

Leading the fight
against dementia

**Alzheimer's
Society**

**Fix Dementia Care
Homecare**

alzheimers.org.uk/fixdementiacare

Document purpose

Fix Dementia Care: Homecare marks the third phase of an Alzheimer's Society campaign looking at the experiences of people affected by dementia in a range of health and care settings. It contains the results and stories from one survey of people affected by dementia with experience of homecare, another survey of homecare workers and a Freedom of Information request to local authorities in England.

It sets out recommendations for key influencers – including local and central government and regulators to – improve the experiences of people affected by dementia in receipt of homecare and Alzheimer's Society will be campaigning to ensure they are implemented.

Title	Fix Dementia Care: Homecare
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Target audiences	Fix Dementia Care: Homecare is intended for a wide range of organisations and people who can improve quality of life for people affected by dementia. It is particularly aimed at central and local government, regulators and NHS bodies, and supporters of Alzheimer's Society campaigns.
Acknowledgements	Alzheimer's Society would like to thank the people with dementia, their families and homecare workers who participated in our surveys, interviews and panels.
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Foreword



Poor care at home has devastating, life-changing consequences for someone living with dementia and their family. People affected by dementia have told us about ending up in hospital because homecare workers failed to identify an infection. They have also described spending the day in soiled clothing as no one could calm their agitation enough to help them change, and walking outside and into the middle of the road at night as their home wasn't left secure.

A significant proportion of dementia care is provided in people's own homes, as it should be. However, our research has uncovered that, for many of the estimated 400,000 people with dementia in receipt of homecare, visiting care workers have been given little or no training on how to reduce the impact of the condition. Homecare workers are supporting some of the most vulnerable people in our community. These professionals can provide excellent care at a low cost to the tax payer that enables people affected by dementia to live well where they most often want to be – in their own homes. We have a right to expect that. In turn, homecare workers have the right to the training and support that enables them to do their job.

Evidence collated by Alzheimer's Society has exposed a desperate situation that must be addressed. People with dementia, their families and carers describe harrowing examples of poor homecare due to a lack of knowledge. Homecare workers themselves have also expressed their fears about feeling ill-equipped to provide the care that is needed.

The homecare sector is operating in an increasingly impossible financial environment. The lack of money in the system has a direct impact on the ability to provide homecare, and, too often, when efficiencies are put in place, the first cut is training and development of front line staff. This is a false economy.

People with dementia are not being treated with the dignity and respect they deserve. Dementia is a complex condition that presents in a number of different ways and therefore affects people differently, requiring skill and understanding from homecare workers to help people and their families live well. In many ways, homecare workers are expected to fulfil the role of a healthcare worker, but are not provided the same level of training and support.

When homecare does not deliver safe, effective and appropriate care it can place intolerable stress on family carers, neighbours and volunteers from organisations like Alzheimer's Society. Good dementia care is person-centred care. When done well, as examples of excellent practice show in this report, homecare can help people with dementia live in the environment of their choice for as long as they wish.

For this to become the norm we must see:

- higher standards of mandatory dementia training put in place for homecare workers
- closer inspection of care provider dementia training by regulators
- greater responsibility for developing dementia care taken by care providers
- wider provision of dementia training opportunities for homecare workers across the country.

In doing so we can help people to live as full lives as possible in their community, reduce unnecessary and costly admissions into hospitals and care homes, and create a culture and environment in homecare that shows dementia matters.

This report is the third in the series of Alzheimer's Society's Fix Dementia Care campaign. Throughout 2016 we have examined the quality of dementia care in hospitals, care homes and care at home. The reports address important issues and include ways to change policy and practice to ensure everyone gets the care they need, whatever the setting. Next year we will campaign to ensure our recommendations are implemented, improving the lives of thousands of people with dementia.



Jeremy Hughes CBE
Chief Executive, Alzheimer's Society

Summary

Most of us take everyday tasks such as washing, dressing or having lunch for granted. But for many people battling with the effects of dementia, these activities can present significant challenges. People with dementia have told us that the care provided in their own home lacks the necessary understanding to support a good quality of life with the condition, and in many cases they reported instances of unsafe and harmful care.

Equally, homecare workers have voiced their concerns to us at a lack of training and support to help them deliver proper care for people with dementia in the community. They have detailed the frightening situations that this has resulted in for them and the people they care for.

Successive governments have pledged to crack this issue:

- In 2009 the National Dementia Strategy for England said that all health and social care staff involved in the care of people who may have dementia should have effective training to gain the necessary skills to provide quality care.
- In 2012 the initial Prime Minister's Challenge on Dementia committed to making sure social care staff 'have the knowledge and skills to help them (people with dementia) lead as fulfilling a life as possible.'
- In 2015 the Prime Minister's Challenge on Dementia 2020 pledged to support 'all relevant health and care staff who care for people with dementia being educated about why challenging behaviours can occur and how to most effectively manage these.'

However, our investigation has uncovered the findings listed below. These are based on one survey of 1,227 people affected by dementia, another survey of 739 homecare workers in partnership with Unison, further research into the workforce commissioned through Skills for Care and 119 Freedom of Information responses from councils in England.

- 38 per cent of homecare workers do not receive any dementia training, and most (71 per cent) do not receive dementia training that is accredited.
 - Only 2 per cent of people affected by dementia say homecare workers 'have enough dementia training.'
 - Half (49 per cent) of people affected by dementia 'disagree' that 'homecare workers understand the specific needs of people with dementia.'
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These key issues translate into harrowing situations that can have far-reaching consequences for people affected by dementia, including:

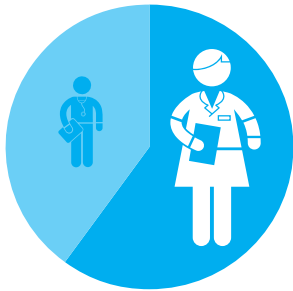
- emergency admission into hospital from a failure to identify infections
- people with dementia – with ineffective safeguarding procedures in place – walking out of a house and into the road
- care workers refusing to make any further visits to someone with dementia as they felt so unprepared and helpless.

To transform the service received by many people with dementia who live at home, Alzheimer's Society is making the following recommendations:

- 1 Minimum training standards for dementia, framed through the Care certificate, should be raised to align with Tier 2 of the Dementia core skills education and training framework.**
 - 2 The Care Quality Commission should include checks for quality of dementia training in their inspection framework for homecare providers.**
 - 3 All homecare providers should have an identified, dedicated dementia lead.**
 - 4 Every local authority should have a dementia-specific training programme for care workers operating within their borough.**
 - 5 Government bodies must find the required resource to enable all homecare workers to receive dementia training.**
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Fix Dementia Care: Key homecare statistics

This report is informed by one survey of 1,227 people affected by dementia, another survey of 739 homecare workers, research into the size and make-up of the workforce and 119 Freedom of Information (FOI) responses from councils in England. Some of the findings from this evidence can be found below.



There are **more homecare workers** in England than all the doctors and nurses in the NHS combined.



60% of people receiving homecare services have **some form of dementia** (400,000 people).



1 in 3 homecare workers have **no dementia training**.



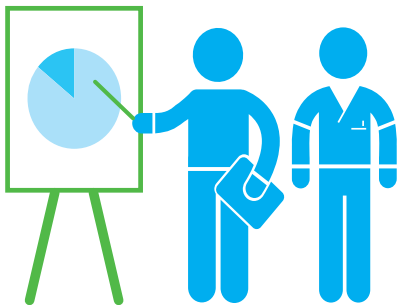
Only 2% of people affected by dementia say **homecare workers have enough dementia training**.



85% of people would choose to live at home for as long as possible if diagnosed with dementia.



Half of people affected by dementia believe that **homecare workers do not understand dementia-specific needs.**



86% of homecare workers believe that **dementia training** would help them to provide **better care.**



An estimated **£2 billion** was spent on homecare for people with dementia in 2014/2015.

1 Introduction

We know that the vast majority of people would want to live in their own home for as long as they are able if diagnosed with dementia (Alzheimer's Society and YouGov, 2014).

To help make this happen, it is estimated at least 400,000 people with dementia and their families rely on professional homecare services as a key part of their support structure (Alzheimer's Society, 2016). This includes, but is not limited to, support with medication, washing, eating and making trips into the community.

Care workers visiting people's homes are well placed to identify changes in condition and behaviour, reduce the impact of symptoms, signpost to other sources of support in the community and boost family carers to keep going. It is often one of the first formal care services accessed by people affected by dementia, and can be vital to providing the early support needed to prevent an issue escalating to the point of requiring hospital admission.

Dementia can impact people very differently, particularly the symptoms, coming to terms with a diagnosis and progression. These aspects can be particularly challenging for people living with another condition, as is the case for 70 per cent of people with dementia (APPG on Dementia, 2016). People with dementia may also experience difficulties with the following:

- previously familiar situations or tasks
- recognising familiar faces
- communication
- decision-making.

These problems can have a significant impact on a person's confidence, health and ability to continue to lead an independent and full life. Remaining in a familiar environment with the right assistance can help to manage these aspects.

A wide-ranging investigation from the Alzheimer's Society into the provision of homecare to people with dementia has revealed a frightening shortage of support to develop the skills, knowledge and understanding required to support these challenges presented by dementia. This is a particular concern if we consider the homecare workforce in England is believed to be larger than the combined numbers of NHS doctors and nurses (NHS Confederation, 2015; Skills for Care, 2016).

Our evidence found many people with dementia receiving homecare services are not being looked after and treated fairly and with dignity, as required in the Human Rights Act 1998. It shows that the principles of wellbeing and safeguarding from neglect, underpinned by the Care Act 2014, remain a long way from reality for a large number of people affected by dementia. Homecare workers delivering care in the community need to understand the specific complexities of dementia, and be equipped through appropriate training to know how best to respond, just as we would expect NHS professionals providing care for diabetes or cancer to understand the disease.

The homecare sector has been heavily affected by significant cuts of almost 40 per cent in council budgets since 2010. As a result a growing number of people have to pay for care from their own pocket and a number of providers have withdrawn from the market. Only last month, a damning report into the state of care from the Care Quality Commission led Chairman of the NHS Confederation and former Conservative Health Secretary, Stephen Dorrell, to claim 'the biggest inefficiency is to use NHS acute hospitals as social care' (Telegraph, 2016).

The issues that arise from failing to adequately resource social care have had an unfair impact on people affected by dementia, a condition that currently relies more heavily on social care than health interventions to manage symptoms. Our investigation shows that the wider health and care system is failing to recognise the value of supporting more people with dementia to remain at home for longer, with the result of avoidable admissions to hospital or care homes for many people with dementia.

This report will set out, drawn from first-hand experiences, some of the things that can and do go wrong when homecare workers lack dementia training. Each angle of the homecare system is considered, from the perspective of people with dementia and their families, to the experience of homecare workers and the impact on the wider health and care system. By exploring these experiences and considering examples of good practice, we are able to make recommendations of what must change, to make sure people with dementia at home receive the quality of care they need and deserve.

The conversation that never happened

Our research found a strong connection between the problems people affected by dementia experienced and the anxieties held by homecare workers around providing care.

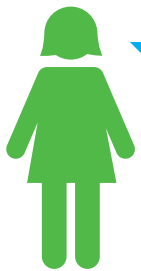


I don't feel like I'm a real person to them...

...They do not have enough knowledge about the illness to be comfortable to talk to me as a person...



...She would often take the painkiller despite not being in pain and be sent to sleep by the medication.



...Most were unable to deal with challenging behaviour and as a result left Mum soiled and dirty rather than learn how to manage her...



...Most carers had very little understanding of his dementia, or of things they could do to support him. Instead they gave him labels (like confused or aggressive) and said the problem was him...





...In-house training told us what dementia was, not how to help someone with dementia...

...There was no explanation of different stages of the disease and how the sufferer's personality can change daily...



...There wasn't enough information about the problems that people with dementia can have with aggression, depression, self-neglect...

...I have been assaulted while working because I didn't understand how to be with the service user...



...My employers simply thought we should understand 'old people'...

2 What can happen to people with dementia when homecare dementia training is inadequate?

Beverley and Margery's story

Prior to Marge's diagnosis of mixed dementia, her daughter Bev had moved to be closer to her mum. When Marge's needs became too much, professional homecare workers came in four times a day. Immediately it was apparent the carers weren't equipped to support Marge. She was terrified of strangers coming into her home and became very distressed. She refused help and often barricaded herself in the home.



Beverley

Bev felt this could have been avoided. The carers did not show an appreciation of how their actions may affect Marge, they did not try to build a relationship with her, and this exacerbated her behaviour and increased her anxiety. Often the carers arrived unannounced, banged around the kitchen, and isolated her. They did not have the skills or understanding of dementia to offer solutions for what she needed.

Some of the homecare workers were very good and understood Marge's needs – they would come in and read her care plan in detail, consider the problems, and ask Bev for advice. They would go above and beyond to introduce themselves, sit down and speak to Marge.

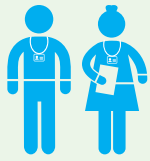
However, many of the homecare workers didn't show any understanding of the specific needs of people with dementia. Despite the progression of Marge's condition, the carers would ask her what she needed doing. Marge often wasn't aware of what she needed and this meant she would remain dressed in dirty clothes and she could end up missing medication that was vital to her health.

Bev watched as one carer stayed for just 15 minutes rather than the hour she was supposed to. This was not an isolated occasion when, rather than continue in a situation that scared them and which they could not cope with, the carers would just go, leaving Marge without the care she needed.

'Mum's care was at times appalling. The lack of understanding the homecare workers showed for Mum's dementia was apparent from day one. This immediately put them on the back foot – they didn't know how to cope with Mum. They didn't see the importance of the care plans and rota, and they didn't appreciate Mum often wasn't able to tell them what she needed.'

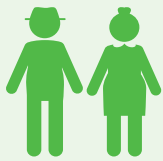
Beverley

Alzheimer's Society found



38%

of homecare workers have had no dementia training.



49%

of people affected by dementia disagree that 'homecare workers understand the specific needs of people with dementia.'

People with dementia who rely on homecare services need the professionals who look after them to understand their needs and enable them to live the life they want in the environment of their choice. However, our investigation has found 38 per cent of homecare workers have had no dementia training at all (Alzheimer's Society, 2016). Moreover, more than two-thirds (71 per cent) do not have dementia training that is accredited (Skills for Care, 2016).

The resulting effects can be devastating. People with dementia and their families told us of people being left in soiled clothing, missing medication, overlooked urinary tract infections and dehydration not being treated. In some cases this led to the breakdown of the family carer from exhaustion after homecare was cancelled for being inadequate, as the responsibility of care fell to that one person. In other cases, people with dementia were admitted to hospital or a care home. More than one family carer also detailed how a lack of understanding of dementia significantly exacerbated the challenging behaviour of someone with dementia, to such a challenging degree that the person was sectioned and removed from their home under the Mental Health Act 1983.

Survey respondents relayed concerns about people with dementia not being treated with dignity. They also referred to problems with the interaction between workers and people with dementia as well as reaction to behaviour that challenges. These issues were so widespread that only 2 per cent of people affected by dementia said they believed homecare workers have enough dementia training.

Nearly half (47 per cent) of people affected by dementia told us homecare workers would address the family member present rather than the person with dementia. Some described incidents of the person with dementia being treated like a child or being ignored completely and made to feel they were little more than an object.

**‘Because they don’t know what I’ve got, they think I’m stupid.
They don’t know how ill some people are – they condemn me for it.’**

Unfortunately, seemingly simple mistakes can lead to dramatic consequences. We were told of how a homecare worker did not recognise that someone with dementia could not differentiate between the table and the bowl, see the food within it or recognise the need for eating. This resulted in the food being untouched, which over a period of time led to malnutrition, increasing the risk of falls, depression and a loss of energy to carry out everyday tasks. Situations like this can and do lead to costly hospital admissions.

Shocking examples of poor care are sadly nothing new. Well-publicised failings at Mid Staffordshire Foundation Trust and Winterbourne View led to formal inquiries into the state of care, known as the Francis and Cavendish reports, in addition to plans for action to end such incidents. Sadly for people living with dementia at home, poor and unacceptable practice still remains widespread. It is happening behind closed doors, without public attention.

These incidents can damage the confidence of someone with dementia, leading to questions regarding their own capability to live a full life. This can snowball, with people believing it is they who no longer fit into society, rather than society failing to respond to their condition and needs. There is convincing evidence that the so called ‘challenging behaviour’ of people with dementia is a result and response to not having individual physical or social needs recognised (Cohen-Mansfield, 2005). Knowledge of the progression of dementia, approaches to assist with daily living, methods to assist with communication and ways to pick up and act on personal preferences are all essential to quality care.



Our recommendations for change

Minimum training standards for dementia, framed through the Care certificate, should be raised to align with Tier 2 of the Dementia core skills education and training framework.

Dementia care must be compassionate and support specific person-centred needs. To achieve this, education and training must acknowledge the unique and complex nature of the condition. A generic approach to care is not acceptable in the NHS, and it shouldn't be acceptable for social care.

The Care certificate, a direct result of the Cavendish review in 2013, was designed to be a set of minimum standards, describing the basic knowledge and skills a homecare worker requires before they can deliver care in the community. Currently however, the certificate, through Standard 9, only requires care workers to be 'aware' of dementia. This minimum is not enough. An 'awareness' of the condition does not provide the knowledge and understanding to deliver care for people with dementia that is person-centred and informed.

Alzheimer's Society is calling for an increase in the minimum standards of training for dementia care, framed by the Care certificate. This is required across the homecare workforce as the vast majority will work with people affected by dementia.

In 2015, Health Education England, Skills for Health and Skills for Care developed the Dementia core skills education and training framework, funded by the Department of Health. The framework includes 14 subject areas and is broken down into three 'tiers' of complexity. At the moment, the Care certificate covers the most basic aspect of the framework, included in Tier 1 around awareness, which is not good enough.

Tier 2 of the framework outlines a selection of subjects that are essential to people with dementia and their families. Homecare workers should be familiar with these subjects and able to action them. This is described within the framework as 'basic skills which are relevant to all staff in settings where people with dementia are likely to appear.'



Our recommendations for change

The Care Quality Commission should include checks for quality and impact of dementia training in their inspection framework for homecare providers.

In an underfunded system of care and support, training is often the first expenditure to be reduced, which we believe is a false economy. Regulation of services has an important role to play in holding providers to account when this occurs, in addition to identifying the resulting negative effect on quality of care. The Care Quality Commission (CQC) regulates homecare services in England. The ratings and reports that they provide, from inspections that assess the care provided, offer an important measure of quality. In 2013, the CQC published 'Not just a number: Homecare inspection programme'. This report listed 'training needs not being identified, or if they are identified, they are not met' as a key concern. The accompanying recommendation stated 'staff should receive the appropriate training to be able to support people in the best way possible; this is a particular issue for people with dementia'.

Currently however, the inspection framework, delivered through a process of Key Lines Of Enquiry (KLOE) that guides how inspections are carried out, is limited in its focus on dementia training. As a result, it is often unclear which homecare providers are doing so to a high standard, and which are failing to ensure their staff are appropriately prepared to provide dementia care. Including a specific prompt within the KLOE framework will encourage standards of dementia training to be included as a standard part of the inspection process for providers of social care, including homecare, across the country. This will provide greater transparency for people with dementia, their families and social care commissioners to base decisions around who they want to provide care, making it easier to navigate a challenging social care system and find the best dementia care possible.

CQC must be explicit on what dementia training care workers have had, and the impact on the care of people with dementia that training has had on the experience, both positive and negative. The inspection framework should include a specific prompt designed to encourage inspectors to identify the difference that good and poor dementia training can make for people with dementia and their families. Inspectors need to produce evidence of what has been found through their written reports, providing transparency and promoting choice and control for people affected by dementia. When dementia training is identified as deficient, CQC must hold providers to account, and highlight outstanding examples for others to learn from. The checks would also form an extension to the first recommendation in this paper, calling for minimum standards to be raised through the Care certificate, meaning greater transparency on where, and how far, increased minimum standards of training are being met.

3 What can happen to family carers when homecare dementia training is inadequate?

Linda and Ken's story

Linda's dad, Ken, was diagnosed with Alzheimer's disease three years before he died. Local authority-funded homecare workers visited Ken's home twice a day. This was a very stressful time for Linda as she lived over 100 miles away and was still working.



Linda

Linda felt that, out of about 30 carers, only two or three seemed to understand dementia and were able to care for her dad well, something that worried her greatly. No one seemed to know how to respond to his increasingly agitated behaviour. The carers would often arrive and ask Ken what he needed, rather than following the care plan, which meant he frequently went without food as he'd think he'd already eaten.

Ken ended up living on biscuits and cold snacks when Linda wasn't there to cook. He weighed as little as seven stone at one point and as a result she would drive the 200 mile round trip three times a week to cook for her dad, bring him takeaway food or take him out for lunch. When Linda looked in the care log, the care was often recorded inaccurately or medicines hadn't been given to Ken at the appropriate time. This gave the family no faith that the carers had the training, confidence or expertise they needed to safely and effectively care for their dad.

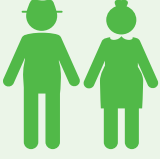
Linda gave Ken a diary. Ken recorded the way he felt about his experience with some of the carers. One entry reads: 'I am getting fed up being used as a guinea pig.'

'Dad was challenging at times and I was told that some carers refused to come back and care for Dad. It meant I felt I could never relax or fully focus on other things. As a family carer, I needed to have confidence that my dad would be cared for safely when I couldn't be there.'

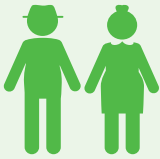
'Without care workers with adequate training, Dad struggled to make sense of his life. He needed someone who understood him and the way he was acting – to speak to him and calm him down. Often I felt like my dad was seen as a nuisance. Dad's last year was a living hell and he was eventually sectioned under the Mental Health Act before dying six weeks later. No one's life should be this way – homecare workers need training to help prevent people like my dad reaching crisis point.'

Linda

Alzheimer's Society found

 **2%** of people affected by dementia believe homecare workers 'have enough dementia training.'

.....

 **58%** of people affected by dementia feel homecare workers have shown 'they cannot manage challenging behaviour from the person with dementia.'

Nearly 700,000 friends and family members provide care for a person with dementia in the UK (Alzheimer's Society, 2014). Dementia can lead to positive and negative changes in relationships. It may bring people closer together, united in a battle against the condition. Alternatively, the changes that can occur due to the condition and its psychological and physical impact can result in relationships and family ties being destroyed.

Helping someone with dementia to live well at home for as long as possible is a priority for family and friends. Good homecare services make this aim easier to achieve. However, the result of poor care is that family members worry that they cannot be away from their loved one, or switch off from their caring duties. In fact, only 32 per cent of family carers agreed that homecare workers understand the specific needs of people with dementia, and nearly two-thirds felt the homecare workers that had visited could not manage any behaviour from the person with dementia that might be challenging.

One family member described how homecare services had to be cancelled at short notice, as the services did not have the capability to provide the required support for her mother. This meant leaving her 83 year-old father as her mother's only support, 24 hours a day. Another wrote about homecare workers being unable to communicate with her husband without her assistance. This meant she never had any time off, causing her own health problems – an all too common tale. Family carers told Alzheimer's Society that, without the necessary support to relieve some of the pressure, caring for dementia at home can be an overwhelming experience, often leading to health breakdown, depression and isolation.

Caring for a family member or friend with dementia has led to people also reporting feelings of guilt, confusion, resentment, helplessness, grief, sadness and fear (Benbow et al 2009; Callaby et al 2012). As dementia progresses and the caring role increases, they have to adapt to a changing relationship with the person with dementia, growing restrictions to their own lifestyle and learning to understand and cope with the person's dementia.

It is estimated that family carers save the economy £11 billion each year through the support they provide (Alzheimer's Society, 2014). Yet 21 per cent of carers give up work or reduce hours at a cost to businesses in England of £1.6 billion (CEBR, 2014). The findings of Alzheimer's Society's investigation raises the concerning possibility that many more are at risk of leaving the workplace, either because homecare services are unable to provide the support required, or they do not feel the standard of dementia care at home is adequate. An appropriately trained homecare workforce, able to deliver care and support that family carers can be confident in, is essential to enabling them to keep going. It is also helpful for family carers to know they are not alone and that they have skilled, appropriate and, above all, available support.

At its best and most effective, dementia care in the home encompasses a whole team, with the person, their family and professional carers all working together to alleviate the symptoms of the condition, promote independence and enable the person with dementia to live as full a life as possible. However, when homecare does not deliver the support that is required, the additional responsibility frequently falls on the shoulders of those who are nearest.



Our recommendations for change

All homecare providers should have an identified, dedicated dementia lead.

Family carers would greatly benefit from the creation of an identified, dedicated dementia lead role within a homecare organisation. The dementia lead would be a key point of contact and source of reassurance for family carers, people with dementia and colleagues seeking to develop their learning. They would help to provide the impetus and oversight for change and improvement within an organisation, sourcing available training for care workers supporting people with dementia and nurturing a dementia-focused approach throughout the organisation. They would help to create a culture and environment that shows dementia is considered in all areas of homecare provision.

The dementia lead role could also help to develop much-needed career pathways within the homecare sector – encouraging care as a vocation rather than a job – and provide opportunities for homecare workers to develop their skillset and take greater responsibility within their organisation.

Dementia lead



A dementia lead is:

- a care worker, either in management or on the front line, who is passionate about dementia care
- enabled to receive additional training and development in dementia care to achieve Tier 3 of the workplace, either because, described as 'leadership'
- dedicated to improving the dementia care and support offered by the provider by ensuring colleagues receive dementia training appropriate to their role
- recognised as a dementia lead within the organisation and as an external point of contact
- a unique selling point for providers to demonstrate commitment to dementia care.

Alzheimer's Society wants to see:

- 50 per cent of homecare providers with a dementia lead in place by the end of 2018
 - 75 per cent of homecare providers with a dementia lead in place by the end of 2021.
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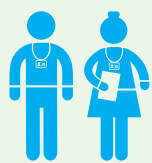
4 What can happen to homecare workers when dementia training is inadequate?

‘I received little training on how to deal with relatives and getting the balance between protecting and caring for the individual and respecting the relatives. Also I wasn't paid for the hours of this training. It was presented as something that I was privileged to be receiving rather than something that was a vital tool to be able to do my job.’

‘I used to be a homecarer to people with dementia. All the time I was doing the job, I never once had any dementia training. I like to think that I treated everyone with dignity and respect and gave appropriate care and support but looking back, the care was not person-centred. The job was totally rushed and how could I have possibly done a good job if I did not have even basic understanding of dementia? I do not have a lot of regrets about what I have done in my jobs, however, I really wish that I, and my co-workers, were given training in dementia. I care.’

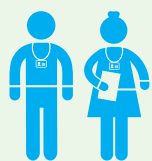
‘I think carers are at the lower spectrum of NHS staff – we get asked to do a lot of nurse related work, but the pay and training does not reflect that. I think it's about time the government treated professional carers like NHS staff and rewarded via pay and pride in a job, acknowledging our skill, rather than making us feel like scum a lot of the time.’

Alzheimer's Society found



520,000

homecare workforce
(more than NHS total
for doctors and nurses).



1 in 5

homecare workers who have
received dementia training
were not paid for that time.

It is not only people with dementia and family carers who want better dementia training for homecare workers. Homecare professionals themselves told us they were often fearful – in most cases this was because they felt unprepared on how to support people with dementia. Our survey of nearly 750 homecare workers, carried out in partnership with Unison, found that 82 per cent of homecare workers have experienced behaviour that challenges them while providing dementia care in the home. Furthermore, 87 per cent agreed or strongly agreed that further training would ‘help me to react to different challenging scenarios when providing dementia care and support.’

The 38 per cent of homecare workers without any training in dementia have little chance of knowing how to help someone who is unsure of why a care worker is visiting and who is unable to communicate their needs, for example that they are in pain or hungry. Homecare workers with dementia awareness training might be able to identify when there is an issue, but will be unlikely to have the skills to know how to respond in a way that will address the problem and prevent it escalating.

For people with dementia, this can mean care workers are too afraid to try and develop a genuine connection, or to ease an escalating situation, for fear of doing something wrong. Frequently, it is the actions of a person without dementia, driven by a lack of understanding, that causes a situation to escalate, not the person with dementia. This can be because of stigma and fear and an associated lack of learning about dementia and how it affects people. In turn, this can lead to an approach that exasperates, frustrates or dehumanises the person with dementia. In some cases, care workers told us how their inability to know how to diffuse a situation meant they faced verbal and physical violence.

Currently, the dementia training available for homecare workers is limited and variable in quality. An Alzheimer's Society Freedom of Information request to local authorities across England found 38 per cent of councils that responded do not fund any dementia training sessions for homecare workers in their borough, and 71 per cent do not include an allocation for training within the contracts they commission to homecare providers.

Of the homecare workers who did have some form of dementia training, many told us that it left them unsure on how to assist people with changes that occur as the condition progresses. Others told us that they had received no information or support about how to include the person's family effectively in the planning and provision of care and support. The three challenges identified as being closely linked to dementia that they felt particularly helpless about responding to are:

- aggression
- self-neglect
- depression.

'The training didn't reflect real life situations or offer practical solutions.

People with dementia being abusive verbally and physically to carers—this is very upsetting and it's hard not to take it to heart. With dementia training I would feel I understood them more and could help prevent these incidents.

I never try to reason with someone with dementia as they do not understand and this often makes them react with aggression.'

There is clearly both an appetite, and an urgent need, for further dementia training, with 43 per cent of homecare workers asking for more from their employer. However, in more than half of those cases this was turned down – some were told it was not a priority for the service and others that money was not available and they would have to pay for it themselves.

Homecare workers perform a very important role, often without the recognition, pay or working conditions they deserve, equipped with only basic training for general care and support. The vast majority want to do their job well, and we must enable this to happen.



Our recommendations for change

Every local authority should have a dementia-specific training programme for care workers operating within their borough.

Local authorities must take greater responsibility for the accessibility and standard of training received by homecare workers supporting people living with dementia in their boroughs. The Care Act 2014 places duties on councils to shape the market for adult care and support. Through this legislation they ‘must facilitate markets to offer continuously improving, high-quality, appropriate and innovative services, including fostering a workforce which underpins the market.’

The Care Act also states: ‘local authorities should consider, in particular, how to encourage training and development for the care and support workforce, including for the management of care services... and have regard to funding available through grants to support the training of care workers in the independent sector.’ However, our Freedom of Information requests to councils across England showed a significant proportion either do not fund dementia training sessions for homecare providers (38 per cent), or include a specific allocation for training within the contracts they commission (71 per cent). Capacity, not quality of services, appears often to be the focus for local authorities. To meet their Care Act obligations on quality services, councils must recognise the need for appropriate training.

Through this recommendation, councils will be asked to commit to establishing dementia-specific training programmes with access for all homecare workers within their local authority. This training should be designed to help the local workforce meet Tier 2 of the framework outlined in the first recommendation of this report. Alzheimer’s Society expects council commissioners to make attendance of these programmes mandatory for any provider seeking to earn a contract to deliver homecare services to local people with dementia. This recommendation also creates the opportunity for a local status or mark that recognises providers for the level of dementia training that their staff have reached.

For people affected by dementia, this would increase the number of staff with recognised training and provide reassurance. Homecare workers will frequently change company, with turnover of front line care staff at around 40 per cent, yet around a third will stay within the sector and within the borough (Skills for Care, 2016). Therefore, if an authority appropriately trains an individual, they will carry that training with them wherever they go, to the benefit of people with dementia, regardless of which provider they receive care from.

Around 70 per cent of homecare provision is purchased by local authorities in England (UKHCA, 2016). Their purchasing power therefore accounts for the employment of a high percentage of the homecare workforce, yet the responsibility for training standards is usually passed elsewhere. The decision of which care provider is chosen to deliver homecare support is usually selected by the local authority, not the person with dementia or their family. Someone living with dementia should be able to expect care from someone trained to understand the complexities of the condition, regardless of employer. We would expect it from the NHS – why not social care?

Alzheimer's Society wants to see:

- 50 per cent of councils with a recognised dementia training programme for homecare workers in place by end of 2018.
- 75 per cent of councils with a recognised dementia training programme for homecare workers in place by end of 2021.

5 Effects on the health and care system when dementia training is inadequate

Charlotte and Jane's story

In the summer of 2011, Charlotte's grandmother Jane was given a diagnosis of dementia. Charlotte would regularly take time from her studies to visit Jane, helping her to attend appointments. In the following spring Jane's dementia reached a stage where more help was needed, which led to two visits a day from homecare workers, organised through the council. Unfortunately, it quickly became obvious that the homecare workers were ill-equipped to provide the support required.



Charlotte with her grandmother, Jane

Despite clear and repeated requests to remove out-of-date food from the fridge, the homecare staff didn't fully grasp why this was important for someone with dementia and didn't always do it. As a result, Jane would regularly eat food that had gone off, making her sick. Care notes would frequently be left on the table, and reading them would upset Jane and increase her anxiety. Jane often remained unwashed for weeks at a time despite it being a clear part of the care plan.

One day, having been alerted by family that her grandmother sounded different, Charlotte drove to visit, but on arrival found an ambulance had been called and Jane had been admitted to an intensive care unit at the local hospital. A homecare worker had found Jane face down on the bedroom floor, barely conscious. The out-of-date food that was left in the fridge had caused regular diarrhoea – this coupled with infrequent washing and personal care had resulted in a urinary tract infection.

If either the infection or Jane's attempts to communicate the resulting pain and discomfort had been identified at an early stage it could have been treated at home fairly swiftly. Sadly, nothing was picked up on or reported for many days until Jane reached a critical state, suffering from hallucinations, affecting her kidneys and reaching a shockingly low level of oxygen.

Jane remained in hospital for 12 weeks. The experience meant the family lost faith in the ability of homecare services to provide support that could keep Jane at home safely. As a result she was transferred from hospital to a care home closer to Charlotte's parents.

'It was terrible to see my gran so unwell. She shouldn't have got as bad as she did. If the homecare had been provided to the level of quality we had hoped, the UTI may not have developed in the first place and Gran could have avoided such an awful stay in hospital. Even if the UTI wasn't spotted, my gran's discomfort should have flagged serious concerns. Instead, our faith in homecare was totally shot. I feel my gran could have stayed at home for longer if things had been different.'

Charlotte

We know that the cost of providing homecare to help people remain at home where they want to be is cheaper than a stay in a nursing home or hospital. Yet, our investigation has shown the health and care system still fails to prioritise quality dementia care in the home as a way to prevent or delay the need for more advanced and costly care. In 2014, the NHS 'Five year forward view' made it clear that a higher proportion of care and support should be delivered in the community. This forward view talks of dissolving traditional boundaries of health and social care and integrating services around the individual. We must unlock the potential of homecare as a powerful ally of the NHS, providing assistance to keep people where they want to be and helping to manage long-term conditions like dementia in the home.

It costs an estimated £400 per day for a hospital stay, (NHS Data, 2015) and more than £700 a week on average to stay in a nursing home (Laing & Buisson, 2014). In contrast, an hour of homecare in October 2016, paid at the Living Wage (as set by the Living Wage Foundation), costs around £19 (UKHCA, 2016). At any one time at least a quarter of hospital beds are believed to be occupied by someone with dementia (Alzheimer's Society, 2016), many of whom have been admitted due to a preventable crisis.

Prioritising quality dementia care at home, in part delivered through training and the calls in this report, could create significant savings for the health service as well as delivering the principles of wellbeing, choice and control for people affected by dementia that are so prominent within the Care Act 2014. Social services currently work in isolation, operating in a disastrous economic climate that has led to reduced services and limited training. Since 2010, the budgets of local authorities have been cut by almost 40 per cent. This has a direct impact on the state of care, with less money for provision, and less money to train a workforce that is ready to take on the task in hand.

People with dementia and their families told us of instances where a poor understanding of how to provide dementia support in the home has led to loved ones being sectioned, missed cases of ill health that resulted in hospital admissions, and early admissions into residential care homes. This is not a system that works for people with dementia. Our **Fix Dementia Care: Hospitals** report (Alzheimer's Society, 2016) found that, of the 60 per cent of people with dementia who went into hospital from their own home, only 36 per cent returned there. Most of the rest were discharged into residential care.



Our recommendations for change

Government bodies must find the required resource to enable all homecare workers to receive dementia training.

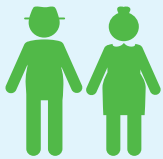
A key commitment within the Prime Minister's Challenge on Dementia 2020 states:

'All relevant health and care staff who care for people with dementia being educated about why challenging behaviours can occur and how to most effectively manage these.'

In 2014, Health Education England (HEE) was given a mandate by the government to make dementia training available to all NHS staff by 2018. As of April 2015, HEE had provided Tier 1 and Tier 2 dementia training to 515,967 NHS staff, exceeding government targets, with the aim of embedding the training into 'business as usual'. Despite providing an estimated 85 million hours of care for people with dementia each year, homecare workers have been left behind their health counterparts. Resources are needed to put the required training into place to address this imbalance and to provide the level of care people with dementia require in their own home.

Alzheimer's Society calls for £25 million, derived from national and local government and NHS funding sources and spread over four years, to be allocated to dementia training for all homecare workers. The Department of Health must provide systems leadership to ensure this is delivered promptly and effectively. Across all 152 local authorities that would amount to as little as £40,000 a year each – a small price compared to the potential benefits for people affected by dementia and the wider health system. This will support the health and care sectors to work together to move away from a reactive system to one focused on the bigger picture, preventing many people requiring acute care by responding to issues before they escalate.

6 What happens when dementia training in homecare goes well



For the person with dementia and their family

'From the moment I decided to bring carers into the home, I knew this was the right thing for my husband. He was so unhappy anywhere, other than in his own home. Over a two year period his care was increased from a couple of morning visits twice a week to a full time live in carer, who was appointed by the care home who also supplied care in the community.

We all worked together as a team to ensure that my husband's care was paramount. I continued to administer his medication until it was no longer possible, whilst the carers attended to everything else apart from cooking his meals. They would wash, dress and feed him besides providing some mental stimulation, and this gave me more time to attend to necessary jobs and more importantly to give him some of my time in a caring and relaxing way.

I believe that we were lucky to find the right people for the job as it could so easily have been otherwise. I have found my personal recovery from his loss to be easier to cope with, knowing that he was as comfortable, well cared for and happy as he could have been, and at home, where he wanted to be.'



Denise, a homecare worker with Dementia Care, Newcastle upon Tyne

‘Before we can go out to help clients, everyone has to finish their training, including in dementia care. All the care workers are required to do extra dementia training, which is delivered by the University of Stirling. It lasted six months, bringing us together to learn from and share case studies and difficult situations we had faced, and to work out how best to approach this in future.

It really boosted my confidence. If you don’t understand dementia – and I didn’t, you don’t appreciate the severity of it and how it affects people. Only when I had my training did I discover how much there is to learn and how much it is needed to help people. It taught me what the dementia was doing to the person, how I could diffuse a difficult situation and calm them, work out what they wanted or what they meant.

The training has helped me to go that extra step, which I always aim to do. The training covered supporting partners – many people don’t realise the impact on them too. One husband, who had been the main carer for ages, was so worn down he could barely get the key in the door. The respite we could offer him meant he was able to keep going. Without him there when we couldn’t be, I’m certain his wife would have had to go into a care home.’



For the wider system – The Hull Dementia Academy – Hull City Council

The development of a Hull Dementia Academy is an initiative developed in partnership with key organisations across the city to drive up standards of care for people with dementia and their carers.

A key objective of the National Dementia Strategy (NDS) is the need to have an informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia need to have the necessary skills to provide best quality care in the roles and settings where they work. The development of the Hull Dementia Academy will achieve this objective by providing effective basic training and continuous professional and vocational development in dementia.

The Dementia Academy provides accredited and quality assured training with the academy establishing a baseline minimum level of training promoting a consistent approach across all service provision. A competency framework and structured training pathway will enable individuals to build and develop their skills and knowledge.

This will help us achieve the improvement of the quality of care for people with dementia across all services in Hull.

Training for dementia care provided in the community must be seen as an investment. The case studies above show that it can be done. It can help people with dementia remain living well at home for longer – reducing or delaying the need for acute or residential care, and helping family carers to keep going and perhaps to remain in work. Furthermore, it can be a significant factor in providing confidence to homecare workers operating in a challenging environment, increasing their sense of worth and appreciation, encouraging career progression and assisting with recruitment and retention.

The recommendations outlined in this report seek to make sure good practice becomes the norm for people with dementia and their families, not the exception. Dementia will continue to impact on more people's lives, with more than 1 million people expected to be living with the condition by 2021. The health and social care system must be proactive in taking action to make sure services are delivered that are person-centred and work for the person and their family. Policy intentions to provide more care and support in the community, helping people remain at home where they wish to be, must be backed up with the necessary resources.

Conclusion

Homecare that demonstrates an understanding of dementia, which is informed and offers a range of approaches, is essential to help people with dementia live well at home. Central to helping people with dementia remain where they want to be is an understanding of the role that training has in developing a workforce that is skilled and equipped to make this happen.

In this report we have seen that it can be done, and that the results can be life changing for the person with dementia and their family. Sadly, our investigation has found this to be the exception rather than the rule, and the negative effects of poor quality homecare impact on everyone involved, from the person with dementia to family, friends and care workers.

The recommendations in this report are designed to create a pathway that leads to the delivery of high quality dementia care in the home, powered by training that develops understanding and daily practice. It should not be seen as a privilege but a right to be cared for by professionals with knowledge and understanding of the condition you battle on a daily basis, just as it should not be seen as a privilege as a care professional to receive training to do the job that has been asked of you.

Recommendations

- 1 Minimum training standards for dementia, framed through the Care certificate, should be raised to align with Tier 2 of the Dementia core skills education and training framework.
- 2 The Care Quality Commission should include checks for quality of dementia training in their inspection framework for homecare providers.
- 3 All homecare providers should have an identified, dedicated dementia lead.
- 4 Every local authority should have a dementia-specific training programme for care workers operating within their borough.
- 5 Government bodies must find the required resource to enable all homecare workers to receive dementia training.

Appendix 1: Report methodology

This report draws on:

- a survey of people with dementia, their families and carers
- a survey of homecare workers, in partnership with Unison
- Freedom of Information requests to councils in England
- Service User Review Panels (SURPs) with people affected by dementia
- public policy documents
- emerging good practice examples
- research on the workforce commissioned by Alzheimer's Society through Skills for Care

The survey with people affected by dementia was conducted over July and August 2016. There were more than 1,200 responses.

The survey of homecare workers, carried out in partnership with Unison, was conducted in August and September 2016. There were more than 700 responses.

Freedom of Information requests were sent to 152 local authorities across England. There were 119 responses (78 per cent) within the timeframe provided for compliance under the Freedom of Information Act.

Alzheimer's Society commissioned Skills for Care to provide detailed information from the National Minimum Data Set (NMDS) on the size and make-up of the homecare workforce, in addition to data around the dementia-related qualifications held by the workforce.

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Notes

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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