

Leading the fight  
against dementia

Alzheimer's  
Society

A photograph of an elderly person with short, light-colored hair, seen from behind, sitting in a blue wheelchair. They are in a hallway, looking towards a white door. On the wall above the door is a white hand sanitizer dispenser and a framed notice. The floor is covered in green patterned carpet. A large, semi-transparent green graphic with a cracked texture is overlaid on the bottom half of the image, containing text.

**Fix Dementia Care**  
**NHS and care homes**

[alzheimers.org.uk/fixdementiacare](https://alzheimers.org.uk/fixdementiacare)

## Document purpose

**Fix Dementia Care: NHS and care homes** marks the second phase of an Alzheimer's Society campaign looking at the experiences of people with dementia in a range of health and care settings. It contains the results of a survey of care home managers and the voices of people with dementia, their families and carers.

The report sets out recommendations for the government and NHS to improve the experiences of people with dementia in care homes. Alzheimer's Society will be campaigning to ensure they are implemented.

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## Title

**Fix Dementia Care: NHS and care homes**

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## Publication date

April 2016

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## Target audiences

Fix Dementia Care: NHS and care homes 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 government, NHS bodies and regulators and supporters of Alzheimer's Society campaigns.

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## Acknowledgements

Alzheimer's Society would like to thank the care home managers who took part in the survey. Thanks also go to the people with dementia, their families and carers and the many Alzheimer's Society staff and others who also contributed to the report's content.

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## Authors

Laurie Thraves, Senior Policy Officer

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## Contact

Alzheimer's Society Policy and Public Affairs & Campaigning teams can be contacted on **020 7423 3500** or **change@alzheimers.org.uk**

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## Web

**alzheimers.org.uk/fixdementiacare**

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# Definitions

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## Care homes

Care homes provide either residential or nursing care. Residential care homes provide help with personal care such as washing, dressing and eating. Nursing homes provide personal care and, in addition, have a qualified nurse on duty at all times.

## Primary care

Primary care is the day-to-day healthcare usually provided by GPs. GPs also refer people to secondary care services (see below).

## Secondary care

Secondary care services include planned hospital treatment, physiotherapy and continence services. In general, people are referred to secondary care by their GP.

## Mental health services

Mental health services include professionals such as community psychiatric nurses, social workers, pharmacists and occupational therapists. In general, people are referred to mental health services by their GP.

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# Foreword from Alzheimer's Society

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**Making the decision to move into a care home can be enormously difficult, both for the person with dementia and their family. As a person's dementia progresses they will need more intensive care and support and so residential care often becomes the most appropriate option. What should make this decision easier is the assurance that, in a care home, a person with dementia will receive the same, if not better, access to healthcare services.**

This should help to reduce distress and pain, maintain independence and avoid the human misery and financial cost of emergency hospital admissions. Yet Alzheimer's Society's latest investigation, conducted in partnership with Care England as part of our Fix Dementia Care campaign, has revealed that this is not always the case.

Seventy per cent of care home residents are living with dementia. Many will be in the later stages of the condition, may struggle to communicate, experience incontinence and live with a number of other long-term conditions. They, like all of us, are covered by the NHS Constitution, which demands that everyone, regardless of who they are or where they live, should have access to the NHS services they need free at the point of use. However, our investigation has found that the rights of people with dementia under the NHS Constitution are not being respected.

Working with Care England's members, Alzheimer's Society has discovered that some GP practices are wrongly charging care homes, and the people who pay care home fees, for services that should be free on the NHS. In addition, people with dementia are often forced to wait months for vital secondary care like physiotherapy or mental health services. In their hour of need, some people with dementia, who have paid their taxes throughout their lives, are paying again to see a GP through their care home fees.

In the best examples, GPs have good relationships with care home staff and residents and do not charge to make regular visits to provide primary care. Access to secondary care services is also timely and effective, allowing people to manage their condition before reaching crisis point. In the worst cases, care homes are being charged up to £36,000 a year to provide services that should be free and available to all.

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Far from having their rights respected, people with dementia are often treated as second-class citizens. This has got to stop.

In this new report, using data from a survey of nearly 300 care home managers and first-hand testimony from people affected by dementia, we set out what needs to be done to ensure people with dementia who live in care homes are given equal access to NHS services they are entitled to and deserve.

This report is not an exhaustive account of all the issues that affect care homes and the people with dementia who live in them. Other important issues include funding, training and turnover of staff, pay and conditions, activities and the physical environment. Access to primary and secondary care is, however, an under-investigated issue of critical importance to people with dementia. By acting on the recommendations set out in this report, the quality of care for those with dementia living in care homes will dramatically increase.

A handwritten signature in black ink, reading "Jeremy Hughes". The signature is written in a cursive style with a horizontal line underneath the name.

**Jeremy Hughes CBE**  
**Chief Executive**

# Foreword from Care England

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**Our members, who provide care for some of the most vulnerable people with the most complex health and care needs, have been telling us for years how difficult they find accessing quality healthcare free at the point of use for their residents. This is due to the health service's frequent disregard for care homes and their residents.**

A care home is a person's home, and health services must treat care homes as vital parts of a community, rather than abandoning older people, as it can sometimes feel for care providers, residents and families.

Good relationships between care homes and GP services are vital for high-quality care, as is an end to charging retainer fees for services that are considered 'core' under the General Medical Services contract. In order to stop unfair retainer fees, which effectively ask care homes and residents to pay twice for care, this report demands clarification about what constitutes core and enhanced services.

As carers and advocates for the people in their care, care homes have also long complained about delays in secondary services that should be offered free at the point of use. We know that mental health care is the subject of a new NHS England taskforce, but care homes are still being disregarded in this area, as this report demonstrates. As well as access to mental health services, basic provision of continence aids varies across the country, with 50 per cent of areas not providing the continence services they should to all care home residents. Good continence management, podiatry and dentistry ensure comfort and dignity for people with dementia, while timely care minimises distress and confusion.

Care England wants to see better working between health and care services, but also more innovative thinking. There are pilots across the country, experimenting with new models of care between GPs and care homes. Clinical commissioning groups (CCGs) must listen to, and engage with, care homes to move this work forward, and the government must invest to give local areas the resources and tools to pursue these new solutions.

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Dementia can be confusing and debilitating, but excellent dementia care can support older people to live dignified and interesting lives at every stage of their condition. Poor healthcare provision must not hamper good care homes from providing good care, and valued members of society from living fulfilled lives.

Care England is very pleased to work with Alzheimer's Society to raise awareness about poor healthcare provision to care homes, and would like to thank the care home managers who participated in this research for their vital and enlightening contributions.



**Professor Martin Green OBE**  
**Chief Executive, Care England**

Department of Health Independent Sector Dementia Champion



# Summary

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**A new Alzheimer's Society investigation has found that the NHS is treating many of the 280,000 people with dementia who live in care homes like second-class citizens. People are receiving a second-rate service and, to add insult to injury, are paying for the privilege.**

Care home managers have told us that the NHS is failing to provide adequate, timely access to vital services including continence advice, physiotherapy and dentistry. We have also found that some GP practices are wrongly charging care homes, and the people who pay care home fees, for NHS services that should be free.

These practices contravene the NHS Constitution, which states that everyone, regardless of who they are or where they live, should have access to the NHS services they need and these should be free at the point of use.

Our investigation, based on a survey of 286 care home managers undertaken in partnership with Care England, found that:

- 45 per cent of care home managers disagreed or strongly disagreed that the health service provides residents with dementia with adequate and timely access to mental health services.
  - 44 per cent of care home managers disagreed or strongly disagreed that the health service provides residents with dementia with adequate and timely access to NHS secondary care.
  - 21 per cent of care homes are charged by their GP practices for regular visits to attend to all registered patients who need primary care which, unless GPs are providing additional services, should be provided for free.
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Poor access to NHS services is damaging the health and wellbeing of people with dementia. Our investigation found shocking examples of the effect of long waiting times and lack of local services. This included people with dementia:

- being prescribed pain relief over the phone for a broken collar bone
- being prescribed the wrong drugs as a result of a GP's insistence on conducting consultations over the phone
- waiting for a year for physiotherapy following surgery
- waiting for three months for continence products
- waiting for eight weeks for a mental health referral, despite being identified as at risk of suicide
- being restrained under an emergency Deprivation of Liberty Safeguard, due to a lack of mental health care
- spending three months in hospital due to a lack of mental health services.

People with dementia are being failed by an NHS that is not person-centred enough. The Secretary of State for Health, Jeremy Hunt, has committed to making healthcare 'human-centred and not system-centred'. But we have found that vital NHS services, such as continence supplies and assessments, are being provided inconsistently and when it is convenient for the NHS, not when it is needed by people with dementia.

Paying for services that should be free on the NHS is unfair on cash-strapped people with dementia, care homes and local authorities. People with dementia and carers are already getting a poor deal – paying two-thirds of the economic cost of dementia.

Carers of people with dementia contribute £11.6 billion of unpaid care and people with dementia and carers spend £5.8 billion on social care as a result of means-testing (Alzheimer's Society, 2014). This is in contrast to other conditions, such as heart disease and cancer, where the NHS provides care that is free at the point of use.

Care homes are also under unprecedented financial pressure as a result of a near one-third reduction in government spend on adult social services since 2010, alongside increases in demand and costs.

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To transform the service that many people with dementia who live in care homes receive, and to end unfair charging, Alzheimer's Society is calling for the government to:

- 1. End charging for providing access to a standard primary care service.** Alzheimer's Society is calling for the government to clarify the GP contract to ensure that GP practices do not charge for delivering a standard primary care service. This should include a clear definition of 'core' and 'enhanced' services.
  - 2. Enforce the NHS Constitution to ensure that people with dementia living in care homes have equal access to secondary care services.** Alzheimer's Society is calling for CCGs and relevant NHS providers to develop effective local pathways to ensure that people with dementia who live in care homes have equal access to secondary services.
  - 3. Enforce the NHS Constitution to ensure that people with dementia living in care homes have equal access to mental health services.** Alzheimer's Society is calling for CCGs and community mental health trusts to develop effective local pathways to ensure that people with dementia who live in care homes have equal access to mental health services.
  - 4. Improved healthcare support for care homes.** Alzheimer's Society is calling for the government to support improvements in the availability of district and community nursing in care homes. This can help people with dementia receive better care, closer to home and reduce pressure on primary and secondary care.
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# Fix Dementia Care:

## Key care home statistics

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This report is informed by a survey of 286 care home managers and the voices of people with dementia, their families and carers. The findings from these investigations can be found below.



**Alzheimer's Society** estimates that the total cost of **GP charges** to care homes exceeds **£26 million** a year in England.



**280,000** people with dementia live in **care homes** in the UK.



**One in five care homes** surveyed are being **wrongly charged** for services that should be **free on the NHS**.



**Poor access to NHS services** has led to people with dementia being **bedbound, incontinent** and **sedated**.

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**GP charges** are as high as **£36,000** a year in **one care home**.



The average GP charge of **£12,191** a year is enough to fund care for a person with dementia for **nearly six months**.



**70%** of care home residents are living with dementia.



**44%** of care home managers surveyed told us that the **NHS** isn't providing residents with dementia with **adequate and timely access to NHS secondary care**.



**45%** of care home managers surveyed told us that the **NHS** isn't providing residents with dementia with **adequate and timely access to mental health services**.

# 1 Physical and mental health needs of people with dementia in care homes

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**Many people with dementia move into care homes as their dementia progresses. Good quality care that preserves dignity, treats people with respect and promotes independence can improve the lives of people with dementia who live in care homes.**

Many people with dementia who live in care homes have high levels of healthcare needs as a result of the cognitive, physical, psychological and behavioural symptoms of dementia. On top of this, many people with dementia who live in care homes have another physical or mental health condition such as heart disease, stroke or depression.

## **Physical health of people with dementia living in care homes**

- 198,000 people with dementia are living in a care home with dementia and another condition
- 41 per cent of people with dementia have high blood pressure
- 27 per cent of people with dementia have heart disease
- 18 per cent of people with dementia have had a stroke or 'mini stroke'
- 13 per cent of people with dementia have diabetes.

## **Mental health of people with dementia living in care homes**

- 90 per cent of people will experience behavioural and psychological symptoms of the condition
  - 60 per cent of residents in care homes have mental health conditions
  - 63,000 of the estimated 280,000 people with dementia in the UK who live in a care home have depression.
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## 2 Unfair charges for GP services

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**The NHS Constitution states that everyone, regardless of who they are or where they live, should have access to NHS primary care that is free at the point of use.**

Many GPs make regular visits to care homes to provide primary care to residents. This recognises the fact that, for a resident, the care home is their home and GPs should make home visits when a person is unable to attend a surgery. Regular visits, from a GP of their choice wherever possible, can have benefits for people with dementia, GPs and care homes as health problems are detected earlier, preventing escalation and making treatment easier. But 44 per cent of care home managers who responded to our survey said that their GP did not make regular visits to provide primary care.

We have found that some GP practices are wrongly charging care homes, and the people with dementia who pay care home fees, for services that should be free on the NHS. Over a fifth of care home managers who responded to our survey, told us that their GP practice charged them for a regular visit to their care home to provide primary care. GPs should not charge for primary care unless they are providing a non-standard service, such as a hospital-style ward round.

Many people with dementia will pay these charges indirectly. Of the people aged over 65 who live in a care home, 53 per cent pay for their own care in full or in part (LaingBuisson, 2015). Care homes fees will usually take into account the cost of core services such as additional GP charges for primary care.

### Cost of charges made by GPs

Our survey of care home managers suggests that some GPs are charging care homes significant amounts of money for regular visits to attend to all registered patients who need primary care. Care home managers reported charges ranging from £1,690 to £36,000 per year for their home, a mean average of £12,191.

Based on these figures, we estimate that the total cost of GP charges for regular visits to attend to all registered patients who need primary care is £26.4 million per year. This calculation assumes, based on our investigation, that 21 per cent of England's 10,331 CQC registered care homes for older people are charged a mean average fee of £12,191 by their GP.

Care homes are being forced to spend money on GP charges that could be better spent on one-to-one care for people with dementia. The average GP charge of £12,191 is enough to fund care for a person with dementia for nearly six months. This calculation is based on the £25,610 average annual cost of residential care for a person with dementia (Alzheimer's Society, 2014).

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## Charging for visits to provide primary care

GPs practices are acting outside their contract if they charge care homes for a visit to provide standard primary care. The General Medical Services (GMS) or Personal Medical Services (PMS) contracts – the main contracts between general practices and NHS England – state that services to patients who are registered with a practice, or who are temporarily registered, must be provided free of charge.

The GMS contract does not permit charging for standard primary care. Schedule 5 of the contract does outline some circumstances under which GPs can charge for services. However, it also states that the service must not be a 'primary care service'. GPs can charge for non-standard primary care, such as a hospital-style ward round to inspect all patients, but only if agreed in a separate contract between the care home and the GP practice.

To end this unfair practice, Alzheimer's Society is calling for the government to clarify the GP contract to ensure that GP practices do not charge for delivering a standard primary care service.

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## 3 Access to primary care

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**Alzheimer’s Society has found evidence that, in some cases, people with dementia are receiving poor primary care. Care home managers and carers told us about GPs prescribing pain relief over the phone for a broken collar bone, prescribing the wrong drugs following a phone consultation and refusing to attend an out-of-hours emergency.**

Effective primary care is essential for people with dementia. GPs provide people with dementia with both direct support, including general advice on health and wellbeing as well as medical advice and treatment, and indirect support through referral to secondary care. Treating even minor complaints can make a considerable difference to a person’s wellbeing.

### The cost of poor access

Poor access to GP services can result in people with dementia experiencing unacceptably long waits for treatment, unnecessary emergency admissions to hospital and worsening of their condition. One care home manager reported, ‘repeated requests for a GP to visit a resident who was not improving following a fall. Three months later, the lady was found to have a fracture of her hip that, upon surgery, was found to be ‘necrotic’ (containing dead tissue, a condition that cannot be reversed). Another care home manager told us, ‘A person had a fall. The GP was requested and did not attend and prescribed pain relief over the phone. Further requests were made for the GP to attend and they still did not attend. The person was taken to hospital for x-ray and found to have a fractured collar bone.’

Refusal to attend can, in many cases, be a false economy as it can result in an avoidable escalation of a person’s health needs. One care home manager reported that a GP who refused to attend the home ‘carried out a consultation over the phone instead and then prescribed the wrong antibiotic, needing us to request a further visit’.

### Refusal to register patients

In addition, we received a small number of reports of GP practices refusing to register older people as patients once they moved into a care home. One care home manager told us that ‘no GP wants them’. Care England has also received evidence from its members that some GP practices are writing to care homes to say that they must de-register the care home completely or de-register individual residents.

Our investigation suggests that many people with dementia who live in care homes receive good access to primary care. However, 15 per cent of care home managers disagreed, or strongly disagreed, that the health service provides residents with dementia with adequate and timely access to GP services. This extrapolates to 1,550 care homes in England. Given the importance of adequate and timely access to GP services for people with dementia, both in terms of access to primary care and referral to secondary care, this is unacceptable.

To help reduce pressure on primary care, Alzheimer’s Society is calling for the government to improve the availability of district and community nursing in care homes. This can help people with dementia receive better care, closer to home and reduce pressure on primary and secondary care.

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## Jean and Tracey's story: access to out-of-hours GP service

Jean, 85, was diagnosed with vascular dementia 13 years ago. She has been in a care home for 11 years and was previously looked after at home by her daughter, Tracey, 50.

Jean has been very well cared-for in her care home but she struggled to get access to an out-of-hours GP at the weekend when she had an allergic reaction to antibiotics. Jean often contracts urinary tract infections, for which she needs antibiotics. On one occasion she had been prescribed antibiotics and a terrible rash appeared on her legs and started to spread rapidly up her body. Having assessed this wasn't an emergency situation, the care home contacted the out-of-hours service to get a GP to come out to see Jean in person. Tracey visited her mum and described how she had a high temperature and was shaking. She was hallucinating and was very upset, pleading with Tracey to help her. Jean also has chronic obstructive pulmonary disease (COPD), which affects her breathing and was exacerbated by the allergic reaction.

The out-of-hours service was called at 10am and the care home was told it would be up to six hours before someone would come. In fact it took 17 hours and numerous phone calls. More than 12 hours after the first call a GP rang the home. He was under the impression that Jean was on a palliative care plan and refused to come out. The doctor was very impatient and rude when care home staff told him that this was not the case. He told them to call the out-of-hours number again so the care home had to re-register the request. Hours later help arrived.

Tracey said, 'The agony my poor mother went through was terrible. Thankfully she recovered, but in those long hours I was so worried. No one seemed to take into account Mum's vulnerability and to wait that long after so much chasing – it was unacceptable. I was left so unhappy and tired because I hadn't left my mother's side from the moment she became unwell until her recovery. The whole incident left me feeling like no one cared about older people, especially not people with dementia'.



Tracey



## Putting it right: integration of primary care and social care in Southend

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GP practices in Southend CCG often have patients on their registers from several care homes due to a higher than average number of care homes in the area. As a result, GPs are often required to visit a number of different care homes. This can make it difficult to build working relationships with care home staff and, because of the travel required, can put pressure on GPs' time. This has created pressure on primary care services in the area.

To help improve the lives of people who live in care homes, Southend CCG has launched a new model of care. The scheme, which is due to start in April 2016, will include a new virtual GP practice that will cover all of the older people's care homes in the area (although care home residents will retain choice over which practice they register with). The service will run initially as a 12-month pilot to enable the service to be tested and refined.

Other features of the scheme include:

- a full medical review and medication review for all new patients
- an agreed care plan, which may include end-of-life planning, for all new patients
- a named care co-ordinator for each patient
- regular reviews for all patients as clinically required
- an out-of-hours GP service
- integration of dementia services into primary care as a result of the mental health review
- pain and depression assessments in all dementia assessments
- close liaison with dementia nurses and Alzheimer's Society.

## 4 Access to NHS secondary care

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**We rely on the NHS to be there for us when we need it. Many of us take this access for granted, but this is not the reality for many people with dementia who live in care homes.**

By letting down people with dementia like this, the NHS is failing to live up to our expectations as a nation. But it is also failing to live up to its constitution which demands that everyone, regardless of who they are or where they live, should be able to access the NHS services that they need.

Many people with dementia who live in care homes have high levels of healthcare needs as a result of dementia. On top of this, many may also have another physical or mental health condition such as heart disease, stroke or depression.

Good access to NHS secondary care can help people with dementia maintain independence, dignity, wellbeing and comfort. Poor access to secondary healthcare services can result in people with dementia being left isolated, distressed, bedbound or left in pain. It also makes emergency hospital admissions more likely.

### **Second-class care**

Alzheimer's Society has found that the NHS is providing many of the 280,000 people with dementia who live in care homes with a second-class service. Of the care home managers who responded to the survey, 44 per cent disagreed or strongly disagreed that the NHS provides people with dementia who live in care homes with adequate and timely access to NHS secondary care.

Our investigation has uncovered troubling examples of the effect of long waiting times and lack of local services. Care home managers and carers told us about people with dementia being robbed of their dignity, self-esteem and independence by waiting months for services such as continence supplies and physiotherapy.

Previous research has also found that people living in care homes have poorer access to NHS secondary care. This is despite the fact that people living in care homes tend to have greater levels of need. In 2010, the British Geriatrics Society (BGS) assessed primary care trusts' (PCTs) provision of core secondary care services including nursing for immediate needs, services that support re-enablement and diagnostic medical services. The BGS found 'important service gaps in most PCTs'. Only 43 per cent of PCTs provided all services to older people living in care homes and 29 per cent provided seven services or fewer. The BGS also found that only 24 per cent of services had a specific referral process for people living in care homes (British Geriatrics Society, 2010).

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We have investigated access to four key NHS services that are vital to the health and wellbeing of people with dementia who live in care homes. These are:

- physiotherapy and reablement services
- continence services
- hospital outpatient services
- dentistry.

To transform the service that the NHS provides to people with dementia living in care homes, Alzheimer's Society is calling for CCGs and relevant NHS providers to develop effective local pathways for referral to secondary care from care homes. Improvements in healthcare support for care homes, as outlined in this report's recommendations, would also help people with dementia receive better care and reduce pressure on primary and secondary care.

### **Physiotherapy and reablement services**

Many people with dementia experience poor balance, which increases their risk of falling, or, following a fall, of reduced mobility. Our previous investigation, *Fix Dementia Care: Hospitals* (Alzheimer's Society, 2016), found that 34 per cent of people with dementia stay in hospital for over a month, four times longer than average, following a hip fracture. In addition, many people with dementia suffer from pain that they struggle to express.

Good access to physiotherapy can help people with dementia to avoid falls by improving balance and co-ordination, to regain mobility and independence following a fall and to live in comfort by identifying and treating pain (Chartered Society of Physiotherapy, 2011).

Poor access to physiotherapy can damage the independence of people with dementia. We have found worrying examples of the effect of long waiting times and lack of local services. For instance, one care home manager told us, 'We had one service user who fell and had a hip fracture. Physio follow-up in the community took over a year.'

## Ben and Frances's story: physiotherapy

Ben, 70, was diagnosed with mixed dementia in December 2013. His wife Frances, 59, was able to care for him at home for almost a year but Ben's dementia deteriorated to the point where he needed 24-hour specialist care. Things reached crisis point and he was moved into a care home as an emergency admission. Ben began to lose weight, dropping five and a half stones. He became very weak and was only able to eat pureed food. He was so unwell that his GP suggested a palliative care plan.

Frances believes the inappropriate use of antipsychotic drugs was responsible for Ben's decline. The GP eventually agreed to stop Ben's medication in March 2015 and he regained his ability to eat and drink, but is still bedbound as he is too weak to get out of bed. He desperately needs access to a physiotherapist. For some time Frances has also been fighting to get him an NHS special wheelchair assessment. After little progress, Ben may be able to receive funding from a charity to secure a wheelchair. For now, however, he is still bed bound.

Frances sums up this experience which continues to be distressing for both Ben and herself and describes her feelings of helplessness: 'Ben has gone from being a strong 14-stone man to a bedbound, eight-and-a-half-stone shell. He needs access to NHS services in order to build his strength and get back some of the independence that he once had. It shouldn't be this hard to try and get him the support he so desperately needs. I've fought like a tiger to try and get Ben back on his feet; it's difficult because he can't ask for the care he needs himself. I visit him every day to always be by his side but it's an hour on the bus. It's so lonely for both of us'.



Frances

## Continence services

Many people with dementia experience difficulties with using the toilet, accidents and incontinence, especially as the condition progresses. These problems can be upsetting for both the person and those around them. But good access to continence services, provided by specialist urologists or continence nurses, can help manage the condition and increase dignity and comfort for people with dementia (Alzheimer's Society, 2013).

Poor access to continence services can rob people with dementia of their dignity and self-esteem. Research conducted for this report uncovered shocking examples of the effect of long waiting times and lack of local services. Care home managers and carers told us about people with dementia waiting for months for continence supplies and assessments. One care home manager told us, 'Assessments take months to arrange, then when the assessment is completed the wait is again months. One resident was assessed in July and was allocated products in October on the next three-month cycle.' Another care home manager explained the human impact of problems with accessing continence services in care homes, saying, 'Residents have to go without continence aids, leaving them isolated, with no dignity and low self-esteem.'

People with dementia are being failed by an NHS that is not person-centred enough. The Secretary of State for Health, Jeremy Hunt, has committed to making healthcare 'human-centred and not system-centred'. But these examples show that this is not the case for many people with dementia.

Previous research has also found poor access to continence services and unfair charging. Care England, in a recent Freedom of Information request, found that only around half of CCGs are funding or supplying continence aids for every care home resident, as they are statutorily obliged and funded to do. The remaining half are either providing continence aids to only some residents on an erroneous and arbitrary basis, or are not providing care home residents with continence aids at all.

## Hospital outpatient services

The number of people with dementia living in care homes who need hospital outpatient services is increasing (Care Quality Commission, 2014). People with dementia may go into hospital for a planned procedure such as an operation, if they are seriously ill or if they have an accident or fall. This report looks at planned procedures. Alzheimer's Society's previous investigation, Fix Dementia Care: Hospitals (Alzheimer's Society, 2016), covers care in hospitals in more detail.

Effective pathways between care homes and hospitals can help prevent unnecessary deterioration in the health and wellbeing of people with dementia. The Care Quality Commission (CQC) has found that comprehensive assessment, sharing information, managing risks and monitoring and improving the quality of care is crucial to improving the experiences of people with dementia as they move between care homes and hospitals.

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Poor arrangements for access to hospital outpatient services can cause people with dementia distress and worsen their condition. This research has found examples of people with dementia being forced to make long, uncomfortable and distressing journeys, then wait for delayed appointments. One care home manager told us, 'Outpatient appointments require our residents to travel some distance and it is difficult to keep our residents comfortable and engaged. It also doesn't help that, once they have arrived at the hospital, their appointment is often not on time so we end up having to wait. What with this, and the time it takes for ambulance transport to pick them up and escort them back, it can sometimes be eight hours before our residents are back home from a hospital visit.'

Previous research has also found that poor pathways between care homes and hospitals are resulting in people with dementia receiving poor care. In 2014, the CQC found variable or poor care regarding arrangements for sharing information when people moved between services in 83 per cent of hospitals (Care Quality Commission, 2014).

### Case study: hospital inpatient services

**One care home manager told Alzheimer's Society about the difficulties she experienced when taking a resident with advanced dementia for an x-ray appointment. Because of his advanced dementia, he struggled to understand why he needed to visit the hospital.**

In order to make the visit less stressful, the care home manager asked whether the hospital could give him a specific time for his x-ray. Based on her experience, she knew that minimising the amount of waiting time 'would help to prevent him becoming distressed in an unfamiliar environment and avoid disruption for the hospital staff'.

Unfortunately, the hospital didn't agree to her request. As a result, the man was 'very distressed throughout the x-ray'. Distressingly, for him and other patients, hospital staff decided that they had to restrain him. Ultimately, he had to be admitted to hospital overnight and returned to the home the next day by special ambulance.

Summing up, the care home manager told us, 'The whole appointment was unsuccessful and distressing for everyone involved. If the hospital had just agreed to give the man a time slot in advance, his x-ray could have been taken without upset and relatively easily. It also would have meant he didn't need to be admitted to hospital and spend the night away from home.'



## Putting it right: integration of secondary care and social care in Sutton

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To help improve the lives of people living with dementia in care homes, the London Borough of Sutton, in partnership with other organisations including Alzheimer's Society, has joined NHS England's vanguard programme to pilot new models of care. The scheme, called Sutton Homes of Care, covers a registered GP population of 203,048 along with 26 GP practices.

Sutton Homes of Care is offering a new model of health and social care that will include expanded in-reach services. This means that, instead of in-patient hospital stays, care home residents will now get the care they need from hospital specialists at home. This is particularly important for people with dementia as it helps to minimise the disorientation and confusion that they can experience in new environments.

To help improve quality of life for people who live in care homes, a care home provider network has been established to support training across local care homes. A multi-disciplinary forum where health professionals and care home managers can meet to discuss any issues has also been created. This has helped to strengthen relationships between health and social care, with care home managers reporting that, 'the agendas and constructiveness of the meetings have gone from strength to strength'.

To support the scheme, Alzheimer's Society is providing each care home with a dementia support worker (DSW) to work with a cluster of care homes and provide guidance and support to staff and people with dementia and work in partnership with care home staff and health professionals to provide a consistently high level of care. The DSW will also develop a tailored support package to: ensure consistent levels of care; encourage a holistic, person-centred approach to healthcare; and facilitate the sharing of best practice.

Sutton Homes of Care has seen a reduction in hospital admissions and, where hospital admission is required, improved handovers between hospitals and care homes. In the longer term, reductions in the length of hospital stays are expected.

## Dentistry

Good access to dentistry can help improve the health and wellbeing of people with dementia living in care homes. It can help prevent pain and discomfort in the mouth and jaw, which can cause distress and worsen the symptoms of dementia. It can also help to limit the adverse impact that chewing difficulty can have on nutrition and general health (British Dental Association, 2012).

Poor access to dentistry is resulting in people with dementia being unable to eat or left in pain. During our investigation we found numerous examples of people with dementia who live in care homes being unable to register with a dentist.

Previous research has also found that many people with dementia have poor oral health and a high level of need for treatment. One study in Cheshire found that care home residents with moderate or severe dementia had worse outcomes with regards to dental plaque and calculus levels and denture stability than residents with moderate or no dementia. Another study in Avon found that 71 per cent of residents had not seen a dentist for five years (British Dental Association, 2012).

### Case study: dentistry

**One carer told us about the struggles she faced in trying to get NHS dental treatment for her mum. Her mum has been living in a nursing home for nearly two years now. In the last few months, she misplaced a set of dentures, making eating difficult as well as having an effect on her appearance.**

‘As a once very smart lady who took great pride in her appearance, it saddens my dad and me to see how she has aged further without her full set of teeth. Her previous dentist no longer has her details registered.

Before her diagnosis, she was reluctant to get new teeth as they felt uncomfortable to begin with so she put off seeing the dentist. With the onset of dementia and the passing of time, her records were closed and every dental practice I have contacted in the area no longer take on new NHS patients or offer support to vulnerable patients, which is really quite unsettling. Imagine if our GPs took the same approach.

Dental health at this age is not taken seriously. Dentists should have a duty of care towards vulnerable people and take on their fair share of residential home patients’.

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## 5 Access to mental health services

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**In its recent update of the NHS Constitution, the government has committed to achieving parity of esteem between mental and physical health services. However, this rhetoric does not match the reality of the experiences of many people with dementia.**

Many people with dementia who live in care homes have high levels of mental health needs as a result of the cognitive, psychological and behavioural symptoms of dementia and other mental health conditions such as depression.

People with dementia who live in care homes need good access to mental health services to treat both the mental health symptoms of dementia and other mental health conditions. Good access to mental health services can help people with dementia to maintain quality of life, wellbeing, social interaction and develop strategies to improve health and wellbeing. Poor access can leave them isolated, anxious and distressed.

Our investigation has found that many people with dementia living in care homes struggle to access the mental health services that they need. Our survey found that 45 per cent of care home managers disagreed or strongly disagreed that the health service provides residents with dementia with adequate and timely access to mental health services.

### Effects of poor access

Evidence collected for this report shows the devastating effect of long waiting times and lack of local services. Care home managers and carers told us about people with dementia being restrained under emergency Deprivation of Liberty Safeguards or placed on antipsychotic medication for months.

Poor access to mental health services is resulting in people with dementia being placed on antipsychotic drugs that are linked to serious side effects, including a doubling of mortality (All-Party Parliamentary Group on Dementia, 2008). One care home manager told us that a person with dementia suddenly:

‘... became anxious, shouting and disturbing to others. A urinary tract infection was treated, but paranoia continued. She was absolutely adamant we were hiding her husband. I approached the council. It took ages to allocate a social worker and, when they did, he naturally wanted a mental health referral. That referral was made by the GP two months ago and still hasn't happened. The lady has ended up on risperidone and heavily sedated most of the time’.

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Poor access to mental health services is also resulting in people with dementia being admitted to hospital or, as the case study opposite shows, being restrained under an emergency Deprivation of Liberty Safeguard. One care home manager told us that, on admission to a local NHS mental health assessment centre, they were told that 'the nearest bed was on the other side of country. The lady's physical health began to deteriorate because of her mental health issues. She ended up in hospital for three months. There was still no mental health bed at the end of that time near her family'. Local authorities can only approve restraint if a set of conditions, known as Deprivation of Liberty Safeguards, have been met.

We are concerned by evidence suggesting that long waiting times and lack of local mental health services may be putting the lives of people with dementia in danger. One care home manager told us that 'a resident with mental health issues who was saying she felt suicidal had to wait over eight weeks to be referred to mental health services'.

### **Underfunding of mental health services**

A number of care home managers blamed underfunding for poor access to mental health services. One care home manager described the impact of underfunded local mental health services. Crisis cases 'are soon closed as caseloads are too heavy for the workers as the service is under-resourced locally'. Professionals also suggested that better use could also be made of available resources. Mental health professionals, for instance, could be more involved in training care home staff and planning support in order to ensure that the maximum number of people with dementia benefit from their expertise.

These findings support previous research indicating that people living in care homes have poorer access to mental health services. This is despite the fact that they tend to have greater levels of need. Previously, the Mental Health Foundation has found that only about 15 per cent of all older people with depression are diagnosed and receive treatment. In 2007, the Royal College of Psychiatrists attributed this to discrimination, saying that, 'older people do not have access to the range of services available to younger adults despite having the same, and often greater, need'.

To improve access to mental health services for people with dementia who live in care homes, Alzheimer's Society is calling for CCGs and community mental health trusts to develop effective local pathways to ensure that people with dementia who live in care homes have equal access to mental health services. We are also calling for greater involvement of mental health professionals in the training of care home staff.

## Case study: access to mental health services in a care home

One care home manager told us about the impact on a person with dementia and other residents when a community psychiatric nurse (CPN) refused to attend. The incident took place just before Christmas. One resident with dementia had become very distressed and bruised another resident in an altercation.

Because of the risk to himself and other residents, the care home manager wanted to move him to a more suitable part of the home. She 'checked with his family and they were happy for us to move him but we wanted to double check with our local CPN that this was a good idea and wouldn't make the situation worse'. However, the CPN told the care home that she was 'too busy because of it being near to Christmas'.

As a result of the CPN's refusal to attend, the care home manager was forced to seek an emergency Deprivation of Liberty Safeguard to restrain him and prevent him harming himself or other residents. She also had to report the incident to the CQC as it had resulted in physical injury. Summing up, the care home manager told us that 'the incident was stressful for all staff involved and I felt very let down by the CPN'.



### **Putting it right: preventative visits to reduce mental health referrals in Gloucestershire**

One care home manager told us about Gloucestershire NHS Trust's care home support team (CHST). This provides a wide range of education, training and hands-on support to care home staff to help improve residents' quality of life. The CHST's mental health professionals focus on people living with dementia and person-centred care.

In order to help identify mental health issues early and reduce emergency mental health referrals, the care home manager told us that one of the CHST's mental health nurses makes a monthly visit to her home. The CHST also provides training for care home staff. For instance, staff are trained to use 'ABC' incident charts to record details of what happened before, during and after a mental health episode. This helps to improve the understanding of the behaviour of residents with dementia, identify triggers for the behavioural and psychological symptoms of dementia and prevent future mental health episodes.

## 6 Recommendations

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To ensure that people with dementia who live in care homes receive the same service the rest of us expect from the NHS, Alzheimer's Society is calling for the government to take the following actions:

### **Recommendation 1: End charging for providing access to a standard primary care service**

Alzheimer's Society has found that a significant number of GP practices are charging care homes for regular visits to attend to all registered patients who need primary care. Alzheimer's Society is calling for the government to clarify the GP contract to ensure that GP practices do not charge for delivering a standard primary care service. This should include a clear definition of 'core' and 'enhanced' services.

### **Recommendation 2: Enforce the NHS Constitution to ensure that people with dementia living in care homes have equal access to secondary care services**

Alzheimer's Society has found that many people with dementia living in care homes struggle to access the secondary services that they need. Alzheimer's Society is calling for CCGs and relevant NHS providers to develop effective local pathways to ensure that people with dementia who live in care homes have equal access to secondary care services.

### **Recommendation 3: Enforce the NHS Constitution to ensure that people with dementia living in care homes have equal access to mental health services**

Alzheimer's Society has found that many people with dementia living in care homes struggle to access the mental health services that they need. Alzheimer's Society is calling for CCGs and community mental health trusts to develop effective local pathways to ensure that people with dementia who live in care homes have equal access to mental health services.

### **Recommendation 4: Improved healthcare support for care homes.**

Alzheimer's Society is calling for the government to support improvements in the availability of district and community nursing in care homes. This can help people with dementia receive better care, closer to home and reduce pressure on primary and secondary care.

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### **Putting it right: care practitioner**

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Barchester Healthcare is investing in piloting and developing the care practitioner role in its care homes.

Care practitioners will be trained in a number of key nursing skills, allowing nurses to focus on more complex nursing tasks and prioritise their workloads more effectively.

Importantly, the care practitioner will not replace a nurse in a nursing home. Care practitioners will instead take on some of the more basic tasks of nursing care and continue to be line-managed by the nurse on duty.

Throughout their training, care practitioners will be paired with a clinical mentor to support their professional development.

The care practitioner role has the potential to manage the impact of the current nursing shortage, improve care quality for residents and reduce pressure on NHS primary and secondary care services.

# Appendix 1: Report methodology

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This report draws on a quantitative and qualitative survey of care home managers conducted in partnership with Care England. The survey was conducted between 6 January and 16 February 2016 and 286 care home managers responded. The report also draws on a survey of people with dementia, their families and carers, undertaken through social media and emails.

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## Appendix 2: References

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# Notes

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Leading the fight  
against dementia

**Alzheimer's  
Society**

**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.**

**Alzheimer's Society**

Devon House  
58 St Katharine's Way  
London E1W 1LB

T **020 7423 3500**  
F **020 7423 3501**  
E **info@alzheimers.org.uk**  
W **alzheimers.org.uk**

Code 946

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