

# **Behind the Headlines: the battle to get care at home**

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## Introduction

Over a third of the calls to Age UK's information and advice line are from older people and families asking questions about social care at home. The stories they relate are deeply revealing; for many older people and their families it seems, getting access to decent quality, reliable home care, and maintaining it, is a real battle.

The cases highlighted in this report are just a snapshot of the queries we received in the 6 months between September 2017 and March 2018 (identifying details have been changed to protect the anonymity of the callers). The same issues come up time and again, from people calling from all parts of the country:

- Long waits to get an assessment
- Services that are disjointed or simply unresponsive
- Social services refusing to get involved
- Fundamental lack of capacity in the system
- Poor quality services and support
- Support and services being cut back
- Help for families providing care being withdrawn

## What is home care?

Home care, or 'domiciliary care' as it's sometimes called, is the term for formal social care services provided to older and disabled people in their own homes, usually by care workers employed by a home care agency. Paid carers may visit anywhere from once a day up to 7 or 8 times in exceptional cases, in order to help people with vital everyday activities such as getting out of bed, washing and dressing, eating and drinking, using the toilet and managing medication. Home care of this kind is an essential public service that helps older people to stay living independently at home for longer.

Nearly all home care (97.5 per cent) is provided by independent organisations, with councils commissioning most of it – approximately 70 per cent of care provided in total.<sup>1</sup> The remainder is organised and paid for privately.

## Who gets home care?

According to new analysis from Age UK, more than 1 in 10 (12 per cent) of people aged over 65 in the UK receive some form of formal help or care in their homes – including domiciliary care, help with household tasks and reablement – from local authority, NHS, voluntary or private sources. This increases to 1 in 5 (20 per cent) people aged 85 and over.<sup>2</sup>

Anyone can organise and pay for care privately. However access to council funded home care is fiercely controlled.

Older people in need of care have to clear the tough twin hurdles of a strict eligibility criteria and a stringent means test.

Firstly, they must show they fulfil the assessment criteria that councils use to decide whether someone has 'eligible needs'. Such is the pressure on the system that these days care is only likely to be available to people who experience very significant difficulties in managing essential day to day tasks.

Secondly, they must demonstrate that their savings and income are sufficiently low to qualify for council funding under the means test. However a low income does not mean

the council will meet the full cost of a person's care, individuals are still expected to contribute what they can towards it.

Home care charging policies can vary from council to council, but the guidance states that people can be charged from their income so long as they aren't left with less than £203.75 a week<sup>1</sup> as a single person or £311 as a couple to live on. Anyone with savings over £23,250 would probably be expected to pay the full cost, regardless of their income.

### **How do you access home care?**

In theory anyone who needs care and support at home should be offered an assessment by their local council. Individuals, or their families, can approach their council directly or they might be referred by other services such as their GP or hospital.

The council should then organise a timely assessment with a suitable professional, a social worker or occupational therapist for example, to see whether their needs and means qualify them for support. People who meet the requirements should receive services and/or funding and support to organise their own care if the latter is what they would prefer. People who fall outside of the eligibility criteria should still be sign posted towards information and advice about how to access help on their own.

### **Home care is in crisis**

Unfortunately, the home care system is in crisis and falling short on just about every measure. And you don't need to look far for the cause.

Since 2009/10 local councils have seen a 26 per cent reduction in their real terms budget.<sup>3</sup> This has led to a 6 per cent real terms cut in direct council spending on adult social care and severely squeezed the operating capacity of social services departments. At the same time, the number of people aged over 65 has grown by 7 per cent and the number aged 85 and over by 6 per cent.<sup>4</sup>

As a result local councils have been left with the impossible task of trying to make shrinking budgets and overloaded social work teams stretch further and further to meet rapidly growing demand – not only from older people as illustrated here but from disabled adults too.

Between 2009/10 and 2016/17, the average spend per adult on social care fell 13 per cent, from £439 to £379.<sup>5</sup> New analysis shows that the amount of home care provided by councils has fallen by 3 million hours since 2015 alone.<sup>6</sup> We also know that between 2009/10 and 2016/17 more than 400,000 fewer older people received social care as the eligibility criteria tightened in response to insufficient resources.<sup>7</sup>

Furthermore, as we see as we see throughout this report, council social services departments are under significant stress and struggling to keep up with their growing caseloads. Since 2012/13 the number of social workers has decreased by nearly 10 per cent. Over the same period turnover increased by around 50 per cent, and in 2016/17 1 in 9 roles were vacant.<sup>8</sup>

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<sup>1</sup> Fairer Charging Guidance 2013 states that charges for care should not reduce someone's net income below the level of pension credit guarantee plus 25 per cent. This is currently £203.75 a week for a single person or £311 a week for a couple.

The impact of council funding cuts has spread throughout the care system.

It is widely acknowledged that the home care market is in a precarious state, and this is having a significant impact on older people who need help at home.

The Care Quality Commission's most recent State of Care report highlights significant 'churn' in the home care sector with around 500 agency registrations and 400 de-registrations each quarter.<sup>9</sup> This suggests there is rapid turnover amongst owners and operators of home care agencies. At the same time we know that there is also a growing workforce crisis. In 2016/17 staff turnover in the home care sector was running at 32 per cent and the vacancy rate was 10 per cent.<sup>10</sup>

The most obvious and distressing consequence of this for older people is the lack of continuity among carers. Age UK regularly hears from older people and families who are sent new care workers on such a regular basis that they never really know who is going to show up on any given day.<sup>11</sup>

Likewise, last year's Association of Adult Directors of Social Services Annual Budget Survey report found 39 per cent of councils had had at least one home care provider cease trading in their area and 37 per cent of councils had at least one home care contract 'handed back' – meaning the organisation had pulled out of providing services to council clients.<sup>12</sup>

The crisis in care also impacts on the quality of services. 1 in 5 home care providers were rated as either inadequate or requiring improvement by the Care Quality Commission in 2017<sup>13</sup>. At the same time public satisfaction with services has declined in recent years, 41 per cent of people reported being dissatisfied with care services in 2017, a 6 per cent increase since 2016 alone.<sup>14</sup> Key concerns include difficulties accessing service, concerns about quality and lack of continuity of care – mirroring many of the issues we raise in this report.

The shocking reality is vulnerable older people at the sharp end of an underfunded and increasing dysfunctional system: one that is fundamentally undermining their health, dignity and capacity to live independently. Another consequence is the added pressures on families and friends, as is seen later in this report.

## **1. Long waiting times for an assessment**

An assessment is the vital first step in accessing home care. Until an assessment has taken place and a care plan has been agreed no local council help will generally be made available. However, we regularly hear from older people and families in pretty dire situations who have been told that they face a long wait before anyone will be able to assess them, even when their health and wellbeing are deteriorating rapidly.

- *Alice's father in law, Andrew, has dementia and usually lives alone. He recently had a flood and his house is currently uninhabitable. He has gone to stay with Alice's brother temporarily but he and his wife work so Andrew is home alone a lot of the time. Alice has called social services and has been told a referral has been made and that a social worker will get in touch – within 6 weeks.*
- *John has been registered disabled for over 10 years. His health problems have got worse over the last year. He is 79 and cannot get washed anymore without help. He is in pain and finding life difficult. He also doesn't have anyone to help locally. John*

*phoned social services and completed a form over the phone but has heard nothing back. At the time he rang, last autumn, his council said it could take until next year for anyone from social services to come round.*

- *Vikram's wife Myrom has MS and he is her main carer. A couple of months ago their GP made a referral for an occupational therapist assessment as Vikram feels he and Myrom would benefit from aids and adaptations at home. Vikram has recently chased this up but has been told that their case is one in 20 and there could be a further 6 week wait. Vikram feels that Myrom's condition has deteriorated to the point where help is needed more urgently.*
- *David has dementia and needs help with washing and dressing as well as eating and drinking. He currently goes to an activity centre but his wife is finding it hard to cope and thinks he needs more support at home as well. David's wife has asked social services for a needs assessment but they have said this won't happen for several months.*

## **2. Disjointed or simply unresponsive services**

At times people simply struggle to get a response from their council at all. In some cases people have had an assessment (or completed telephone or online assessments) and then heard nothing back. In others, people simply can't get hold of anyone to talk to. In the meantime older people and families are forced to cope alone without any idea of when the process to start getting help may even begin.

Older people and their families more generally report that the process for accessing help is opaque. It is often unclear who you should call, there are rarely any direct numbers and information is poorly signposted.

- *Brian had an assessment by social services three months ago but hasn't heard anything from them since then. He is having to stay downstairs, sleeping on the sofa, because he can't get up and down stairs without help. He hasn't been able to get any support from his GP and now he feels suicidal.*
- *Nadia has been trying to get social services to come and assess her father. Someone was due to come several weeks ago but they 'forgot'. Someone is finally coming today and Nadia thinks that is for an assessment. However Nadia's father has deteriorated, he's now immobile and he's not eating or drinking properly. Nadia has injured her shoulders and knees as a result of providing care and is seeing a physio. She and her brother have both had to take time off work and Nadia's daughter has been providing care as well. Nadia she feels she can't continue anymore and is going to have a breakdown.*
- *Dan's mother has gone into hospital leaving his father, Bill, at home. Bill can't be on his own and has been staying with various family members, but this is no longer sustainable. Dan contacted social services about a week ago but has had no response.*
- *Clare's brother, James, is disabled and uses a wheelchair. He is mainly looked after by their other sister Sarah. Sarah is in hospital at the moment and Clare has been stepping in. However Sarah has been in hospital much longer than expected and Clare is struggling to cope with caring for her brother alone alongside looking after her grandchildren. Clare has been trying to get in touch with social services for*

*some help. She has been calling for 2 weeks and keeps being promised a call back but this never happens. She has also approached GP and asked them to help but none was forthcoming.*

### **3. Social services refusing to get involved**

The Care Act 2014 gives the right to everyone to have an assessment if it appears likely that they have a need for care and support. Individuals or their families can approach their council directly or they might be referred by other services such as their GP.

Where someone else approaches the council on an individual's behalf, the person in question has the right to refuse an assessment, in which case the council is not required to carry one out. However there are some important provisos. If the council identifies that someone lacks mental capacity and that an assessment is in their best interests they are required to go ahead regardless. The same applies when the council believes someone is at risk or experiencing abuse or neglect – including self-neglect. In cases such as these the council should undertake an assessment in so far as is possible and keep in contact in case the person changes their mind.

It is therefore very concerning to hear of cases of social services refusing to get involved on the basis that someone 'doesn't want help', despite the fact that they are obviously at risk.

- *Joel's aunt, Rita, lives alone and has little in the way of savings. Rita has multiple health problems and is struggling with her memory. She recently spent several hours in supermarket foyer because she couldn't remember where she lived. Rita doesn't have heating or running water indoors and lives in filthy conditions. Sometimes she doesn't wash or dress, she rarely sees anyone and Joel doesn't think she eats regularly. Joel has tried to engage social services but they just say Rita doesn't want help.*
- *Lesley's mother, Margaret, has been living at home with Lesley's brother. However her brother is now in residential treatment for substance misuse and it is unclear if or when he will return home. Margaret has a serious undiagnosed mental health condition but she won't go for tests. Lesley has contacted social services who say they cannot do anything until her doctors say she lacks mental capacity. However, at present the family are going in every evening and finding her sitting in soiled clothes and not having eaten. She often calls multiple times during the day and at night and gets very confused and is clearly distressed.*
- *Louisa's father in law, Phil, lives in sheltered housing. In the last few months Phil has become more confused and forgetful – including setting fire to things on the hob and developing issues with personal hygiene. The housing warden has arranged for the hob to be disconnected and for microwave meals to be delivered instead. Louisa has contacted social services but they won't come out without Phil's consent. However, Louisa is worried he might get aggressive if she suggests it.*

### **4. Basic lack of capacity in the system**

Even after someone has successfully navigated the assessment process, met the council's strict eligibility criteria and demonstrated they fall below the thresholds for the means test, there is still no guarantee they will actually receive the care they need.

Instability and lack of capacity in local care markets means councils can't always find a suitable organisation able to provide the care set out in their care plan.

- *Sally's father in law, Fred, was discharged from hospital after a fall that resulted in a broken leg. He is also incontinent and has cancer. Although social services assessed Fred's needs and agreed he was eligible for a means tested care package, they say they don't have the capacity to fulfil it at the moment. Social services cannot arrange early or late enough visits, meaning that Fred will be left too long without his medication. Fred's sister has also been providing additional care but has had to return home, meaning Sally is now coping alone.*
- *Chris's mother, Vera, lives with them and after a recent stay in hospital she received a social care needs assessment which concluded that she needed care visits in the morning and evening. However, social services have informed Chris that they are unable to locate a care agency to provide them at the moment as they are all at full capacity. Chris feels the support is required urgently.*
- *Michelle's uncle, Bob, was assessed as needing three care visits a day a few months ago, but the local authority said the care provider they contract with could only provide one a day due to lack of capacity. Bob's family have been carrying out the other two visits. However, the care provider pulled out of the remaining visit last night and the local authority has said the only way forward is for Bob to go into a care home as an emergency measure. Michelle is unhappy about this as they have had bad experiences in the past when Bob went to a care home for respite.*
- *Sheelagh's brother, Jake, is in hospital at the moment. He gets very confused, wanders and has got hurt in the past as a result. He has also had a stroke. Social workers have told Sheelagh they can't get carers who can meet his needs.*
- *Sarah's father in law, Michael, has a heart condition and dementia. He is also incontinent and uses a wheelchair. He was offered a place in a care home on a temporary basis as the local authority couldn't implement his care plan due to lack of available home care locally. The placement was meant to be for 6 weeks while care was sorted out, however it's been going on for more than 3 months. In that time Michael's condition has deteriorated and social services are now saying that he needs a care home permanently. However, Sarah feels that he would be better off at home and that being in a care home has exacerbated his conditions.*

## **5. Poor quality services and support**

When older people are able to access care too often they experience problems with either the quality or reliability of services. Over and over again, older people and their families have told us that the system does not allow professional carers to give the care they might want to give. They are not trained to a consistent standard, they are in such a rush that they do not stay for the full length of their planned visit, they 'box tick' and there is no continuity, with many seeing multiple different carers each week. As a result, there is no time to build a relationship or establish good communication.<sup>15</sup>

- *Libby's mother, Donna, is severely disabled and has been assessed by social services as needing multiple care visits a day. However, Libby is concerned carers have only actually been coming a couple of times a day, which is not enough. Libby*

*complained to their social worker over a week ago and apparently the matter has been escalated to a manager but Libby still hasn't heard anything back.*

- *James is severely disabled and bed bound, and he has recently been in hospital following an infection. He should have four care visits a day but has called in distress as no one has turned up yet today. He has repeatedly tried to phone social services this morning but the line is constantly engaged. He doesn't know who else to ring.*
- *Richard gets local authority funded care at home but his daughter, Ruth, is concerned they carers do not provide the quality of care he needs. Richard needs a catheter bag changed regularly but the carers don't know how to do it. Ruth has called social service and held a meeting with the care agency, during which they said their staff are not trained to work with catheter bags. Ruth wants to complain but neither the care agency nor the local authority will take responsibility for the problem. Ruth has been told she can't contact CQC as an individual and she doesn't know where else she can turn.*

## **6. Support and services being cut back**

As funding for social care has been cut, so have the services on offer to older people. As we set out above, we know that local councils are commissioning less home care than they did in the past and spending less per head. As a result older people are receiving smaller care packages than in the past and some are actually having their support cut, even though their needs have stayed the same or increased.

- *Lisa's father in law, Nigel, has multiple health problems including COPD and severe depression. He has had several falls and has been hospitalised twice this year. Nigel also has liver damage as a result of non-adherence to medication. He had been assessed by social services and was getting 4 care visits a day. However, the local authority has recently reviewed his care package and it has been reduced to just 3 short visits a day to give him his medication. Social services have said Nigel no longer needs support for other day to day activities as he goes to the local shop, on trips and to the pub. However, Lisa says he has not been to the pub, he can only walk a very short distance and the trip was organised specifically for people with disabilities. Lisa says Nigel can't cook for himself and is still at high risk of a fall if he goes out alone.*
- *Stephen's mother, Deborah, has a number of health conditions including severe dementia and receives care at home as well as support from Stephen and his wife, Pam. Deborah has monitoring equipment provided by the local authority which helps Stephen and Pam to check she is ok at home and keep track if she leaves the house. The local authority has now said they can't fund this anymore due to funding cuts and Deborah will have to pay for it herself. However, Deborah is already contributing towards the cost of her care and that takes up most of her income.*

## **7. Help for families providing care being withdrawn**

The overwhelming majority of care is actually provided on an unpaid basis by families and friends. Over 2.7 million older people receive informal support – almost double the number who receive formal services.<sup>16</sup> In addition, even when someone is receiving

formal home care, families are still usually highly involved and carry a lot of responsibility, for example, for co-ordinating care and .

The Care Act sets out the right for family carers to have an assessment of the support that they need to maintain their own health and wellbeing and to be able to perform their caring role. However, increasingly support is being withdrawn from families providing this essential care.

- *David is a carer for his daughter, Gina. David had had a carers' assessment and been provided with support for him to go to the gym, join a local club and have weekend breaks. However, recently the local authority did a new assessment, after which they withdrew all support, simply stating that David no longer meets their eligibility criteria. David has been given no reasons explaining why he no longer meets the criteria. His social worker told him to take it up with the manager.*
- *Jane's mother in law, Grace, lives with her and her husband Ian. Grace is disabled and needs a lot of support. Providing such high levels of care is very stressful for the family and Jane has become very distressed. Jane asked social services for some respite care so that they can have a break and take a family holiday – previously she had been promised that respite care would be available, free of charge. However, since then their social worker has tried to persuade Jane to give up the family holiday and ensure either Ian or one of their children stays at home to care for Grace. Furthermore, the social worker has said respite will not be free of charge and in any event will need to be approved by a panel.*

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<sup>1</sup> LaingBuisson Homecare and Supported Living Report, April 2018

<sup>2</sup> Age UK calculation based on Understanding Society Survey Wave 7 (2015/16) data and ONS mid-year 2016 estimates. In 2015/16 the Understanding Society survey asked a sample of people about the help they receive at home. Those aged 65 and older who reported that they had difficulties with ADLs (activities of daily living such as managing the stairs, washing or dressing) or IADLs (instrumental activities of daily living such as shopping for food, doing routine housework or paying bills) were asked who had provided support to them with these activities in the past month. To calculate how many people in the UK receive formal care in the home we included those who reported receiving help from a home care worker, home help or personal assistant, member of the reablement, or intermediate care staff team, occupational therapist, physiotherapist, or nurse, voluntary helper, warden or sheltered housing manager or cleaner.

<sup>3</sup> A time of revolution: British local government finance in the 2010s, Institute for Fiscal Studies (October 2016)

<sup>4</sup> Estimates based on ONS midyear population estimates from 2010 and 2016

<sup>5</sup> Lord Darzi Review of Health and Social Care Interim Report, April 2018

<sup>6</sup> LaingBuisson Homecare and Supported Living Report, April 2018.

<sup>7</sup> The Autumn Statement, Nuffield Trust, King's Fund & Health Foundation (November 2017)

<sup>8</sup> Skills for Care, National Minimum Data Set for Social Care, 2017

<sup>9</sup> The state of health care and adult social care in England 2016/17, Care Quality Commission (October 2017)

<sup>10</sup> Skills for Care, National Minimum Data Set for Social Care, 2017

<sup>11</sup> Why call it care when nobody cares?, Age UK (April 2018)

<sup>12</sup> Annual Budget Survey Report, Association of Directors of Adult Social Services (2017)

<sup>13</sup> [http://www.cqc.org.uk/sites/default/files/20171123\\_stateofcare1617\\_report.pdf](http://www.cqc.org.uk/sites/default/files/20171123_stateofcare1617_report.pdf)

<sup>14</sup> <https://www.kingsfund.org.uk/publications/public-satisfaction-nhs-2017>

<sup>15</sup> Why call it care when nobody cares?, Age UK (April 2018)

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<sup>16</sup> Age UK calculation based on Understanding Society Survey Wave 7 (2015/16) data and ONS mid-year 2016 estimates.