Housing options for people with dementia

Discussion Paper
Prepared by Dementia Care
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Executive Summary

Dementia is becoming widely recognised as a critical issue to be addressed by governments and their health and care services. It is currently estimated that there are 850,000 people in the UK living with dementia. This number is expected to exceed 2 million by 2050.

Surveys of older people consistently show that people want to enjoy the best possible quality of life for as long as possible. When the time comes, end-of-life for both the individual and their carers should be calming, supportive, loving and dignified in a homely, caring environment, surrounded by friends, loved ones and personal belongings.

A key element affecting the quality of life for someone with dementia is the place in which they live. However, the housing components in the National Dementia Strategy and other government proposals are relatively undeveloped, with little detail provided.

The most common choice for the majority of people with dementia is to remain in their own home (with support) or move into a residential or nursing home setting.

The reality for many older people is that living in their own homes can result in:

- Loneliness and social isolation.
- Care and support (unpaid or professional) falling short of the level required.
- Home maintenance becoming more challenging.
- The cost of running a home becoming an issue.

The impact of all of this is that there are a number of health issues directly related to people’s inability to look after themselves in their own homes, including malnutrition, risk of falls, urinary incontinence and depression. All of the above issues tend to be exacerbated when the older person living in their own home has dementia.

Dementia is increasingly becoming one of the reasons why someone moves into a care home setting. The fundamental approach of most residential care homes is to be like living in a hotel. Experience is showing that the old phrase ‘use it or lose it’ has a lot of truth and
that living with dementia in an environment where the resident is not expected or encouraged to do anything for themselves can lead to a more rapid loss of ability to perform Activities of Daily Living.

Good practice around design principles for specialist housing and care settings for people with dementia is slowly but steadily growing. However, only limited research has been undertaken to date to identify good housing and care models for people with dementia and the outcomes that they can deliver compared to residential care or nursing care, both in terms of quality of life for people with dementia and in terms of lifetime cost of care.

Extra-care housing is increasingly being provided but in many cases this is an extra step in the dementia journey, delaying but not necessarily removing the need for a move to residential or nursing care. For many people, some form of specialist dementia housing model is needed as an alternative to moving to a care home as their dementia develops.

Dementia Care has developed a model of small group, independent supported living for people with middle to late stage dementia and, in most cases, through to end-of-life. This is an alternative to a residential care home and for more people, negates the need to move to a nursing home for end-of-life care.

The evidence gathered to date suggests that this model provides:

- higher quality of life, choice and control,
- continued independence for longer,
- low use of anti-psychotic medication,
- no emergency and fewer non-emergency hospital admissions,
- earlier discharge from hospital and better reablement; and
- a greater chance to pass away in a homely environment, surrounded by their loved ones, which ultimately is what the majority of people want.

As with everything to do with dementia, there is no one size fits all and housing is no exception. Further research is needed to confirm the results of the Dementia Care model, to improve the model and to use this research to develop models better suited to other people with dementia.
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Introduction

The dramatic increase in average life expectancy throughout the world is possibly the greatest achievement of the last century. Improvements in sanitation, nutrition and living standards generally, combined with advances in medical science have resulted in average life expectancy in the UK rising from around 50 years in 1900 to over 80 years today. This continual improvement has meant a significant increase in the number of older people, with 17.7% of the UK population (11.4 million people) now aged 65 and over\(^1\). The fastest growth is in the 80+ age group, with almost 3 million people now aged 80 and over.

Whilst the increase in total life expectancy is clearly good news, a better measure of improvement is healthy life expectancy. This is also improving, but the inevitable consequence of more people living longer is that there are more people living with long term illness and the length of these long term illnesses is also increasing. The King’s Fund estimates that 58% of people over 60 are living with one or more long term conditions.\(^2\)

This impacts significantly on health services. People with long-term conditions now account for about 50% of all GP appointments, 64% of all outpatient appointments and over 70% of all inpatient bed days.\(^3\) The Department of Health reported in 2012 that treatment and care for people with long-term conditions in the UK is estimated to take up around £7 in every £10 of total health and social care expenditure.\(^4\)

Within this overall trend, dementia is becoming widely recognised as a critical issue to be addressed by governments and their health services. Whilst there are many causes of dementia, the single most significant risk factor in dementia is age. The incidence of dementia increases significantly with age, with one in 50 people between the ages of 65 and 70 having a form of dementia, rising to one in five people over the age of 80.\(^5\)

It is currently estimated that there are 850,000 people in the UK living with dementia, although updated statistics from the government reported that only 61.6% of people in

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\(^1\) Mid-2014 Population Estimates, ONS 2015  
\(^2\) Long-term conditions and multi-morbidity \(\text{\textsuperscript{i}}\) The King’s Fund website  
\(^3\) ibid  
\(^5\) Alzheimer's Society website
England with dementia have actually received a formal diagnosis. Although the incidence of vascular dementia (the result of mini-strokes) is falling as certain risk factors fall (e.g. high blood pressure and effects of smoking), overall the number of people with dementia in the UK is expected to increase to 1 million by 2025 and to over 2 million by 2050, assuming that age-specific prevalence remains stable and increases are only driven by demographic ageing.

This is hopefully a worst-case scenario. Improvements to education standards, cardiovascular health, activity levels and other known risk factors may all help to reduce dementia prevalence in the future. However, all current projections assume a significant increase in the numbers of people with dementia in the coming decades.

Recent policy publications by UK governments include:

- **Living Well with Dementia: A National Dementia Strategy (2009)** focusing on raising awareness and removing stigma; improving diagnosis rates; and increasing the range of services for people with dementia and their carers.

- **The Prime Minister’s Dementia Challenge (2012)**, a programme to build on the progress made through the National Dementia Strategy designed to make a real difference to the lives of people with dementia and their families and carers. The three priorities set out are health and care, improving dementia research and creating dementia-friendly communities.

- **The Prime Minister’s Dementia Challenge (2020)** updating the 2012 Challenge and setting the twin objectives of making England the best country in the world for dementia care and support; and the best place in the world to undertake research into dementia.

Dementia is also one of the six main ambitions in Public Health England’s Health and Well-being Framework (2014), with the focus on the prevention of dementia.

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Given that the prevalence of dementia is directly proportional to the age profile of the population, not surprisingly there are differences in the number of people with dementia across the regions and nations of the UK. The need for dementia care and the cost to health and social services is therefore unevenly distributed, with more people with dementia living in rural and coastal areas and traditional retirement areas, such as Devon and Cornwall and The Lake District.

All of this assumes that there are no major medical advances in the prevention or treatment of dementia. There is currently no medical prevention or cure for the dementia, although research is suggesting that life-style choices may have an influence. A small number of drugs are now being used to treat the behavioural and cognitive symptoms of dementia, but these have no effect on the underlying disease process. Their use is limited and in most cases they are not prescribed. To date, the quality of evidence as to their effectiveness is poor and the benefits are variable and often small.

One particular area of concern identified in the Prime Minister’s Dementia Challenge (2020) is the inappropriate use of antipsychotic medication for people with dementia. This re-iterated the recommendations of a 2009 report by Professor Sube Banerjee for the then Minister of State for Care Services that highlighted the need to make a reduction in the use of antipsychotics for people with dementia a clinical governance priority for primary and secondary care. It also identified the need to improve the management of such drugs in both care homes and for people with dementia living in different housing settings in the community.

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7 The use of antipsychotic medication for people with dementia: Time for Action, Professor Sue Banarjee, King’s College London, 2009
The current model of dementia care

For the majority of people diagnosed with dementia, the initial diagnosis does not lead to any real change. Despite the various governmental strategies and challenges that have been published, a survey of 1,000 GPs published by the Alzheimer’s Society in July 2015 reported that seven out of ten GPs felt that people diagnosed with dementia received no support from social services and the NHS. Only where diagnosis comes at a relatively later stage in the dementia is support provided by Adult Social Services or the NHS.

This is especially true of where and how people with dementia and their families live. Surveys of older people in general consistently show that:

- People want to enjoy the best possible quality of life for as long as possible. Whilst recognising that some physical and/or mental decline is an inevitable part of the ageing process, ideally the decline should be slow initially, allowing them to remain living independently or with minimal support in their own homes.

- When the time comes, end-of-life for both the individual and their carers should be calming, supportive, loving and dignified in a homely, caring environment, surrounded by friends, loved ones and personal belongings. Research published by the National Audit Office in 2009 suggested that the majority of people (between 56 and 74 per cent) expressed a preference to die at home, although this proportion may decline as death becomes more imminent and people want access to more extensive support, such as from a hospice.

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8 Dementia care onus falls on families, say GPs, Alzheimer’s Society website, July 2015
9 End of Life Care, National Audit Office, 2009
For people diagnosed with dementia, a typical journey in terms of where they live could be:

Depending on the point at which the dementia is diagnosed, the journey for each individual may be different. For example, late diagnosis arising from informal carers reaching a crisis point could lead to a move straight to a residential or nursing care home.

Given that the choice for the majority of people with dementia is to remain in their own home (with support) or move into a residential or nursing home setting, it is important to consider the issues that can arise with either option.
Remaining in your own home with dementia

Issues for older people in general

Currently, 93% of older people live in mainstream housing. As well as ‘ordinary’ housing, this includes housing considered especially suitable for older people, e.g. bungalows or houses with stair-lifts.

The vision older people have of remaining in their own home is of living with a high quality of life, in a familiar, homely environment, with the support of family, friends and professional carers. However, according to AgeUK\textsuperscript{10}, the reality for many older people living in their own homes can be very different:

- Loneliness and social isolation are widely recognised to be harmful to health and well-being in later life.

Loneliness can be as harmful for our health as smoking 15 cigarettes a day.\textsuperscript{11} More importantly in the context of this paper, people with a high degree of loneliness are reported as being twice as likely to develop Alzheimer’s as people with a low degree of loneliness.\textsuperscript{12} Despite this,

- 36% (3.5 million) of people aged 65+ live alone. Nearly 70% of these are female. The likelihood of living alone increases with age, with 2 million people aged 75+ living alone (75% female).
- 13% of people aged 75+ said that they were always or often lonely.
- Nearly half of older people (49% of 65+) say that television or pets are their main form of company.
- 5% of people aged 65+ spent Christmas Day 2010 alone.
- As we age, our circle of friends naturally shrinks. Only 35% of over 65s reported spending time with friends most days and 12% reported never seeing friends.

\textsuperscript{10} Later Life in the United Kingdom, AgeUK, August 2015
As families become more widely spread geographically, time spent with family also declines. Only 46% of over 65s reported spending time with family most days and 12% reported never seeing family.

- Care and support (unpaid or professional) can fall short of the level required.

In England, almost 418,000 people aged 65+ received community-based care and support at home in 2012/13.

- However, in real terms, spending on social care in England has fallen by £770 million since 2010.
- The most common requirements for care and support are:
  - Personal care (68%)
  - Feeling safe & secure (55%)
  - Meals (54%)
  - Keeping my home clean and comfortable (51%)
  - To have control over daily life (49%)
  - Social contact with people I like (42%)
  - Doing things I value and enjoy (33%)

- With social care budgets under increasing pressure, the emphasis is on providing the basics of home care, principally personal care, safe administration of medication, provision of meals and home cleaning. Nearly 200,000 older people in the UK reported that they do not receive the help they need to get out of their house or flat. This leads to further social isolation and loneliness, with 9% of older people feeling trapped in their own home and nearly 600,000 older people leaving their house only once a week or less.

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13 ICM Research survey for One Voice, Age Concern and Help the Aged, 2008
14 TNS Loneliness Survey for AgeUK, April 2014
15 One Voice: Shaping our ageing society, Age Concern and Help the Aged, 2009
• Home maintenance can become more challenging in later life.

As we age, the ability to maintain our own home can decline, both through declining physical ability to do DIY and through the lack of desire and/or finances to pay other people.

- DCLG reported in 2012 that 26% of the homes occupied by older people in England fail the decent homes standard.\(^\text{16}\)
- Whilst over 750,000 people aged over 65 need specially adapted accommodation because of a medical condition or disability, 145,000 of them report living in homes that do not meet their needs.\(^\text{17}\)

• The cost of running a home is an issue for many older people on low incomes.

Recent increases in gas and electricity costs have hit pensioners hard. Every year, 28,000 older people die of the cold. As well as financial issues, often the inability to maintain a house at an adequate temperature is due to poor insulation, inefficient heating systems and single older people or older couples continuing to live in large houses (three or more bedrooms), rather than downsizing.

- There is a strong relationship between poor insulation and heating of houses, low indoor temperature and excess winter deaths of older people.\(^\text{18}\)
- Over a third of older people report living in one room in the winter to reduce their heating bill.\(^\text{19}\)

The impact of all of this is that there are a number of health issues directly related to people’s inability to look after themselves in their own homes:

- Malnutrition – Latest estimates suggest that 1.3 million people aged 65+ are malnourished and the vast majority (93%) of these live in the community.\(^\text{20}\) This is

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\(^{16}\) English Housing Survey Household Report 2010-11 Annex Table 6.2, DCLG, 2012
\(^{17}\) Housing in England 2006/07, Communities and Local Government, 2008
\(^{18}\) The Health Impacts of Cold Homes and Fuel Poverty, 2011
\(^{19}\) Labour Market Statistics, ONS, December 2012
evidenced by the fact that 32% of people aged 65+ who were admitted to hospital in 2011 were found to be malnourished at the time of admission.\textsuperscript{21} In terms of cost to the NHS, malnourished patients stay an average of 5-10 days longer in hospital.

- Over 30% of older people say that they are unable to cut their own toenails.\textsuperscript{22} More than half of new episodes of foot care are for people aged 65+.
- About a third of all people aged 65+ fall each year\textsuperscript{23}. As well as being the largest single cause of emergency hospital admissions and accounting for 40% of ambulance call-outs to homes for people aged 65+\textsuperscript{24}, falls are a major precipitant of people moving from their own home to long-term nursing or residential care.\textsuperscript{25}
- There are around 3.2 million people over 65 suffering from urinary incontinence.
- Declining general health can be associated with depression among older adults, alongside other risk factors, such as loneliness, poverty and poor housing conditions. Depression is estimated to affect over 2 million people aged 65+ in England.\textsuperscript{26}

Remaining in your own home with dementia

All of the above issues tend to be exacerbated when the older person living in their own home has dementia. A survey by the Alzheimer\'s Society in 2014\textsuperscript{27} found that only half of those surveyed felt that they are living well with dementia.

If they are living with a partner, often that person will deliver the bulk of the care, affecting their own physical and mental health.\textsuperscript{28} Only 47% of those surveyed by the Alzheimer\'s Society said that their carer received any help in caring for them.

Social isolation is a real issue, with less than half of the people with dementia surveyed saying that they felt part of their community, 40% reporting feeling lonely (62% for those living alone) and almost 1 in 10 only leaving their house once in the previous month.

\textsuperscript{21} Ella M, Russell C (2014), Nutrition screening surveys in hospitals in the UK, 2007-2011, BAPEN
\textsuperscript{22} Feet for Purpose?, Age Concern, 2007
\textsuperscript{23} Masud T, Morris RO (2001), Epidemiology of falls, Age and Ageing, 30-S4: 3-7
\textsuperscript{24} Snooks H, Cheung WY, Gwini SM, Humphreys I, Sanchez A, Siriwardena N (2011), Can older people who fall be identified in the ambulance call centre to enable alternative responses or care pathways? Emergency Medical Journal, 28(3), e1-e1
\textsuperscript{25} DoH (2012), Improving outcomes and supporting transparency, NHS Choices website
\textsuperscript{26} Health Survey for England 2005, Health of Older People, IC NHS 2007
\textsuperscript{27} Dementia 2014, The Alzheimer\'s Society, 2014
\textsuperscript{28} Improving Dementia Services in England, NAO, 2007
Dementia can also significantly increase the risks of malnutrition (through poor diet or simply forgetting to eat), dehydration, falls, accidents, issues with personal hygiene and problems due to incontinence.

Cost of supporting people to stay in their own homes

As highlighted above, the cost of social care has fallen in real terms since 2010. Supporting people in their own homes is a costly model, with care workers spending time travelling between calls. In addition, paying for one-to-one care on a per hour basis is significantly more expensive than providing group care in a care home environment.

As identified above, many of the problems are due to older people living in poor or inappropriate housing. The NHS first year treatment costs resulting from older people living in poor housing are estimated at £1.4 billion, including £848 million as a result of excess cold, £435 million as a result of falls, £25 million as a result of fires and £16 million as a result of damp and mould.

Despite all of the above, 97% of over 65s when surveyed\(^{29}\) said that they were satisfied with their accommodation and 59% were ‘very satisfied’, the highest for any age group. The question is: ‘how much is this response dictated by the thought of moving into a care home as being the only alternative?’

\(^{29}\) Survey of public attitudes and behaviours towards the environment, DEFRA, 2011
The care home alternative

AgeUK estimates that there are 5,153 nursing homes and 12,525 residential care homes in the UK\textsuperscript{30}, providing accommodation for 426,000 older and disabled people, of whom 405,000 are aged over 65. Despite an increase of 11% in the overall population of those aged 65+ since 2001, the care home resident population has remained constant.\textsuperscript{31} As a result, only 16% of people aged 85+ live in care homes in the UK.

Care homes can broadly be divided into:

- Residential care ï– providing general personal care, food and accommodation, but without nursing staff.
- Nursing care ï– providing general personal care, but with medically trained nursing staff to provide nursing care as required.

As we support increasing numbers of older people to remain in their own homes for longer, the effect is that the resident care home population is ageing and people move to a care home setting later in life and when their health has deteriorated significantly. Whilst around 27% of people surveyed in 2011\textsuperscript{32} had lived in their care home for more than three years, the median period from admission to a care home to end-of-life is only 15 months.

Whilst there are lots of good care homes across the UK, unfortunately people’s perceptions of care homes are tainted by the media finding and highlighting bad practice on a regular basis. Statistics show that not all care in a care home setting is of an acceptable standard:

- 52% of older people admitted to hospital from care homes were found to be malnourished.\textsuperscript{33}
- Depression affects 40% of older people in care homes.\textsuperscript{34}
- Only 36% of people aged 50+ are confident that older people who receive care services, either at home or in a care home, are treated with dignity and respect.\textsuperscript{35}

\textsuperscript{30} Care of Elderly People Market Survey 2013/14, Laing & Buisson, 2014
\textsuperscript{31} Changes in the Older Resident Care Home Population between 2001 and 2011, ONS, 2014
\textsuperscript{32} Length of stay in care homes, Forder J and Fernandez JL, PSSRU Discussion Paper 2769, 2011
\textsuperscript{33} Ella M, Russell C (2014), Nutrition screening surveys in hospitals in the UK, 2007-2011, BAPEN
\textsuperscript{34} Depression and older people: Toward securing well-being in later life, Help the Aged, 2004
For many residents and their families, the hotel-style environment can also become impersonal and this increases with the size of the care home. Based on the above figures, the average size for a care home in the UK is around 24 beds, but this can vary from 5-bed conversions of large old houses to 70+ bedroom purpose-built homes. The standard of accommodation can also vary from conversions of very old houses to new-build, purpose-built, two or three storey blocks.

There is a general feeling that care homes are good at prolonging quantity of life, but many fail to provide good quality of life. It is not surprising therefore that very few older people positively choose to move to a care home environment.

**The care home environment for people with dementia**

Dementia is increasingly becoming one of the reasons why someone moves into a care home setting. The Alzheimer’s Society estimates that one third of people with dementia live in a care home and 80% of care home residents have some form of dementia or memory issues.

Whilst some care homes specialise in dementia care and train their staff to a high standard, for many the standard of dementia care is poor. Staff often receive only basic dementia-awareness training.

The fundamental approach of most residential care homes is to be like living in a hotel. This can sound attractive when initially looking at residential care, especially if the choice of care home is with the family, rather than the person with dementia. However, experience is showing that the old phrase ‘use it or lose it’ has a lot of truth. Living with dementia in an environment where the resident is not expected or encouraged to do anything for themselves can lead to a more rapid loss of ability to perform Activities of Daily Living.

Professor June Andrews, author of Dementia, The One-Stop Guide, gives the following advice for people with dementia and their families when looking for a care home:

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35 Tracker survey for AgeUK, TNS, Feb 2015
• Is everyone treated with dignity and respect?
• In the public areas, is the TV on, is anyone watching it and is the programme relevant to the residents?
• Do residents talk to you? If not, this may be a sign that they are used to being ignored.
• Are a lot of residents sleeping in the middle of the day?
• Do care plans include meaningful activities?

All too often, families are impressed by the hotel-style environment and do not look beyond this to the actual care that is being provided, especially for people with dementia.

Residential care may not be the final move

Moving home can be extremely stressful and confusing for people with dementia and their families. Unfortunately, for many people with dementia the move to residential care is not the final move they have to make. Many people in the advanced stages of dementia require a great deal of one-to-one support in terms of eating, personal care and moving and assisting. Unless there are other medical conditions present, this care can be provided by non-medically qualified carers. However, in most cases, residential care homes do not have the staffing resources available to provide this level of one-to-one support. Residents are therefore moved onto nursing care homes where the care may be funded by the NHS. This is extremely costly for the NHS, as they are paying for nursing care when in many cases only social care is required. Nursing homes are typically also more like hospital-style environments and so not where most people would want to end their days.

People with dementia that exhibit behaviours that we find challenging may be moved to live in an Elderly Mentally Infirm (EMI) care home (or EMI wing of a larger care home). Although this is considered to be an outmoded term, EMI is still commonly used to refer to care homes with mental health nurses on duty and with additional measures to ensure the safety of staff and residents.
Demand for dementia-specialist accommodation

A key element affecting the quality of life for someone with dementia is the place in which they live. However, whilst Objective 10 of the government’s National Dementia Strategy 2009 proposed that the needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare, the housing components in the National Dementia Strategy and other government proposals are relatively undeveloped, with little detail provided.

In its report ‘Home Truths: Housing services and support for people with dementia’ published in 2012, the Alzheimer’s Society provided the following insights concerning housing for people with dementia:

- Much of the UK’s current housing stock is poorly designed to meet the needs of older people generally.
- Although there is a strong emphasis in dementia policy on supporting people with dementia to remain independent in their own homes, there is only limited emphasis on the needs of people with dementia in current housing policy.
- There are significant barriers to people with dementia moving home, either within mainstream housing (e.g. downsizing), to specialist housing or to a care home setting.
- Information and advice on the choice and suitability of housing options is often limited.

As with everything to do with dementia, in terms of housing there is no ‘one size fits all’ solution and everyone will have different requirements. The Alzheimer’s Society report found that people with dementia and their carers have mixed and often quite strong views on the type of housing in which they wish to live and what would be the most appropriate to meet their individual needs.

The need for specialist housing for people with dementia

As outlined above, at the current time, people with dementia typically have a choice between living at home in mainstream housing or living in a care home. There are only a small number of specialist extra-care housing schemes (or wings of schemes) for people with dementia. What is clear is that there needs to be a broader range of housing options and support choices for people with dementia and their carers.
The current supply of specialist housing for people with dementia is very low, with most local authorities having no or very low numbers of specialist housing units, either in existence or planned.

The (SHOP) Strategic Housing for Older People Resource Pack (Association of Directors of Adult Social Services (ADASS), Housing Lin 2011) is the most commonly used model for benchmarking supply of specialist accommodation for older people. This model identifies the need for an initial target of six units of specialist housing for people with dementia per 1,000 of the population aged 75+.

The number of units needed for each ADASS region are set out in Figure 1 below.

![Figure 1: Projected Housing Need, 2014 and 2034](image)

This is calculated by applying the SHOP model to the ONS 2010-based sub-national population projections. This shows a need for a total of 26,443 units across England today, rising to 43,569 units by 2034.

Within this, there is a specific requirement will be for specialist housing for people with early onset dementia, defined as those people diagnosed with dementia before the age of 65. There is a particular housing issue for these younger people with dementia if they are
not able to continue to live in mainstream housing. Currently their only choice is to live in a care home setting with much older people with dementia.

The importance of dementia-friendly design

The design of housing and the wider environment can play a key role in ensuring that people with dementia enjoy the best possible quality of life. The National Housing Federation published a report on dementia and housing in 2013. This included a number of recommendations to housing associations to improve housing options for people with dementia, including a recommendation to invest in specialist housing that is care-ready for people with dementia.

Good practice around design principles for specialist housing and care settings for people with dementia is slowly but steadily growing. A number of design principles and good practice are now widely understood and there is an emerging consensus surrounding the design of supported housing for people with dementia.

Much of this is concerned with allowing people with dementia to be as independent as possible within their own homes. Key design recommendations include:

- creating a pleasant, familiar, domestic environment,
- providing ‘domesticity’ in both scale and character,
- providing space for residents to be surrounded by personal possessions,
- designing a simple, easily understood layout,
- ensuring visual accessibility, with open plan areas and key vistas; and
- providing visual cues and way finding features, personalising entrances and using colour and artwork as guides.

However, further research is still needed in this area and challenges remain in terms of the adoption and uptake of dementia-friendly design in mainstream housing and care homes.

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37 Dementia, Finding Housing Solutions, NHF, 2013
38 Design Principles for Extra Care, Housing LIN, 2008; Design guidance for people with dementia and for people with sight loss, Thomas Pocklington Trust, 2010; The design of housing for people with dementia, Utton D, Journal of Care Services Management, 3, 4, 380-390, 2009
This will require the housing sector to fully engage with the development of dementia-friendly communities. Local authorities will need to work with housing developers and housing associations to ensure that there is a mix of housing options available. People with dementia and their families will also need to have access to independent information about the housing options available to them and the pros and cons of each.

New housing options for people with dementia

Much of the research literature covers design features inside and outside the homes, hospitals and care homes. However, much less research has been undertaken to identify good housing and care models for people with dementia. A number of local authorities and care commissioners have begun to develop new housing models for dementia care. These fall into four broad categories:

- Small, shared housing schemes, where residents have their own room but share communal facilities.
- Small assisted living schemes, where residents have their own self-contained accommodation (i.e. their own front door) with some communal areas.
- Extra-care housing where parts of the scheme are designated for people with dementia.
- Close care housing, comprising self-contained housing units (usually flats or bungalows) built in the grounds of a residential care home or nursing care home.

There has been little in the way of formal research about different housing models and the outcomes that they can deliver compared to residential care or nursing care, both in terms of quality of life for people with dementia and in terms of lifetime cost of care. However, what is clear is that there is no single model of housing that works for everyone with dementia and at every stage.
Extra-care, Assisted Living and Close Care alternatives

Extra-care housing developments (also called very sheltered housing, assisted living or close care schemes) are a growing and popular part of the housing with care market. Most people living in such schemes are older people and they often find it attractive because it offers them independent living in a home of their own with other services on hand if they need or want them.

Good extra-care housing schemes can remove a number of the issues faced by older people continuing to live in their own homes that have become unsuitable for their needs or challenging to maintain. A factsheet published by Housing LIN suggests that extra-care housing is gaining a reputation for being able to accommodate people who would otherwise be frequent users of acute services, largely because their housing is unsuitable for them to self-care.39

Extra-care, assisted living and close care housing schemes can vary widely, covering:

- Purpose built retirement villages.
- Large blocks of apartments with a restaurant or other linked buildings.
- Leisure complexes.
- Developments of bungalows and a mix of apartments and a central resource building that houses community health services or other facilities serving the occupants and local people.
- Sheltered housing schemes.
- Hotels.

Typically, each resident will live in a self-contained home, with their own front door. What further defines a development as ‘extra-care’ relates more to the services provided than the physical buildings. A typical extra-care scheme will include:

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39 Extra Care Housing - What is it? Riseborough M & Fletcher P, Housing LIN website, 2015
• On-site building maintenance services, removing the need for residents to have to organise the maintenance of their own homes.
• Homes designed or adapted specifically for the needs of older people.
• Care services (possibly) on-site.
• Access to domestic services (cleaning, laundry etc.).
• Communal activity areas (residents’ lounge, dining room etc.).

Social sector extra-care schemes tend to focus more on the support services available and can often be a hub to support older people in the wider community. Private extra-care developments on the other hand tend to be exclusively for the benefit of their residents, focusing on leisure and social activities.

Extra-care for dementia

A study by the Housing and Dementia Research Consortium in 2012\textsuperscript{40} suggested that between 15% and 35% of people living in extra-care housing have dementia, although the numbers vary according to the specific extra-care models and referral and admissions criteria. However, more recent research by the Alzheimer’s Society\textsuperscript{41} suggested that the figure could be much lower, at around 8%.

A key desire for people with dementia is to remain connected with the local community. However, the Housing and Dementia Research Consortium identified a number of challenges in designing an integrated extra-care model, where people with dementia are integrated with other households in the same scheme:

• Of six integrated schemes examined, none had any specific eligibility criteria for referrals of people with dementia.
• Dementia-friendly design was limited to some colour coding of different floors and doors.
• There was little dementia-friendly provision within the residents’own flats.

\textsuperscript{40} Provision for people with dementia within Housing with Care: Case Studies from the HDRC Steering Group Providers, HDRC, 2012
\textsuperscript{41} Dementia UK Second Edition Overview, Alzheimer’s Society, 2014
• Only two of the six schemes provided any activities specifically tailored to the needs of people with dementia.
• There was generally a low level of dementia-related training for staff.

Some extra-care developments include a wing, or a part of the development, for people who have dementia. People who have moved into extra-care and later develop dementia almost always continue to be supported by their neighbours.

Moving people in with dementia to live alongside people who don’t have dementia is more complicated, particularly for people who have moderate or severe dementia. The main challenge identified by staff in integrated schemes was coping with negative attitudes from other residents who did not have dementia. Experience so far has shown that integrated extra-care is appropriate only where careful thought is given to matching with the neighbours and where staff are well trained to provide care and support. It can also be an excellent choice for a couple where one partner is caring for the other who has dementia, if neighbours are supportive.

In an article in Building.co.uk in September 2014 on Extra-Care housing[^42], David Hughes, Chief Executive of Pozzoni, commented that:

> Anecdotal evidence shows that while extra-care housing is suitable for people with relatively low or mild levels of dementia, it is not suitable for people with its more severe forms, who inevitably have to move on to a specialist high-dependency care environment, which contradicts the principle of a ‘home for life’. Providing a dementia care facility on site can, to a degree, resolve this, as an individual is still in the same place and with the same housing provider, hence the rise of ‘continuing care communities’.

Extra-care housing can therefore be viewed primarily as an extra step in the dementia journey, delaying but not necessarily removing the need for a move to residential or nursing care. Evidence would therefore suggest that whilst extra-care housing certainly has a role to play in keeping people with dementia independent in their own homes for

[^42]: Cost model: Extra care housing, from building.co.uk, September 2014
longer, for many people some form of specialist dementia housing model is needed as an alternative to moving to a care home as their dementia develops.
The Dementia Care model

Dementia Care has developed a model of small group, independent supported living for people with middle to late stage dementia and, in most cases, through to end-of-life. This is an alternative to a residential care home and for more people, negates the need to move to a nursing home for end-of-life care.

Dementia-friendly building design

A typical Dementia Care scheme consists of five (or more) five-bed bungalows located together in a close. Each bungalow is built following dementia design guidelines developed by the Dementia Services Development Centre at the University of Stirling.

The buildings are owned by a housing association or Registered Social Landlord and the residents each have a secure tenancy for life. Each resident has their own room with en-suite toilet and washbasin. There is a communal lounge, dining room, conservatory and kitchen/utility room. Outside is an enclosed rear garden.

Bungalows can be same-sex or mixed gender, depending on the individuals concerned. The majority of residents are female, as more women tend to have dementia. In some cases, women and men can happily share a house. However, some individuals may not feel comfortable sharing a house with members of the opposite sex. Of eight homes currently being managed by Dementia Care, six are single sex (five female and one male) and two are mixed gender.

All rooms are single and the bungalow design currently does not support couples continuing to live together. It is unlikely that a partner without dementia would find it suitable to live in a shared home with other people with dementia. Furthermore, our experience is by the time a person requires our supported living, the unpaid carer is often burnt out from their caring role. The model is particularly suitable for single people with dementia without immediate family or whose family are unable to visit regularly, as it can provide a family environment and promote social interaction.
Specialist care provision

Whilst the physical design of the bungalows is important, key is the nature and level of care provided by Dementia Care staff.

Each bungalow is managed by a Team Leader, responsible for all staff working within the bungalow. A Specialist Support Worker supports the Team Leaders and oversees the whole development.

Care is provided through one member of staff being in the bungalow at all times, on a 12-hour shift system. All staff receive specialist dementia training by Dementia Care, based on training developed by the University of Stirling and other leading care training providers.

The core principle for all care provided is the promotion of supported living. Unlike the ‘hotel model’ of residential care, residents are encouraged and supported to do as much as they can in terms of Activities of Daily Living. Residents are involved in on-line shopping for food, in cooking and making drinks, in cleaning their own rooms, in dressing and undressing, washing and bathing and in personal hygiene. There are no set meal times and residents can please themselves as to their daily routine.

The advantage of grouping the bungalows together is that activities can be organised across all residents. With a mix of 25 residents, lots of interests can be provided for and residents can make friends both within their own bungalow and with residents of other bungalows.

Cost model

Costs are typically shared between public and private funding, broken down into:

- Placement care – standard weekly cost for care, in most cases paid by Adult Social Services or the CCG (through Continuing Health Care funding).
- Additional one-to-one care or end-of-life palliative care is funded by Adult Social Services or the CCG on a case-by-case basis.
- Rent and service charge – paid privately or through housing benefit (depending on the individual’s personal circumstances).
• Food and personal expenses ï managed by Dementia Care against a weekly budget, paid by residents.

Although the level of staffing and associated care is far higher than in a residential care home, for care commissioners the costs are typically at or below the standard rate for placement care and significantly below the cost of nursing care or intensive home support. Whilst outcomes are difficult to measure (see below), for the NHS the level of care provided can result in real savings in terms of avoiding costly admissions to hospital as each person’s dementia progresses. For care commissioners, significant savings can be achieved over the longer term, as the model removes the need for the individual to ultimately move into more expensive nursing care.

Outcomes

When looking at outcomes, it is important to stress that Dementia Care only supports people with middle to late stage dementia and almost everyone is in later life. Outcomes therefore need to be judged in comparison to people with dementia that otherwise would be living in a residential care home, or in many cases, a nursing care home.

• Maintenance of life skills

Since December 2013, Dementia Care has been recording the capabilities of 33 residents in its independent supported living service. These are recorded twice each day and cover 17 Activities of Daily Living:

- Bathing
- Dressing
- Eating
- Toileting
- Hair Care
- Medication
- Communication
- Domestic Skills
- Shopping
- Meal Preparation
- Out & About
- Personal Interests/Hobbies
- Sleeping during the day
- Use of Objects
- Looking at Newspapers/Magazines
- Mobility
- Handling Money
Each question is scored 1 to 4, on the following scale:

1. Can start and finish on own, although may need some reminding during the activity.

2. Cannot start without prompting. Shows continued engagement. May need further prompting but will complete the activity.

3. Cannot start without prompting. Shows period of engagement. Will need further prompting. May not be able to complete the activity.


This large dataset is being analysed to draw out longitudinal outcome results. Examples of data sets produced are shown for two residents below, where GH has been in our Independent Supported Living for 8 years, 8 months and MS for 17 years.

This shows that over a period of 16 months, GH’s abilities to do things unaided declined in many areas as her dementia progressed. However, she was able to maintain the ability to perform tasks unaided in terms of dressing, eating, toileting and communicating.

For MS, again over a 16 month period, she was able to continue to perform a number of activities unaided (dressing, eating, toileting, hair care, communication) or showed only small declines in ability (medication, domestic skills, personal interest). Importantly, she became more active, taking part in activities outside the home, including attending our day centre.
GH - Progression Measured on Day Shift Data
02/12/2013 and 31/03/2015

MS - Progression Measured on Day Shift Data
01/02/2014 and 26/06/2015
The problem with outcome measurement for people with dementia is that everyone with dementia is different. Without a statistically valid sample size, it is very difficult to draw firm conclusions. Also, as care homes do not publish similar data on residents’ abilities to the same level of detail, there is also no comparative data against which to benchmark the Dementia Care model.

However, based on the data collected so far, the Dementia Care model appears to help people with middle to advanced stage dementia to maintain life skills over a longer period than would normally be expected. In some cases, it has even been possible to recover previously lost skills.

- Avoidance of hospital admissions

The age range currently across 32 residents is from 51 to 93, with a median age of 83.

As such, many residents will have other co-morbid health conditions, in addition to dementia. Despite this, in the last 12 months, there have been no emergency hospital admissions. As is the case for most good care homes, Dementia Care staff are able to monitor for common infections, such as chest infections and UTIs. With GP support, these can be prevented from escalating, avoiding the need for hospital admission. Some low-level nursing can also be provided by Dementia Care staff. Again, in the
last 12 months, none of the residents have been admitted to hospital with UTIs or other common infections.

This compares with a recent report by Public Health England\textsuperscript{43} that showed a 48% increase in emergency admissions involving people identified as having dementia since 2008/09. Of emergency admissions involving people with dementia, 20% were for potentially preventable acute conditions, including disease of the urinary system, pneumonia and lower respiratory infections.

**Case Study 1**

93 year old J has been a resident since 2009. Now frail, J will spend much of her time asleep. Our staff know this person well and can tell by the loss of ‘sparkle in their eyе’ that they may be starting with a UTI. A quick sample to the GP and precautionary dose of antibiotics (until sample results return) means that they do not need to be admitted to hospital or confined to bed. The key point is that staff know the people so well that they can recognise the most simple of changes in the overall health and well-being of an individual.

- Faster discharge from hospital

Where a resident is admitted to hospital, the level of care and support provided usually means that they can be discharged and return to Dementia Care more quickly than if they lived in their own home. Even where short-term additional care is required, this can usually be put in place before the hospital is ready to process the discharge.

This shorter stay in hospital is beneficial financially for the NHS, but even more beneficial for the person with dementia, as their abilities often decline during a stay in hospital.

\textsuperscript{43} Reasons why people with dementia are admitted to a general hospital in an emergency, Public Health England, August 2015
• Reablement post hospital

Having had a period in hospital, it is often the case that with the right level of specialist dementia care, residents can recover some of the abilities that they have lost during their time in hospital.

• Reduced 1:1 packages

A number of people referred to Dementia Care exhibit behaviours that we find challenging or require a high level of support due to physical changes/needs. This can be in terms of frustration, distress, physical aggression, agitation, lack of mobility, inability or unwillingness to eat or drink or incontinence. This can lead to the need for intensive, 24/7 one-to-one care or a move into the equivalent of EMI care. People with advanced forms of dementia are also sometimes treated with anti-psychotic drugs.

There are a growing number of case studies in Dementia Care demonstrating that with the right level of specialist care, this additional care can be reduced over time.

Case Study 2

W moved to Dementia Care in his seventies when his partner died. He has dementia and when he moved in he was agitated, would physically hit out at staff, was distressed and had sleepless nights. As a result, W was assessed as requiring 24/7 one-to-one support and was prescribed Risperidone. Over the last three years, W started to sleep throughout the night, allowing the care to be reduced to a sleep-in carer for the 8 hours in the night and one-to-one care during the day. After a year on Risperidone, the dosage was gradually reduced and W is now no longer on medication. The care package has now been further reduced to just 9 hours one-to-one care during the day and no additional care at night.

• Building friendships and creating a family feel

Each bungalow has a homely feel and treated very much as the residents' own home. Families can visit at any time and communal activities involving families can be
arranged, such as Christmas Day lunch and birthday parties. Unlike in a care home setting, when family members visit, it is just like visiting their relative’s own home. Family members are encouraged to cook, prepare and enjoy a meal together with their relative.

Matching residents is a key part of the assessment process. The model is particularly suitable for single people with dementia, especially those without family members close by that can visit regularly. Despite their dementia, a number of residents have become good friends. Staff continuity is also important, so that carers get to know the residents really well.

- A home for life

As stated earlier in this paper, a survey by the National Audit Office found that the majority of people expressed a preference to die at home. The traditional model of care for people with dementia means that, unless death is the result of another medical condition or accident, the majority of people with dementia end their days in a hospital, residential care home, or in many cases, a nursing care home, rather than their own home.

In the Dementia Care model, of the last 10 residents to pass away, one moved to live with her grand-daughter at the end (at the grand-daughter’s insistence and against the advice of Dementia Care), one died in hospital (as he needed regular medical interventions) and the other eight all died in their bungalow, in a homely environment, with family and caring, familiar staff around them.
**Conclusion**

This paper has shown that the current provision of home support, often to a point of crisis, followed by a move to residential care and then nursing care is not be the best model of dementia care in all cases. However, the current supply of specialist housing for people with dementia is very low, with most local authorities having no or very low numbers of specialist housing units, either in existence or planned. Using a projected requirement of six units of specialist housing for people with dementia per 1,000 of the population aged 75+ shows a need for a total of 26,443 dementia-specific units across England today, rising to 43,569 units by 2034. A range of alternative models need to be developed, giving people with dementia and their families the choice of where and how they want to live, in order to maintain the best possible quality of life for as long as possible.

A number of different extra-care style models are now in operation. The majority focus on the provision of better quality housing and support for people in the earlier stages of dementia. This often provides another step in the journey, not necessarily preventing the move to residential or nursing care.

Dementia Care has developed a model of small group, independent supported living for people with middle to late stage dementia and in most cases through to end-of-life. The evidence gathered to date suggests that this model provides:

- higher quality of life, choice and control,
- continued independence for longer,
- low use of anti-psychotic medication
- no emergency and fewer non-emergency hospital admissions
- earlier discharge from hospital and better reablement; and
- a greater chance to pass away in a homely environment, surrounded by their loved ones, which ultimately is what the majority of people want.

As with everything to do with dementia, there is no one size fits all and housing is no exception. Further research is needed to confirm the results of the Dementia Care model, to improve the model and to use this research to develop models better suited to other people with dementia.