

Why it's important to review the care of people with dementia

What the data and people's experiences tell us about social care reviews, reassessments and their outcomes for people with dementia

July 2019



Imelda Redmond CBE, Healthwatch England

Social care has been in a fragile state for some time.

Last year, more than 9,000 people shared their experiences of social care with Healthwatch, including the countless barriers to accessing and finding support.

For people with dementia, these barriers can be even greater. Only 8% of the feedback we hear about dementia care is positive. What people tell us is that services are not equipped to meet their needs and staff are not trained to deliver the care that they need.

The NHS and social care can be confusing to navigate, and the divide between the two can impact people with dementia more than most. For example, people with long-term health conditions, such as cancer, can be eligible for NHS Continuing Healthcare funding to meet their needs at home. However, those with dementia are subject to the rigorous needs and means testing of the social care system if they require ongoing support and frequently have to meet the cost of their personal and social care.

Dementia can have a devastating impact, not just on the person with the diagnosis, but also on families and carers. It is a condition that gets worse over time. As such, it is vital that support is set out in care plans and is responsive to people's changing needs.

To be responsive, care plans should be reviewed regularly, and the Care Act 2014 sets out how councils should do this. As a minimum, plans should be reviewed annually. But our research highlights that this is not happening - in fact only 45% of people with dementia received a planned review last year.

Whilst councils and services are undoubtedly under pressure, people with dementia and their families cannot be left to manage alone without the right support.

Jeremy Hughes CBE, Alzheimer's Society

Decades of underfunding of the social care system, exacerbated by cuts to budgets of local authorities tasked with providing state care, have negatively impacted the quality and volume of care that people with dementia receive. Far too often Alzheimer's Society hears of the devastating consequences of inadequate care - our Fix Dementia Care campaign revealed people with dementia were left in soiled sheets or left for days without food.

With an estimated 70% of care home residents and 60% of homecare recipients living with some form of dementia, there are hundreds of thousands who rely on the principles enshrined in the Care Act to deliver the support they need. Yet evidence gathered for this document highlights this is simply not happening, and as a result people with dementia - a progressive condition - are being left with unmet and unrecognised care needs.

This report further demonstrates the system is unfair, unsustainable and needs long-term overhaul, to ensure that people with dementia receive affordable and high-quality care when and how they need it. It shows decision makers cannot continue to put off difficult choices. People with dementia frequently face catastrophic care costs of up to half a million pounds. More than a fifth of services offering dementia care are failing standards set by the regulator.

There is no excuse for allowing some of the most vulnerable in society to slip through the cracks in the care system, and to expect them to be the ones to pick up the pieces. This work is vital in projecting the voices of people affected by dementia and their experiences, and those in power must listen and deliver the action that is so desperately needed.

Why dementia matters

Dementia is a degenerative condition, which affects how people understand and engage with the world. There are many different types of dementia, but what they have in common is that they worsen over time and there is no known cure.

We've heard from people whose lives have changed drastically over time because of dementia. Not only does dementia make it harder for people to stay independent, it can also affect their relationships.

One of the most common things we hear about is the impact dementia has on families and friends, and how it can be a constant struggle to get the right support from social care services. Many families face issues finding a suitable care home, providing financial assistance, as well as getting information about what they're entitled to, such as care plan reviews.

People with dementia who use social care services should expect high quality support from staff with specialist training. They have the legal right to have this regularly reviewed to ensure that this support continues to meet their needs throughout their life.

However, evidence suggests that access to care is variable. Some people receive poor quality, unreliable care, and others go without any formal support at all. Having good quality support in place can be transformative for those living with dementia and their families - particularly as the condition can deteriorate.

Over 850,000 people live with dementia in the UK and this number is set to increase considerably over the coming years.¹ The Alzheimer's Society estimates that two million of us will live with the condition by 2051,² so it's critical that councils and social care services listen to what people need, and as a minimum provide support in line with the Care Act.³

What we did

To find out whether people are getting the right dementia support as their condition deteriorates, we reviewed:

- What people told us about their care
- Local council data about whether people's needs are being assessed and reviewed

The Care Act states that everyone who uses social care must have at least one review each year, but this isn't always the case. This briefing summarises our findings and offers recommendations to help address this issue.

¹ The Alzheimer's Society, Key Facts and Statistics <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media>

² The Alzheimer's Society, Key Facts and Statistics <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media>

³ Department of Health and Social Care, Care and Support Statutory Guidance <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

Key findings

Fewer than half of all people with dementia who use social care are getting the regular care reviews they are entitled to. Councils must ensure that these reviews are happening in a timely fashion, to meet the requirements of the Care Act 2014 and to make all care plans responsive to people's changing needs.

- Dementia is a condition that can deteriorate quickly. Under the Care Act 2014, people who use long-term social care services should receive at least one review of their care plan each year to ensure they have the right support in place.
- However, our research found that:
 - Only half of those using social care services received a planned review last year and this was even lower for people with dementia (45%).
 - One quarter of people with dementia had an unplanned review last year, due to an emergency or sudden change in circumstances.
 - 65% of people with dementia who had a review were referred for a full reassessment. However, half of these reassessments led to no change in the level of care and support. This is concerning and may suggest that professionals are either inconsistently interpreting the eligibility criteria, or incorrectly referring people for a reassessment.

The Care Act: What are people's rights?

The Care Act sets out what support people are entitled to from their local council and what they should expect from social care services.

Some of the rights we all have under the Care Act include:

- Anyone with appearance of needs, regardless of their financial situation, is entitled to a full assessment for social care from their council.
- The council must maintain a free information and advice service to help people understand the range of care options available in their area, and to plan for the type of support they want.
- People who use long-term social care services should have their care plan reviewed once per year as a minimum, although it's good practice for care plans to be kept under ongoing review so that care is as responsive as possible.
- Local authorities should also review a person's situation in the event of an emergency or sudden change in circumstances.
- If a review finds that someone's needs have deteriorated or improved significantly, it should lead to a full reassessment of need as they may have become eligible for much greater levels of support. For example, a person using a home care service may require more intensive nursing support that they were not previously eligible for.¹

People's experiences of assessments and care reviews

Having the right support in place is essential for people with dementia and their families. Over the past three years, over 700 people shared with us their experiences of accessing and using dementia services. What we hear is that having a clear understanding of what support is available and how to access it is critical. When this is missing, it can be detrimental.

On average, people wait over two months between requesting dementia support from their council and that support being put in place.⁴ However, as it can be difficult to find support and access it correctly, as by the time people ask for care, they have often reached crisis point.

Many people who were able to access a review said they were unhappy with the process and outcome of their social care assessment. Often the reason behind a decision and eligibility threshold were poorly communicated, or they felt that the care package agreed was not enough to meet their needs.

Patricia and Simon's story

***Patricia spoke to Healthwatch Kent about the challenges her uncle, *Simon, faced trying to get support from the council.**

Simon and his family were self-funding his care in a local care home, which was supporting him well with his dementia. However, in 2017 their funds began to run low and they were approaching the £23,250 threshold and which point their local council would have to step in and help pay for Simon's care.

They approached Kent County Council who completed a full needs assessment. The council assured them that their case was being processed and they would pay towards the cost of Simon's care, as well as providing backdated payments for the time they had waited. But Simon and his family were left with a great deal of uncertainty and confusion about the process.

Within seven months of the assessment, Simon's needs had deteriorated significantly. He had been in and out of hospital several times having fallen, requiring operations on his hip. At this stage he could no longer walk and had to be hoisted for all personal care. The assessment and his care plan were not reviewed following this significant change.

As Simon required complex medical support, the care home said they would not be able to support him any further, because their staff were not qualified or resourced.

In response, the council provided Simon's family with a list of nursing homes in the area that could meet his complex needs. But he would now have to pay an additional £148 per week on top of what the council would pay towards his care.

Patricia wrote to the council trying to resolve the issues and find a care provider that could both meet Simon's needs and was affordable. Communication from the council was poor and she often received contradictory advice.

During this time Simon was receiving care and support that was not appropriate or enough to meet his needs and help him live well with dementia. He had been happy in the care home, but as his needs changed and his condition deteriorated, the council was unable to arrange the high-quality specialist care he needed.

⁴ Healthwatch England, What do people want from social care? <https://www.healthwatch.co.uk/report/2018-09-18/what-do-people-want-social-care>

Clear information and advice

Our evidence shows that finding information and advice about dementia care and how you pay for it can be confusing. Without guidance, people struggle to understand what social care support is available, what their rights are, and what they can expect from services.

Whilst this is common across the social care sector, as dementia affects memory and cognition, there are additional barriers to getting the right information. Many people are also unaware that they may be eligible to access further support through a review, if there is a change in their circumstances over time.

“I have not been given any information or support. I always have to fight for information. I have never been offered dementia training, I would have liked to receive it to understand more about my father’s behaviour.”

Carer speaking to Healthwatch Middlesbrough

How many people get care plan reviews?

From our insight, we know that not everyone with dementia is offered a review every year as outlined under the Care Act. Care plans are often not responsive to people’s needs and do not adapt to changes in their condition or circumstances. What this means is that people are missing out on critical support, with families often having to take on additional responsibility and pressure.

To understand this issue, we asked every council which commissions or provides social care in England:

- How many people with dementia in the area use council funded social care services;
- How many of them received an annual review of their care needs, which they are entitled to; and
- What the outcome of the review was.

Our findings

97 councils (64%) responded to our request for information and provided the data we asked for.⁵ Across those areas, 91,100 people with dementia used long-term social care services in 2017/18.

Only 45% of people with dementia who use social care services received a planned review last year.

The table below compares the number of people with dementia, who received planned or unplanned reviews, compared with all people who use long-term care services.

	Planned review		Unplanned review		Both	
	Dementia	All support reasons	Dementia	All support reasons	Dementia	All support reasons
2016/17	44%	50%	26%	17%	15%	8%
2017/18	45%	51%	25%	18%	14%	9%

It is concerning that only half of those using social care services received a planned review in 2017/18 and this was even lower for people with dementia (45%).

In an emergency or sudden change in circumstances, people using social care should receive an urgent review. People with dementia are more likely to receive an unplanned or urgent review. One in four people with dementia received this type of review last year, compared to one in five of all social care users.

Councils are clearly struggling to provide timely care reviews to people with dementia, this is likely to have an impact on whether support services are suitable and how responsive they will be to people's changing needs.

The proportion of people with dementia who receive an unplanned or urgent review (25%) is significantly greater than the figure for all support reasons. This could suggest that councils are prioritising unplanned reviews for people with dementia, or that this group is more likely to experience a sudden change in their condition.

However, one third of people with dementia who use long-term care services did not receive any review, either planned or unplanned.

⁵ The majority of councils who could not provide the information we asked for did not hold information about people with dementia or held the information in a way they could not report because it was recorded consistently.

Reassessments and outcomes

If a review finds that someone's support needs have changed significantly, it should trigger a full reassessment.

We asked councils what proportion of the reviews they completed last year resulted in a full reassessment and what the outcome of that reassessment was.

In 2017/18, 65% of all reviews for people with dementia resulted in a full reassessment. This would suggest that a significant deterioration or improvement in the person's condition had been identified. Given that dementia is a degenerative condition, it is reasonable to assume that most reassessments would be a result of a person's support needs increasing.

Where people's support needs have decreased, this could be due to a carer taking on greater responsibilities.

What is a personal budget?

Everyone who receives council funded social care should have a personal budget. This is funding that the council decides is needed to meet a person's needs. That person can choose whether to take the budget as a cash payment, known as a direct payment, or to have the council spend the budget for them.

In theory, if someone's needs increase, it should also result in an increased budget to fund the additional support they require.

Looking at the outcome of reassessments for people with dementia in 2017/18, we found that:

- 34% had an increase in personal budgets
- 8% had a decrease in personal budgets
- 57% experienced no change to their personal budget.

It is concerning that over half of reassessments resulted in no change to people's personal budget amount. It is unclear why this is the case, a potential reason could be that the eligibility criteria for social care is being interpreted differently by people doing reviews and those carrying out full reassessments.

This means that people are being referred for reassessments when they do not require one or that they are getting the wrong outcome from their reassessment. This could have serious implications for the quality of care people receive.

Conclusion and recommendations

It's clear that accessing social care services is not always easy for people with dementia. Information is not presented in a way that is accessible and the specialist services they require may not be available or difficult to find and access.

Dementia is a degenerative condition, so people's care and support needs will become greater over time. The speed at which this happens varies, which is why social care needs to be flexible to respond to sudden or unexpected changes.

The Care Act outlines that anyone using a long-term care service should, as a minimum, receive at least one review of their care plan each year. However, good practice suggests that care plans should be kept under a constant, but light touch, review so that plans can be as responsive as possible.

Fewer than half of all people with dementia received a care plan review last year, and this is something that must be addressed. Local authorities have some way to go in achieving full compliance with this aspect of the Care Act.

The high number of people going through a full reassessment which resulted in no change is also concerning. This suggests that people are either being referred for reassessment when they shouldn't be, or that the eligibility criteria is being interpreted inconsistently by professionals at review and reassessment. Not only does this exhaust limited resources, but it also puts vulnerable individuals and their families under undue stress.

Recommendations

- Councils should ensure that everyone with a diagnosis of dementia, with eligible care and support needs in accordance with Care Act guidance, has a personalised care plan in place. This should be subject to at least one planned review per year.
- In accordance with guidance from the National Institute for Health and Care Excellence (NICE), local authorities and social care providers must provide information and advice during the care planning and assessment process in a manner that is clear, transparent and accessible.^{6,7}
- Local authorities should take steps to implement and evidence the use of care plan monitoring systems that will support them to achieve and exceed Care Act compliance.
- The Department of Health and Social Care should review national eligibility thresholds and how consistently they are being used, to ensure that all reviews and reassessments have fair, proportionate and accurate outcomes.
- Councils should routinely collect data on care reviews and outcomes on a service user level, broken down by primary support reason, including dementia, for NHS Digital to report nationally.

⁶ NICE, Dementia: assessment, management and support for people living with dementia and their carers: <https://www.nice.org.uk/guidance/ng97>

⁷ NICE, Quick Guide, What to expect during assessment and care planning: <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/what-to-expect-during-assessment-and-care-planning>

Thank you

Thank you to everyone who is helping us improve health and social care, including:

- Members of the public who shared their experiences and views with us
- The Alzheimer's Society, with whom we worked to develop, draft and scope this project
- Local Healthwatch whose work and insight informed this report, including Healthwatch Calderdale, Healthwatch Dorset, Healthwatch Kent, Healthwatch Lambeth, Healthwatch Middlesbrough, Healthwatch Sutton and Healthwatch Wiltshire.