship to the older person.

Gender	
Female	12
Male	3

Relationship to older person	
Mother or father	11
Member of extended family (e.g. aunt, uncle, cousin)	1
Grandparent	2
Other	1

Age breakdown	
18 - 34 years old	1
35 - 54 years old	7
55+	7

Quantitative research

ComRes ran an online survey of 510 people who have helped an older person arrange and pay for a care home place. Data were weighted to be representative of the older person's method of paying for care as well as the type of home they live in.

Type of care home	
Nursing home	52%
Residential care home	48%

Funding method	
Self-funded	66%
Top-up fees	34%

We also recorded data about the respondent's gender, the region of the older person's care home, their age and relationship to the older person.

Regional breakdown	
North West	18%
North East	7%
Yorkshire and Humber	13%
West Midlands	11%
East Midlands	8%
East of England	6%
South West	7%

South East	21%
London	9%

Age breakdown	
18 - 34 years old	9%
35 - 54 years old	33%
55+	58%

Relationship to older person	
Mother or father	47%
Member of extended family (e.g. aunt, uncle, cousin)	23%
Grandparent	11%
Friend	10%
Husband, wife or partner	2%
Other	6%

Power of attorney	
Respondent has power of attorney	48%
Respondent's family member or friend has power of attorney	28%
No one has power of attorney	21%
Don't know	4%

We help people find a way forward

Citizens Advice provides free, confidential and independent advice to help people overcome their problems.

We advocate for our clients and consumers on the issues that matter to them.

We value diversity, champion equality and challenge discrimination.

We're here for everyone.



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