

Dementia

Finding housing solutions



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The Dementia Services Development Centre, based at the University of Stirling, is an international centre of knowledge and expertise dedicated to improving the lives of people with dementia. It draws on research and practice, from across the world, to provide a comprehensive, up-to-date resource on all aspects of dementia and provides award-winning training and education.

www.dementia.stir.ac.uk

The Housing Learning and Improvement Network is a member of the Dementia Action Alliance. Get further information about the Housing LIN's comprehensive list of online resources at 'In Focus: Innovations in Housing and Dementia', and opportunities for shared learning and service improvement:

www.housinglin.org.uk

Foundations is the national body for home improvement agency and handypersons services. Foundations provides support to the home improvement agency sector through providing advice, training and support to home improvement agency staff, and representing the sector in discussions with government and other stakeholders.

www.foundations.uk.com

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Foreword

Improving the quality of care for people with dementia is a national priority. We know that timely diagnosis and intervention can help prevent crisis, which may result in unnecessary hospital admissions. Diagnosing dementia, and providing the support and advice following diagnosis can allow people to live well with their condition. However, it is the integration of care across health and social services which will help allow people to return to their own home following an admission.

Dementia costs more than cancer, heart disease and stroke combined, with the cost of care accounting for a large part of the total expenditure¹. Delaying the need for nursing and residential care would reduce this cost and improve outcomes for people with dementia. Early intervention could also shorten the length of stay when someone is admitted to hospital, and the chance of readmission following discharge. It can also reduce the need for longer term forms of institutional care, such as nursing or residential care².

I believe we need to think more about the role that housing organisations have to play in providing the infrastructure and the services that allow people with dementia to carry on leading their lives, as part of the community, in their own homes.

There are many examples of good practice in this guide, from housing associations and home improvement agencies, providing a range of flexible support, specialist housing and home adaptations, which allow people to live well with their condition. This in turn helps their families and carers, the local NHS and social care services.

When frontline housing staff are equipped with the necessary skills to spot the signs of dementia, housing organisations are well placed to develop dementia friendly communities. They can not only support their own residents, but also those in the wider community, to get a formal diagnosis and access advice and support. Becoming a Dementia Friend³ is a great way of doing this.

Over the next ten years, the number of people living with dementia is set to rise to over one million. The majority of these people will live in the community, in their own homes, and they want to stay there for as long as possible. Early intervention services centred on people's homes have the greatest potential to improve the quality of life of people with dementia and their carers.



A handwritten signature in black ink that reads "Alistair Burns". The signature is written in a cursive style with a horizontal line underneath.

Alistair Burns
National Clinical Director
for Dementia for England

1. Lluengo-Fernandez R, Ieal J, Gray A (2010), Dementia 2010
2. Department of Health (2009), The clinical and health economic case for early diagnosis and intervention services in dementia
3. Dementia Friends is a scheme run by the Alzheimer's Society

Summary

There are 800,000 people with dementia in the UK at present and this is expected to rise to 1m by 2021¹. The Alzheimer's Society estimates that dementia costs the UK £23bn per annum, with £8bn of that cost hidden by the work done by family carers supporting people at home².

In recent years we have begun to improve our understanding of what it means to live with dementia and the ways in which people can be supported to continue living independently with the condition. Dementia is now firmly established as a priority for action in the UK. In 2009, the Department of Health published Living Well with Dementia, the national dementia strategy, which set out proposals for raising awareness of dementia, improving dementia care and encouraging early diagnosis. In March 2012, the Prime Minister set out the challenge on dementia, which aims to push progress on all the areas identified in the strategy by 2015.

However, our awareness needs to move beyond the scale of the challenge to understanding different ways to meet these growing needs. People with dementia are currently occupying a staggering 40% of general hospital beds³. The role housing organisations can play in helping people with dementia live independently for longer needs to be clearly understood.



Dementia costs the UK £23bn per annum.

This report highlights how good housing and related services can impact positively on the lives of people with dementia, from delaying more intensive forms of care to preventing admission and readmission to hospital. Case studies from housing associations and home improvement agencies show how appropriate housing can:

- reduce or delay demand for health and social care services for people with dementia
- improve the rate of diagnosis of dementia
- deliver improved health and social care outcomes at a lower cost

The report recommends that commissioners and their local partners work together with housing organisations to enable people with dementia to retain their independence for as long as possible:

- Clinical commissioning groups should work closely with the housing sector to identify where costs build up in different parts of the care and health system, and to design home based solutions that will relieve these pressures.
- Local authorities, housing providers, home improvement agencies and NHS Trusts should work in partnership to develop support services for people with dementia. These bodies should build on existing resources such as specialist housing and frontline support services to maximise opportunities for diagnosis and early intervention.
- Directors of public health should work with housing organisations to increase the diagnosis rates of dementia, building on the existing infrastructure of housing management and support services present within current housing services.

1. Alzheimer's Society Factsheet, 2013

2. Alzheimer's Society Factsheet, 2013

3. Department of Health (2010), Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

Living in your own home – early diagnosis and intervention

Two-thirds of people with dementia live in their own homes or specialist housing, while one-third live in care homes⁴.

Most people with dementia say they would prefer to stay in their own home for as long as possible⁵. Despite half of those who live in their own home living alone⁶, the home can be the best place for someone to manage the consequences of dementia.

It is certainly possible for people with dementia to live independently and have access to support and advice services if they are diagnosed early. Early diagnosis means that the person can maintain and even build on the social and support networks that will keep them independent for longer, and help them prepare for the future and avoid crises⁷. This is much more preferable to people being diagnosed at a time of crisis, leaving them ill prepared for the illness they are living with.

Dementia already costs more than cancer, heart disease and strokes combined, and the cost of institutional care accounts for a very large part of that⁸. Delaying the need for institutional care would drastically reduce that cost. Investing in early intervention services centred on the home improves the quality of life of people with dementia and their carers, allowing them to remain living in the community. Nevertheless, resources are currently being spent ineffectively⁹; despite the strong argument that investing in the early part of the pathway leads to savings later on¹⁰.

The key to early intervention is encouraging people who show signs of dementia to get diagnosed early. By providing support at the point of diagnosis, people with dementia can have more control and be better equipped to manage their condition, cope with the symptoms, and make informed choices about their care.

In the UK only 46% of people with dementia have had a formal diagnosis¹¹. For many people, a diagnosis of dementia is made late on in the illness when they are admitted in an emergency to a general hospital. Only 21% of people with dementia have their dementia diagnosed before hospital admission¹². However, there is strong evidence for the benefits of early diagnosis to individuals and families, as well as to the taxpayer¹³.

There are real advantages for the individual if their dementia is diagnosed early. People with an early diagnosis of dementia appreciate the opportunity to make decisions and plan for how decisions will be made should they lose the competence to make them. Early diagnosis also improves the quality of life of the person with dementia and can reduce stress for carers and other family members¹⁴. Research has shown that giving carers support and counselling at the time of diagnosis can also reduce placements in care homes by 28%¹⁵.



Half of those with dementia who live in their own home live alone.



Early diagnosis and intervention can help to prevent crises, which result in increased hospital admissions for acute medical episodes of care (which often lead to deterioration in someone's condition¹⁶), longer lengths of stay when admitted, increased chance of re-admission when discharged, or other longer term forms of institutional care such as nursing or residential care¹⁷. Early provision of support at home can actually decrease institutionalisation by 22%¹⁸.



Early provision of support at home can actually decrease institutionalisation by 22%.



Only 21% of people with dementia have their dementia diagnosed before hospital admission.



Early diagnosis opens up opportunities for people to put in place positive interventions that help them manage the consequences of their dementia. These preparations might include personal health measures, design and technology adaptations for the home to help manage the behavioural symptoms of dementia, legal preparation for handing over executive and financial functions to trusted friends or relatives, and conscious planning to maximise quality of life. Advice and information can be delivered by a range of community professionals or providers of peer support.

4. Alzheimer's Society (2011), Support. Stay. Save.
5. Alzheimer's Society (2011), Support. Stay. Save.
6. Alzheimer's Society (2011), Support. Stay. Save.
7. Molyneux P (2010), Health and Housing: Worlds Apart?, National Housing Federation
8. Lluengo-Fernandez R, Leal J, Gray A (2010), Dementia 2010
9. NAO (2007), Improving services and support for people with dementia
10. Department of Health (2009), National Dementia Strategy
11. Alzheimer's Society website, 2013
12. RCPsych (2011), Report of the National Audit of Dementia Care in General Hospitals
13. Department of Health (2009), Living well with dementia: A national dementia strategy
14. Mittelman MS, Roth DL, Clay OJ and Haley WE (2007). 'Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention'. American Journal of Geriatric Psychiatry, 15:9, 780–89.
15. Mittelman MS, Roth DL, Clay OJ and Haley WE (2007). 'Preserving health of Alzheimer caregivers: impact of a spouse caregiver intervention'. American Journal of Geriatric Psychiatry, 15:9, 780–89.
16. Alzheimer's Society (2009), Counting the Cost: Caring for People with Dementia on Hospital Wards
17. Department of Health (2009), The clinical and health economic case for early diagnosis and intervention
18. Gaugler JE, Kane RL, Kane RA & Newcomer R (2005), 'Early Community-Based Service Utilization and Its Effects on Institutionalization in Dementia Caregiving'. The Gerontologist, 45, 177–185.

Spotting the signs of dementia

Dementia is the umbrella term for a range of symptoms including memory loss, mood changes, and problems with communication and reasoning. It is caused by diseases of the brain. 62% of people with dementia have Alzheimer’s disease and 17% have vascular dementia. The rest have either a combination of these or dementia with Lewy bodies, Creutzfeldt-Jacob disease or Fronto-temporal dementia.

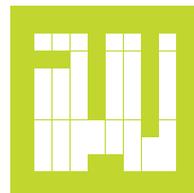
The behavioural symptoms of dementia are reasonably consistent across all its forms. These include depression, apathy, agitation, aggression, delusions, hallucinations, disinhibition, sleep disturbances, wandering and repetitiveness. Depression is often reported in people with mild cognitive impairment or the early stages of Alzheimer’s. Aggression is more common in the more advanced stages of dementia. Agitation is common at all stages, but mostly the middle to later stages. Table 1 illustrates the behavioural symptoms associated with dementia. These symptoms – especially wandering, sleeplessness and anxiety – can create risks for the individual and lead to increased stress for carers, as well as admission to institutional forms of care.

What dementia means in practical terms (Table 1)



Impairment of memory

- Increasing difficulty in remembering recently acquired information
- Difficulty recognising friends and family
- Forgetting names of friends and common objects



Impairment of reasoning

- Difficulty in working things out
- Not being able to use a new design of kitchen appliance
- New-found difficulty handling money



Impairment of learning

- Inability to learn or remember names of people or objects
- Repetitive questioning due to inability to remember the answer
- Problems learning how to learn to use new objects



Increased stress levels

- Becoming distressed if you are in an unfamiliar environment
- Anxiety from not recognising people
- Inability to recognise, understand or adapt to what’s going on around



Reduced capacity to deal with age-related changes

- Forgetting to use recently acquired prosthetics, eg, glasses or hearing aids
- Neglecting to keep the house warm
- Forgetting to eat or drink enough fluids

The housing offer

Housing organisations are well placed to develop dementia-friendly communities.

Many reach out to people living with dementia in the wider community, providing services such as floating support, assessment and delivery of adaptations and housing advice. When staff are equipped with the necessary skills, and there is continued investment in services, housing providers and home improvement agencies are able to assist with a wide range of housing choices for individuals with dementia. This includes making homes more accessible or more dementia-friendly or helping with moves to specialist housing. These organisations are also often able to help with day-to-day tasks such as shopping, household chores and organising domestic bills.

What are dementia-friendly communities?

Where businesses, organisations and services understand and respond to the needs of people with dementia: for example, by training staff to be aware of dementia or designing services with dementia in mind. These communities strive to improve the inclusion, independence and quality of life of people living with dementia and their carers.

The Prime Minister's challenge on dementia promotes the development of dementia-friendly communities and sets out an ambition that by 2015 up to 20 cities, towns or villages will have signed up to be dementia friendly.



Specialist housing can ensure a person's home is 'care ready', responding flexibly to their changing needs.



These services focus on ensuring that people with dementia are able to remain in their own home, continue to live independently, connect with other services and resources in the community, and able to return home after any crisis or illness. Specialist housing can ensure a person's home is 'care ready', responding flexibly to their changing needs¹⁹. Investment in specialist housing for vulnerable and older people, where care and support are available on-site, results in a net cost benefit to the public purse of £639m a year²⁰.

For people with dementia, home adaptations and home support services can bridge the gaps between an admission to hospital, reablement and returning to living independently at home. A study of the benefits of support services estimated that a £1.6bn annual investment in housing-related support services generate annual cost savings of £3.41bn to the public purse. Telecare interventions, which facilitate the delivery of care in people's own homes, can also support independent living.

19. All Party Parliamentary Group on Housing and Care for Older People (2012), Housing our Ageing Population: Plan for Implementation

20. HCA (2010), Financial benefits of investment in specialist housing for vulnerable and older people

Housing staff may be in a position to identify when someone is showing signs of dementia, and help support people and their families to get a diagnosis with access to specialist support.

Rather than leaving someone without support until they reach crisis point (a fall in their home, or a sudden escalation of their symptoms), the ongoing involvement of housing staff can help ensure that problems are resolved.

Solutions range from signposting and fitting adaptations including ramps and grab rails to make homes more accessible, to local peer

support and supporting moves into specialist housing with on-site care and support provision. Some organisations even have a specialist dementia housing worker who is able to work across a range of residences and provide support during periods of transition, including the point of diagnosis when there is a threat of having to move into care, or at the end of life when the person may wish to die at home²¹.

Table 2 sets out the top ten recommended housing adaptations for making homes more dementia-friendly.



Rather than leaving someone without support until they reach crisis point, the ongoing involvement of housing staff can help ensure that problems are resolved.



Top ten housing adaptations (Table 2)

Double the usual levels of lighting in the home.	Pay attention to acoustics and reduce noise pollution.	Use contrast of tone (rather than colour) to differentiate between walls, skirting boards and floors. Ensure that floors are of a consistent tone.
Ensure there is good signage mounted low enough for poor eyesight.		Use contrast of colour or tone to make switches and objects easily visible.
		Use objects or pictures rather than colours to differentiate different parts of the building.
	Ensure that people can see important rooms such as the toilet, that furniture and fittings give strong clues to the purpose of the room and that there are clear signs.	Ensure that kitchens and bathrooms are easy to understand. Avoid new designs for things such as taps or kettles.
Place illuminated clocks in each room indicating whether it is a.m or p.m.		All doors should be visible on entering the dwelling. Cupboards should be glass fronted or open.



An estimated 40% of hospital beds are occupied by people with dementia.

We believe that there are three priority areas where housing can offer big benefits to people with dementia, also taking the pressure off their family and carers, and local NHS and social care services:

Preventing health emergencies & reducing hospital admissions

Dementia is a significant challenge for the NHS with an estimated 40% of hospital beds occupied by people with dementia²². People with dementia stay longer in hospital than other patients who go in for the same procedure and are often subject to delays when leaving²³. The longer the hospital stay, the worse the effect on the symptoms of dementia and the person's physical health. Longer admissions also make discharge to a care home and the prescribing of antipsychotic drugs more likely²⁴. People with dementia in hospitals are also dying at a significantly higher rate than people without the condition²⁵. Given these adverse effects, NHS trusts and local commissioners should focus on preventing hospital admissions by investing in support services and specialist housing to help people to live independently in their own home.

Currently 60% of people with dementia enter hospital from their own home, but just 36% return home after discharge²⁶. The Commissioning for Quality and Innovation (CQUIN) payment framework aims to incentivise the identification of patients with dementia to ensure appropriate referral and follow up after they leave hospital.

Part of the referral stage should include hospitals engaging with services in the housing sector to ensure people can return to their own home as quickly as possible²⁷. When working in partnership with housing associations and home improvement agencies, any crisis intervention should be based and designed on the aim that, where appropriate, the person will remain in or return to their own home.



Currently 60% of people with dementia enter hospital from their own home, but just 36% return home after discharge.

Delaying a move to residential care

Recent research has shown that more people than ever before are living in care homes are living with dementia. 80% of people living in care homes have dementia or severe memory problems²⁸, an increase of around 15% since 2007²⁹. Over 9.3m UK adults (19%) know someone with dementia in a care home³⁰.

22. Department of Health (2010), Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

23. Department of Health (2012), Using the Commissioning for Quality and Innovation (CQUIN) payment framework Guidance on new national goals for 2012-13

24. Alzheimer's Society (2009), Counting the Cost: Caring for People with Dementia on Hospital Wards

25. Care Quality Commission (2013), Care Update

26. Alzheimer's Society (2009), Counting the Cost: Caring for People with Dementia on Hospital Wards

27. Care and Repair England (2012), Home from Hospital Pack

Residential care can provide an excellent option for someone with dementia, particularly as their care needs increase. However, funding pressures are set to increase. The Local Government Association has highlighted a £16.5bn annual shortfall between revenue and spending across all local government funding by 2019/20. To reduce the social care bill, commissioners must address the housing needs of people with dementia. Through supporting the delivery of care and assistive technology to an adapted home, as well as providing specialist housing, local authorities can substantially reduce the demand for, and the cost of, social care.

Informed use of design and technology in the home increases independence and safety, which can delay the need for more costly residential care³¹. Elements such as lighting, acoustics, layout and design of outdoor spaces can be adapted to ensure that homes are as dementia-friendly as possible. Design and adaptation can have a positive impact on the behavioural symptoms of dementia and can help people to stay independent for longer³².

Facilitating early diagnosis and early intervention

People often do not visit their doctor about symptoms of dementia³³. An inquiry by the All Party Parliamentary Group on Dementia found that more than a third of people with dementia waited longer than a year to go to their GP, with nearly 10% not going at all³⁴. In fact, the majority of people with dementia receive a diagnosis when it is too late to provide any support and they have already been admitted to hospital³⁵. Whilst many people might go to

their own GP to ask for advice, they are just as likely to turn to other trusted sources of advice and information.

Housing associations and home improvement agencies run a number of community services that could help to increase dementia diagnostic rates in the areas where they work. Housing staff are well rooted in the community, commanding a high degree of trust among their own tenants, as well as those living in the wider neighbourhood who may use their community facilities or care and support services.

The Alzheimer's Society importance of trained housing staff, who understand dementia and can support families by providing information and advice on local services and housing options³⁶. With the right training and continued local investment in support services³⁷, frontline housing staff, home improvement agency case workers and advice services could pick up on signs of dementia, and work with GPs, families and carers to ensure people get a full diagnosis.

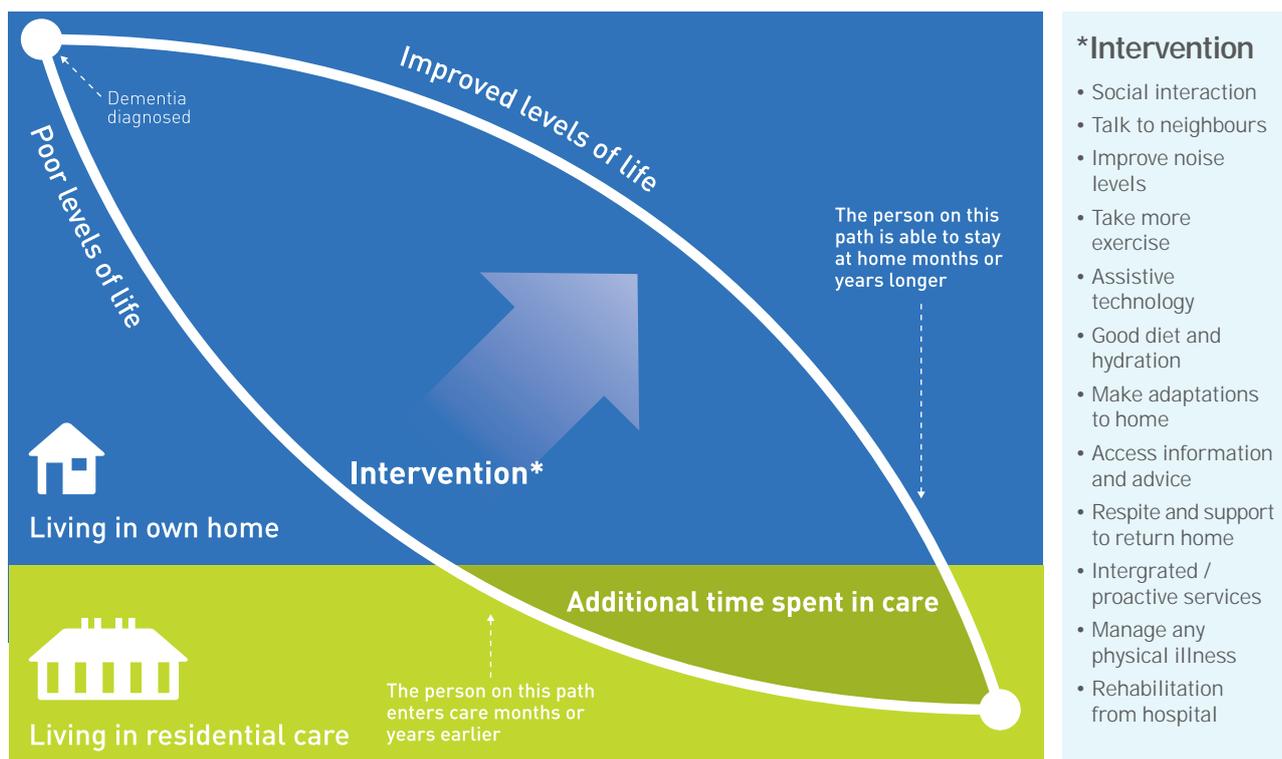


A third of people with dementia waited longer than a year to go to their GP.



28. Alzheimer's Society (2013), Low Expectations
29. Alzheimer's Society (2007), Home from Home
30. Alzheimer's Society (2013), Low Expectations
31. The King's Fund (2013), Developing supportive design for people with dementia
32. The King's Fund (2013), Developing supportive design for people with dementia
33. All Party Parliamentary Group on Dementia (2012), Unlocking Diagnosis
34. All Party Parliamentary Group on Dementia (2012), Unlocking Diagnosis
35. Royal College of Psychiatrists (2011), Report of the National Audit of Dementia Care in General Hospitals
36. Alzheimer's Society (2011), Home Truths Housing Services and Support for People With Dementia
37. Alzheimer's Society (2012), Home Truths: Housing Services and Support for People With Dementia

The value of housing and early intervention (Table 3)



© Dementia Services Development Centre 2013

Housing and related services, together with other interventions, can improve the quality of someone’s life and reduce their need for care. Through a combination of changing behaviour, home adaptation and support, a person can achieve a higher quality of life in the time available to them. This can also reduce the need for more costly institutional forms of care. The following case studies provide a snapshot of the types of services and integrated care packages on offer through housing organisations, such as housing associations and home improvement agencies.



Improving the rate of diagnosis

Early and accurate diagnosis means that both medication and social interventions, such as peer support and low-level care services, can be used to help a person with dementia maintain a good quality of life and live independently. Housing staff may be able to help those diagnosed in the early stages of dementia access sources of information, care and support, as well as home adaptations and telecare equipment such as sensors and alarms. In some cases, staff may also be able to support continued independent living by helping to manage household bills, GP appointments and medication.

This requires housing and care staff to have appropriate training. From a housing perspective, there are multiple incentives for intervening early and providing support and advice to people with dementia. By identifying needs early on and providing suitable accommodation, people can be supported to live well in their own home and expenditure on repairs and adaptations can be reduced. Early intervention can also help to reduce behaviours which other residents might view as antisocial, thus helping to support more cohesive and neighbourly communities.

Focus on Riverside Housing Association – Health check service

Overview: Riverside is a housing association working primarily in the North West of England. Because 39% of its tenants are over 60, Riverside set up a service called LiveTime, which looks at better ways of supporting people over the age of 60 living in general needs accommodation. As part of the project Riverside undertook a survey of their older tenants, which highlighted that a significant number were anxious and concerned about dementia.

LiveTime service: The service supports older people living in general needs accommodation by providing face-to-face health checks and organising activities to combat isolation. With a team of five people and a project manager, the service covers 2,300 older people living in Liverpool, Leicester, Carlisle and Newcastle. The service offers signposting to resources such as adaptations and financial inclusion support. It has mapped out the dementia support services in each region and is ensuring that those living with dementia, as well as their carers and family, know what is available to them.

The LiveTime team has been trained in dementia awareness and communications skills, meaning that staff members better understand the social, physical and accommodation needs of tenants with dementia. Staff are also able to encourage tenants to seek a diagnosis if they are concerned about any symptoms.

Outcomes: LiveTime has encountered several cases of people living with dementia who were accessing either little or no support. The service has developed support packages for these people and has also been successful in helping five people receive a diagnosis of dementia via contact with GPs and social services.

Contact:
Jane Mindar – Jane.Mindar@riverside.org.uk

Focus on Notting Hill Housing Trust – Dementia Champions

Overview: Notting Hill Housing Trust (NHHT) has developed a dementia strategy, which sets out ways to raise awareness of dementia and encourage residents to seek help. The strategy has ensured their members of staff are informed about potential signs of dementia, which has led to innovation in practice and service delivery. Core to the strategy is a group of dementia champions who challenge colleagues and promote best practice.

Dementia Champions: NHHT trained a group of staff from across their services (extra care housing, sheltered housing, floating support and their resource centre) to improve awareness of dementia across the organisation. These 12 staff completed a Level 2 Certificate in Dementia Care at Harrow College. Their role is to act as champions of best practice in dementia care and support, and be a point of contact for customers, relatives and colleagues.

Dementia Champions support customers by:

- responding to residents' concerns about health and well-being and providing reassurance to customers and relatives
- carrying out personalised assessments of residents' individual dementia care needs
- sharing useful information and signposting people diagnosed with dementia towards help and support.

Dementia Champions are part of NHHT's in-house 'Be Dementia Aware' campaign to raise awareness of dementia across schemes and departments.

Outcomes: NHHT's awareness campaign and their group of Dementia Champions have led to clear improvements in the health and well-being of their customers. They have been able to reach out to almost 900 customers. Some of the successes of the dementia strategy include:

- A reduction in the stigma around the issue of dementia, based on feedback from customers and staff. This is particularly evident among NHHT's sheltered and extra care residents.
- Extra care staff members have been able to bring examples of changes in customers' health and well-being to the attention of GPs who can then refer on to memory clinics or specialists.
- Improved access for staff, customers and their families to information on dementia, with signposting to other organisations such as the Alzheimer's Society and Dementia UK.
- Since January 2011, 136 members of staff have received specialist dementia training, leading to improved skills and confidence levels.

Contact: Elizabeth Clarke –
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Preventing hospital admission

Housing organisations have a good track record of providing specialist housing and delivering services that are designed to improve health and well-being, prevent falls and other accidents in the home and promote independence. These services have been proven to prevent admission and readmission to hospital, allow reablement after an accident or illness, delay the need for intensive care services and reduce the likelihood of emergency admissions³⁸. One case study of an individual with dementia being supported to live independently in Extra Care housing highlighted savings of up to £17,222 a year to health and social care budgets³⁹.

Housing organisations have also introduced assistive technology to ensure that people with dementia are able to stay independent and in familiar home environments⁴⁰. Telecare solutions are a proven alternative to institutionalisation for people with dementia, helping individuals to retain independence and dignity and assisting their carers. By installing assistive technology, housing associations can allow a carer to have a good night's sleep or leave the house for short periods safe in the knowledge that should their loved one leave the house, cause the bath to overflow or even leave their bed for a prolonged period of time, they will be alerted. Technology can also help staff to provide a safe environment for someone through flood detection, gas shut-off systems, pagers, and medication alerts.



Housing organisations have also introduced assistive technology to ensure that people with dementia are able to stay independent.

38. National Housing Federation (2011), On the Pulse

39. National Housing Federation (2013), Providing an Alternative Pathway

40. Appleton N (2012), Board Assurance Prompt – Specialised Housing for Older People. Good Governance Institute and Housing Learning and Improvement Network

Focus on Rochdale Boroughwide Housing – Assistive Technology Service

Overview: Rochdale Boroughwide Housing (RBH) runs a supported housing and assistive technology service that works with people with dementia to support them to live independently in their own homes, regardless of their diagnosis.

Assistive Technology Service: Tenants with dementia can be provided with a fall detector, fitted on their waist band, which instantly alerts the response centre if they have a fall. First aid trained staff respond to each tenant alarm. Staff are equipped with specialist emergency lifting cushions to assist with lifting tenants who have fallen, so no manual handling is involved. The service means that an ambulance does not have to be called out unless the tenant has an injury from the fall and requires medical assistance.

RBH has also fitted property exit sensors on their sheltered accommodation schemes where there are people with dementia. These detect when someone leaves the building, and can prevent people with dementia getting lost in the surrounding neighbourhood. Without the sensors, the police will often be called out by neighbours.

Outcomes: The service has had an impact in reducing the need for residential care and hospital visits, as well as improving tenants' standard of living and customer satisfaction. The fall detectors have massively reduced the frequency of paramedic call-outs, as well as admissions to accident and emergency departments. In Rochdale, the average cost of each paramedic call-out is £257, and the average hospital admission is £686, therefore each incident costs an estimated £943. Over a one-year period, the service responded to 416 incidents and RBH estimated that it had produced savings to the public purse of £392,288.

The RBH mobile warden team also responds to around 15 call-outs a month where a property exit sensor has been triggered. This saves the police an estimated £200 per incident (based on a non-bluelight call-out, two police officers, a patrol car, and the control centre response⁴¹).

Contact: Peter Smith – peter.smith@RBH.org.uk

Providing information and advice on housing

Evidence from people with dementia and their carers suggests that access to information and advice is inadequate⁴². Yet these services are essential if people are to remain independent in their own homes and enjoy a good quality of life. Housing options advice services, often run by home improvement agencies, help older people to consider the practical and financial issues related to staying in their current home or moving elsewhere. Housing options workers

may help tenants liaise with landlords and/or make applications for specialist housing, help home owners through the practicalities of moving home, and provide advice on related welfare benefits and home support services. Home improvement agency services can then help people undertake home adaptations, repairs, organise finance and related care and in some cases, help people to move home.

41. Rochdale Boroughwide Housing (2012), Evaluation of the Assistive Technology Service

42. Alzheimer's Society (2011), Support. Stay. Save.

Focus on Care and Repair England – Advice on housing options

Overview: Care and repair services work with health and social care providers to identify those at risk of losing their independence or experiencing a decline in their health and well-being due to housing shortcomings.

They then coordinate a range of interventions including home adaptations and repairs, safety and security measures, assistive technology, telecare, equipment and housing-related support services. The aim of the 'If only I had known...' initiative was to enable older people, their families and carers to make an informed decision about future housing, care and support, either following hospital admission or where an older person has a long-term health condition.

Home from Hospital service: The project involved providing housing and care service information to patients, initially via a Going Home from Hospital pack placed in bedside cabinets. This was combined with local Care and Repair (or similar voluntary sector service) staff undertaking regular ward rounds. Staff top up the information provided in the Going Home from Hospital pack. They talk to ward staff and take direct referrals, from both patients and professionals, of older people

who wished to discuss their housing and care options and/or who needed practical housing-related help in order to be discharged safely from hospital.

The initiative also aimed to enable older people with long-term health problems to think through the housing implications of their condition and to make plans accordingly – for example, to adapt an existing home or move to somewhere more suitable whilst they are able.

Outcomes: The initiative enabled older people with dementia to return home more quickly. In the case of carers' hospital admissions, it helped to reduce the length of time their partner with dementia needed to be in respite care. One example was installing a key safe through the Care and Repair handyperson service so that paid carers could let themselves in, enabling the person with dementia to remain in their home. This intervention alone delivered an overall saving of £2,464 to local social services⁴³.

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Improving hospital discharge

Across the NHS older people occupy some 60% of hospital beds⁴⁴ and it is estimated that 40% of these people have dementia⁴⁵. In addition, a report commissioned by the National Audit Office noted that 70% of patients with dementia in an acute hospital setting were medically fit to be discharged⁴⁶. Hospital stays are recognised to have detrimental effects on people with dementia, even where they recover from the reason for the original admission⁴⁷. Many people with dementia become more disorientated and suffer seriously reduced functional capacity following a hospital admission.

It is not always possible to avoid a hospital admission, but with continuity of support and care and an emphasis on maintaining as much functionality as possible, it is possible for people to return to their previous lifestyle. People with dementia need to be supported while they are in hospital to allow them to return home as soon as possible. Given their knowledge of the residents living in their accommodation, specialist housing staff can help to reduce the anxiety that someone with dementia can feel when they are admitted to hospital and help them to recover as much of their normal routine as possible.

43. Care and Repair England (2012), Home from Hospital Pack and summary

Focus on Housing 21 – Integrated health, care and housing

Overview: Housing 21, a housing association providing extra care accommodation across England, offers frailer older people varying levels of on-site care and support. It developed the Portable Care pilot scheme in response to national evidence which showed that for many people with dementia, a stay in hospital is a negative experience, with patients suffering poor quality care, discrimination and deteriorating health. The organisation felt that these issues could be overcome if its staff could support tenants, particularly those with dementia, when they stay in hospital.

Portable Care: The pilot saw Housing 21's extra care staff supporting residents through formal visits to hospital. Staff provided support and advocacy for residents going into hospital: for example, by aiding communication with those who are hard of hearing and ensuring patients are eating properly and having their personal hygiene needs met.

Housing 21 has a strong ethos of enabling people to maintain their independence at home and it developed the service in partnership with North Bristol NHS Trust, NHS Bristol and Bristol City Council. Funded through the NHS Innovation and Excellence Fund, the project looked at the effects on patients and staff when care is transferred from the extra care housing setting to the hospital setting when a service user is admitted to hospital. The Portable Care pilot scheme ran from April 2010 to March 2013 in two of Housing 21's extra care schemes, which housed 80 tenants.

Outcomes: The service has improved health and social care outcomes by improving the quality of life for people with dementia, minimising the effects of dementia and helping people to recover their independence after illness or injury. The Portable Care service has so far provided support to 22 hospital admissions, resulting in 42 visits totalling 92 social care hours. This has contributed to:

- 33 bed days saved through quicker hospital discharge, resulting in a saving of £11,715 (£355 per bed day⁴⁸)
- 95 bed days saved through managed readmission, resulting in a saving of £33,725⁴⁹.

Additional savings are expected for clinical commissioning groups through reductions in unscheduled care and unnecessary admissions, as well as adult social care in the form of reduced or stable care packages on discharge⁵⁰. The final project report to be published in summer 2013 will include a more detailed analysis of the cost-effectiveness of the service. Project management and staff contingency costs are additional to this, and are currently funded by the Department of Health's Voluntary Sector Innovation, Excellence and Service Development Fund.

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44. Royal College of Psychiatrists (2005). 'Who cares wins. Improving the outcomes for older people admitted to the general hospital: Guidelines for the development of Liaison Mental Health Services for older people.

45. Department of Health (2010), Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

46. The Balance of Care Group in association with the NAO and the Lincolnshire Health Economy (2007), 'Identifying Alternatives to Hospital for People with Dementia

47. The King's Fund (2013), Developing supportive design for people with dementia

48. This figure relates to bed days saved by the intervention and getting tenants out of hospital before their estimated discharge.

49. This figure relates to planned admissions and discharges and the number of days saved through working with hospital staff to enable the tenant to go home between treatments and avoid a longer admission.

50. National Housing Federation (2012), On the Pulse: Housing routes to better health outcomes for older people.

Promoting independence at home

Housing organisations have developed services that help deliver a more integrated approach to the delivery of health and social care. They can provide the home in which care is delivered, the adaptations that can make health and social care services work better, and the community-based services that support people across the neighbourhood.

Many home improvement agencies run handyman services which carry out small home repairs and minor adaptations to enable older and disabled people to remain living independently in their own home.

Home improvement agencies may also offer assistance with hospital discharge to enable care at home, such as fitting key safes, equipment delivery, and moving or raising chairs and beds.

They also focus on prevention, carrying out home safety measures including fire safety checks, fitting smoke alarms, gas monitors and flood monitors. They also offer fall and accident prevention checks. All these measures help people to live independently in their own home.

In contrast to more institutional forms of provision, specialist housing, such as extra care housing, allows people to stay in their own home for longer with care and support on site. More importantly extra care supports the person in maintaining their chosen lifestyle by providing well-designed housing, a wide range of activities and opportunities to socialise⁵¹. An extra care scheme allows someone's home to be 'care ready' so the service can adapt quickly to an individual's requirements as their needs change. The accommodation is accessibly designed and residents have the option of an emergency alarm system⁵².



An extra care scheme allows someone's home to be 'care ready' so the service can adapt quickly to an individual's requirements as their needs change.



51. Mitchell L (2012), At a glance: A checklist for developing dementia-friendly communities

52. Utton D (2013), Taking extra care with dementia-friendly design: Brookside Retirement Living Village, Lancashire. Housing Learning and Improvement Network

Focus on the Extra Care Charitable Trust – Enriched Opportunities Programme

Overview: The ExtraCare Charitable Trust (ECCT) operates 12 retirement villages and 17 smaller housing schemes, which are home to almost 4,000 older people. ECCT provides flexible care and support to service users in their own homes, an estimated 18% of whom experience dementia.

The Enriched Opportunities Programme: ECCT has developed the Enriched Opportunities Programme (EOP)⁵³ which focuses on supporting older people with dementia to help them live independently for longer in extra care housing. The programme offers tailored activities for those residents with dementia-related issues, aiming to reduce the disabling effects of the condition. The programme is implemented through specially-trained support workers known as 'locksmiths'. The locksmith works with individuals to ensure care is personalised. Specifically, they work to enable vulnerable residents to achieve their goals and to identify types of interventions, occupations and activities that are most likely to unlock the potential for well-being and help them achieve their goals.

Outcomes: Ten extra care schemes, including five control sites (where no intervention took place) took part in a two-year study to evaluate this approach. The research found that EOP participants:

- were 50% less likely to move into a care home (compared to control sites), and
- experienced a 42% decrease in hospital stays.

There were also significant cost savings in health care. At projects sites, there was an overall cost saving of £15,383 over a six-month period, compared to a cost increase of £55,376 at the control sites. An independent evaluation by the National Audit Office concluded that if the programme were rolled out nationally, to all providers of extra care housing, savings to the public purse could amount to £21m over two years. Since this successful research programme, ECCT has implemented the EOP across all its locations.

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Focus on Care and Repair Leeds – Minor adaptations and hospital discharge

Overview: Referrals are made to Care and Repair from occupational therapists based in hospitals in Leeds and in the Joint Care Management and Intermediate Care Teams based in Leeds Council. The referral contains information on the client and details the minor adaptations that are needed to prevent them from going into hospital or, if already admitted, allow them to return home.

Minor adaptations and hospital discharge:

The service deals with approximately 1,800 referrals per year and the type of work includes fitting rails to stairs and bathrooms, moving furniture, and reducing general safety hazards. These referrals are checked against guidelines agreed with Leeds Adult Social Care, processed and passed on to a self-employed joinery firm who specialises in this type of work and is registered with Care and Repair (NE Handrails Ltd). The joiners carry out the work defined on the referral form within the stated time period. Quality checks are carried out in accordance with Care and Repair Leeds' contractor monitoring procedures. The service is funded by Leeds Adult Social Care Department and Leeds housing management service.

Memories Reminiscence Activity Library:

Care and Repair Leeds also offers a free reminiscence library for use with people living with dementia within their own homes.

Current products include discussion cards of events and well-known people from past decades. Memorabilia packs, games, books and jigsaws are available, as well as CDs of radio theme tunes and large print song books of popular older songs. It helps to prompt discussion amongst family members and friends and break down barriers caused by dementia.

Outcomes: Leeds Care and Repair has calculated that the average cost of maintaining someone in hospital after their treatment is completed is £350 per day (based on actual figures supplied to Care and Repair Leeds from St James Hospital). The average cost of providing their service is £107 per client. If the 1,800 clients referred to the service had stayed in hospital unnecessarily for an additional day, the cost to the hospitals would have been £630,000, whereas the service would have cost £190,000.

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Designing dementia-friendly homes

Well-designed homes, which are accessible, with good natural light and good insulation to improve warmth and reduce noise, can promote health and well-being⁵⁴. Good design can also help with the management of dementia⁵⁵. People with dementia are calmer and less likely to get lost or become distressed in an environment designed with their needs in mind⁵⁶. This has been recognised by the Department of Health, which has made up to £50m available to NHS trusts and local authorities to help tailor hospitals and care homes to the needs of people with dementia⁵⁷.

However, these interventions can be extended to specialist housing and those living in their own home. Preventative interventions rooted in the design of the home environment, such as the dementia proofing and retro decorating work below, can also reduce the pressure on social care and health budgets. By providing practical, low-cost ways to help dementia patients live safely at home for longer, these individuals will have a higher quality of care and standard of life.



People with dementia are calmer and less likely to get lost or become distressed in an environment designed with their needs in mind.



54. Thomson H, Petticrew M, & Morrison J (2001), Housing improvement and health gain: a summary and systematic review
55. Morrison A (2013), Facing the future with dementia: designing buildings that will be adaptable. Housing Learning and Improvement Network
56. Department of Health website: Health Secretary announces funding for care homes and wards specially designed for people with dementia
57. Department of Health website: Health Secretary announces funding for care homes and wards specially designed for people with dementia

Focus on Irwell Valley Housing Association – dementia-friendly specialist housing

Overview: Shore Green is an extra care housing scheme with six apartments and four bungalows, developed by Irwell Valley Housing Association in collaboration with Manchester City Council. It offers a specialist care service for older people with dementia and other memory loss conditions. Residents have assured tenancies, pay their rent and utility bills and are encouraged to live as independently as possible. It was developed in response to Manchester's ageing population and the increased demand for nursing home placements among people with dementia.

Shore Green: The scheme enables residents to continue a level of independent living in an environment where support is available when it is required. It contains features which are designed to assist clients with day-to-day living, including:

- unique building design that minimises confusion
- culture of dignity, fun and 'can-do'
- gas monitors that cut off the gas supply if a cooker is left on
- door sensors that alert the night care worker if a tenant has opened a door
- colour coding and personalisation (shelves/cubby holes with personal items) at the entrances to each flat to help each tenant identify their door

- glass-fronted kitchen units so tenants can see which cupboards items are kept in
- a single secure entrance and exit to ensure the safety of residents, both in stopping unwanted visitors coming in and by reducing the risk of tenants wandering.
- a visitor sleepover facility so friends and family can visit the tenants: this facilitates continued contact and has reunited people on occasions after contact had been lost.

Outcomes: Shore Green gives people with dementia more choice and control over their lives and the support they receive, meaning that more than 50% of its high need clients are able to live independently until the end of their life. The former Department of Health Care Service Efficiency Delivery programme⁵⁸ concluded in 2009 that the scheme offered good value for money as better outcomes were being achieved at a marginal extra cost. In particular, the scheme has reduced demand for NHS services from people with severe dementia through a marked reduction in visits to A&E, hospital admissions and ambulance and police call-outs (in relation to less incidents of wandering).

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Focus on home improvement agencies – dementia-proofing and retrofitting

Overview: Two home improvement agencies in Lancashire and Merseyside are using reminiscence techniques to create a low-cost way of helping people with dementia live independently in their own homes. 'Retro-decorating' and 'dementia proofing' interventions focus on the environment of a client's property and his or her life experiences rather than drug treatments. Although in their infancy, these approaches are beginning to improve the mood, socialisation and short-term memory of people with dementia and reduce the need for residential care or hospital admission⁵⁹.

Dementia-proofing: Hyndburn Homewise Society in Accrington is developing a model of non-drug-based therapies for people with dementia. One technique is 'dementia-proofing' which can include the installation of open-fronted chests of drawers, grab rails, walk-in showers, flood alarms, ramps, glare-free lighting, appropriate placement of mirrors and coloured tape going up and down the stairs.

People with dementia are much more sensitive to their environment. Lighting glare can distort visual perception and difficulty with depth perception can make climbing the stairs much harder. Forgetting day-to-day tasks such as where clothes are stored, when to make meals and turn off taps can also present difficulties, so small practical adjustments can really help. 'Dementia-proofing' interventions can prevent trips, falls and other accidents that often lead to hospital admission and delayed discharge.

Retro-decorating: Riverside Home Improvement Agency (HIA) in Liverpool is beginning to retro-decorate the homes of some older clients who have dementia.

This technique involves helping residents to choose vintage furniture and older looking items that bring back memories of happy times – such as bakelite telephones, mid-century arm chairs, flying wall ducks, 1950s gramophones, posters of old pop and film stars, vintage sewing machines and 1960s crockery.

Riverside HIA also uses some reminiscence furniture that has the appearance of coming from the past but is actually designed for people with dementia – such as a wardrobe with see-through panels that looks like it is from the 1950s. Surrounding someone with furniture from their past can help them to remember their daily routine – such as sitting down for a meal, washing themselves, making a cup of tea or putting on the right clothes. It can also help to keep people with dementia calm, reducing the need for anti-psychotic medicine or residential care.

Outcomes: These approaches are all in an early stage of delivery at both Riverside HIA and Hyndburn Homewise Society but initial results are encouraging. It is felt that dementia proofing, retro-decorating and life experience therapies may help to improve the mood and feeling of well-being of people who live with dementia. The techniques appear to be effective on people who may have entered an uncommunicative state. They can boost the socialisation of clients and residents become more inclined to visit family and take part in social sessions at day care centres and memory clinics.

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Rising to the challenge

How the needs and aspirations of people with dementia are met is a challenge for everyone.

The pressure points in the dementia care pathway, where services are either unavailable or are letting people down, are already well understood. As highlighted in this report, the low rates of diagnosis, the lack of services and advice available following a diagnosis, the lack of available home-based care and support, and the lack of integrated care offered to help those in hospital to return home quickly all need to be addressed.

The challenge is huge. It is predicted that in less than 40 years' time 1.7m people will be living with dementia. It is time to stop thinking of dementia as a terminal diagnosis and start thinking of it as a long-term condition, and focus on how the experiences of people living with dementia can be improved.

There remains a clear and growing need for services which intervene shortly after diagnosis, and which focus specifically on helping someone continue to live independently in their own home. Intervening early can significantly improve people's experience of living with



It is time to stop thinking of dementia as a terminal diagnosis and start thinking of it as a long-term condition.



dementia. As this report highlights, there are already plenty of models of progressive interventions which can be drawn upon. Such services can take the pressure off carers and residential care as well as prevent hospital admissions and extended hospital stays.

The drive to create dementia-friendly communities across the country is an important opportunity to harness the role that housing can play in helping people with dementia remain living independently in the community. Integrating housing into the dementia care pathway can deliver better outcomes, better value for money and help to meet the aspirations of those living with dementia.



It is predicted that in less than 40 years' time 1.7m people will be living with dementia.



There are three ways in which commissioners and their local partners can work together to rise to the challenge and improve the experiences of those living with dementia:

Recognise the role of housing in improving the lives of people with dementia

In developing services to meet the joint indicator in the NHS and Adult Social Care Outcomes Framework on the effectiveness of post-diagnosis care for people with dementia, clinical commissioning groups should work closely with the housing sector to identify where costs build up in different parts of the care and health system, and design home-based solutions that will relieve these pressures. These should focus on two priority areas: the delay of more intensive care through independent living, and a reduction in overall healthcare costs by, for example, reducing the number of emergency admissions to acute hospitals.

Create partnerships to integrate housing, care and support

Local authorities, housing providers, home improvement agencies, GPs and NHS Trusts should work in partnership to develop support services for people with dementia. These bodies should build upon and continue to support existing resources, such as specialist housing, and the expertise of frontline support staff. Better communication between these bodies can help to highlight where barriers are preventing early intervention in the dementia care pathway and where outcomes are being limited by fragmented services.

Work with housing providers to drive up the diagnosis rates of dementia

Directors of Public Health should work with housing organisations to identify ways of meeting the indicator in the Public Health Outcomes Framework on diagnosis rates for people with dementia. This report has highlighted the types of services that local authorities could jointly fund with housing organisations and NHS trusts, such as health checks and housing options advice.



Integrating housing into the dementia care pathway can deliver better outcomes, better value for money and help to meet the aspirations of those living with dementia.



