Innovation in housing for people with dementia

Nil Guzelgun, Policy Officer
• Why do we need better housing solutions for people with dementia?
• Policy context for ‘dementia-friendly housing’
• What do people with dementia want?
• What does Alzheimer’s Society do to support people with dementia to live in their homes?
• Some examples of dementia-friendly homes
• Questions for the group:
  • What do you like about these examples?
  • What opportunities are there to adopt some of these ideas in your own localities?
  • What challenges could emerge?
People with dementia, alongside other older people with long-term health conditions, have changing housing needs which are not currently met by their homes, or recent housing developments.

850,000 people are estimated to live with dementia.

This number is set to rise to over 1 million by 2021/22 and to over 2 million by 2050.

2/3 of people with dementia live in the community, mostly in mainstream housing.

1/3 of these people with dementia live alone in their homes.
Why do we need better housing solutions for people with dementia?

There is only enough specialist housing to accommodate 5% of the over 65 population.

2 million older households are living in non-decent homes.

Home adaptations improved the quality of life for 90% of recipients as well as for carers.

Two-thirds of people with dementia live in the community, mostly in mainstream housing, a third live on their own, predominantly in the owner occupied sector.

95% of homes lack even basic accessibility features.

An Alzheimer’s Society’s report found that more needed to be done to ensure homes were designed and built with the needs of people affected by dementia in mind.
The Dementia Challenges puts a strong emphasis on supporting people to live independently in their own homes.

There is limited government policy on housing and dementia.

Housing policy remains distinct from health and social care and many stakeholder organisations involved in housing express concerns about co-ordination between housing, health and social care.

It is widely recognised that much of existing housing is poorly suited to the needs of older people and to people with dementia in particular.
What do people with dementia want?

- People with dementia want to live in their own homes for as long as possible.
- People with dementia want to remain part of their communities.
- People affected by dementia want better information about alternative forms of accommodation.
- People want adaptations not to look ‘clinical’ as this makes them feel more vulnerable and less independent.
What ‘home’ means to people with dementia

- Connectedness
- Actively personalising and creating home
- Control over decisions about how and where we live
- Locality - the importance of familiarity; the sense of connection to people and places
- Cultural expectations and needs

Beyond the Front Door (2016) Life Story Network
What does Alzheimer’s Society do to support people with dementia to live in their homes?

Bringing together existing resources and research

Aimed at:
- Supporting people with dementia to live independently
- Helping housing professionals in their support of people living with dementia in their own homes

Provides access to:
- The knowledge to plan and prepare for future projects, developments and services by influencing initial design and planning of future housing stock
- Knowledge and resources to make relevant ongoing adaptations and repairs to current housing stock to support people with dementia

Showcases:
- Case studies across the sector
What does Alzheimer’s Society do to support people with dementia to live in their homes?

**Current outputs:**
- Dementia-friendly housing charter
- Dementia-friendly Financial Services Charter
- Dementia-friendly Employers’ Guide
- Dementia-friendly Arts Venue Guide
- Dementia-friendly Technology Charter
- Accessing and Sharing Information publication
- Dementia-friendly Retail Guide
- Dementia-friendly Church Guide

**Upcoming projects / outputs:**
- Dementia-friendly Heritage Guide
- Dementia-friendly Cinema Guide
- Dementia-friendly Air Transport
- Dementia-friendly Sport Venues Guide
Innovative examples of housing for people with dementia
The house, features a vast collection of intuitive ideas, all grounded in the latest academic evidence, from simple open-plan living spaces to more hi-tech innovations such ‘talking cushions’, which promote activity after long periods of rest, sensory ‘smart chairs’, self-regulating climate control and safety sensors in high risk areas, such as the kitchen.

All of the features in the home were designed around a range of unique personas, created especially for the project, which reflect four progressive stages of dementia, from early onset to end-of-life.

Examples of features include:
- Clear lines of sight and use of colour through the home help guide people towards specific rooms and reduce the risk for slips and trips.
- Increased natural lighting, which has been shown to help people stay alert during the day and to sleep better at night.
- Noise reduction features, to reduce stress and agitation.
- Space to install a lift so the lounge does not become a bedroom when the stairs become difficult.
- Non-scalding faucets, self-closing fridge doors, glass cabinets, simple switches, adequate contrast between floors and walls, large clocks and furniture with no protruding corners to minimise injuries from falls.

The demonstration house cost £300,000 to create, but this figure is not reflective of the actual cost people would have to pay for this home.

This prototype building is inhabited by a couple with dementia to continue gathering data and improving the features of the house and make it market-ready.

Importantly, the features of this house are considered as good-practice for inclusive design and can benefit other people’s needs, too.

Shared Lives

*United Kingdom*

Shared Lives is a national scheme that provides an alternative to home care and care homes for adults. It is used by around 15,000 people in the UK and offers a range of long term, short break and day services.

Shared Lives services are all about one household sharing their lives, families, home, interests, experience and skills with others who need help and support to live their lives to the full. The person is welcomed as a member of the family and supported by a Shared Lives carer who is checked and approved, trained and monitored by the Shared Lives scheme. Shared Lives is highly personalised and delivered by the local community in the local community.

A Shared Lives carer and someone who needs support get to know each other and, if they both feel that they will be able to form a long-term bond, they share family and community life. This can mean that the individual becomes a regular daytime or overnight visitor to the Shared Lives carer’s household.

There are more than 150 Shared Lives schemes across England. Most are based in local authorities but some are run by independent third-sector organisations. Traditionally, Shared Lives schemes have supported people with learning disabilities but increasingly they are working with different user groups including people with dementia.

5 localities participated in a prototyping scheme supporting specifically people with dementia. The independent evaluation found the scheme to be successful and makes a business case for shared lives schemes to be adopted in the national dementia strategy to support people with dementia to live in the community for as long as they wish.

Source: https://www.youngdementiauk.org/shared-lives
The programme has seen students in their early twenties sharing lives with residents in their eighties and nineties. In exchange for 30 hours of volunteering work per month, students are able to stay in vacant rooms, free of charge. As part of their volunteer agreement students spend time teaching residents new skills, like email, social media, Skyping, and even graffiti art.

Each volunteer receives a comprehensive training as well as continuous personal guidance. The training and educational services are organised by the Humanitas Academy.

Behind Humanitas programme is research showing that reducing loneliness and social isolation improves wellbeing and extends life expectancy in older people. Importantly the programme involves also people with dementia.

This intergenerational housing project has been adopted by different housing providers in the Netherlands, the UK, France and Australia as it proves a promising model of care.

Source: https://www.citylab.com/equity/2015/10/the-nursing-home-thats-also-a-dorm/408424/
What distinguishes this village from a care home or nursing home is that people can move freely in the village, and that every house is designed according to different lifestyles. There are seven lifestyles reflecting elements of Dutch society: cultural, urban, homely, Indonesian, spiritual, rustic and upper class.

Each of the 23 households is made up of 6 to 7 residents who share common values or interests. Each household has a kitchen, dining and living areas. Residents eat and relax together and can contribute to the village life to the degree they wish to.

Residents have to go outside in order to access communal facilities, such as a café, restaurant, theatre, supermarket, a traditional Dutch pub and a hairdresser. 250 staff work at the facility, in addition to the 140 volunteers supporting the residents. Staff working in the village blend in with the residents and look like normal hairdressers or shop owners instead of nursing home staff.

The cost of living in the village amounts to £4,500 per month, which is partly covered by the long-term care insurance scheme and partly by individual contributions which are capped at £1,800 per month.

Residents performed better activities of daily living, were more socially engaged than in traditional residential settings and had a reduced need for continence materials and sleeping pills and demonstrated low levels of challenging behaviour.

The dementia village model has attracted a lot of media attention and is planned to be adopted in the UK, Australia, Switzerland, and France.

1. What do you like/not like about these examples?
2. What opportunities are there to adopt some of these ideas in your own localities?
3. What challenges could emerge?
Dementia and DToC

UK Dementia Congress 6-8\textsuperscript{th} November 2018

National Body for Home Improvement Agencies
Improving Delivery of the Disabled Facilities Grant
Highly Personal

- Noise, Light & Place worsens confusion
- Lack of Activity increases dependence
- Staff ill-equipped to deal with agitation & anxiety
- People experience difficulties in eating, drinking & staying clean
- ½ experience pain which goes untreated
- Carers marginalised
The Scale of the Challenge

- 70% living with dementia have another medical condition or disability

People with Dementia experience the pressures on acute care disproportionately:

- They twice as likely to be readmitted
- ¼ of Hospital beds are occupied by people living with Dementia
- Spending 4.2 million days in hospital 2015-16, up from 3.5 million in 2009-10
- 36% will have been admitted to hospital from their own homes but do not return there
- They are likely to stay twice as long
- They are 20% more likely to die
- They are 3 times more likely to fall in hospital
- They account for 80% of people in care
What Works?

- Incorporate service changes over time
- Unpaid carers immensely important in successful solutions
- Better end of Life services are needed
- multi-component approaches more likely to be successful
- Involve People with dementia & carers

Caveat!

- Small number of papers evaluating outcomes
- Inconclusive

"Beautiful young people are accidents of nature, but beautiful old people are works of art."
—Eleanor Roosevelt
If not in Hospital or care then where?

Home

- 2/3rds of people with Dementia live in ordinary houses.
- 85% of them say they want to stay
- Life Story Network: Beyond the Front Door
- Dementia & Housing Working Group
  - Address the A&I deficit
  - Address the design challenge
  - Provide better information on outcomes: -Research and evaluation
  - Person Centred ways of working – work better together and work better with people living with Dementia
Housing & Health responses......

- On DToC:NHSE Acute Provider Engagement Programme:
  - Housing advice in Hospital
  - Practical help to repair & adapt in the community
  - Stepdown accommodation

- On Prevention:
  - Early Stage:
    - Scotland
    - Worcestershire
  - Late Stage:
    - Importance of informal carers & respite
    - End of life planning
Scotland’s Dementia Enablement Pilot

- Life Changes Trust & C&R Scotland
- 4 local Care and Repair agencies
- In its 2\textsuperscript{nd} Year Evaluation:
  - 400 people living with dementia
  - 1600 hours of face to face time with specially trained caseworkers
  - 1860 pieces of enabling equipment
  - >£250K benefits & grants raised
- Most popular: Dementia friendly clocks & changes in lighting.
- Independent evaluation is pending
Worcestershire's Dementia Dwelling Grants

- Top-sliced DFG
- District-County-Health partnership
- Non Means-tested
- Delivered by C&R Worcs & AgeUK
- In its 1st Year Evaluation:
  - 500 people living with dementia
  - 380 grants accepted
  - Average grant £138
  - 86% are home-owners
  - People choose: based on what works for them
- Most popular: Dementia friendly clocks & mainstream changes in lighting.
- Independent evaluation Uni of Worcester
Medium and Long-Term Responses

- More Flexible use of existing Social Housing Stock and services
- Reablement and Intermediate Care
- Step-Down Accommodation
- Respite for Informal Carers
- Better collaboration between Acute, Community and Accommodation based services
- Earlier and more integrated advanced planning services about where people want to live and die.
Promoting the strategic role of housing
UK Dementia Congress
Thursday 8 November

Ruth Eley
Chair, Liverpool DAA
Liverpool DAA

- Launched Liverpool DAA in May 2014
- 68 member organisations currently
- 4 RSLs
- Members sign up with action plans and pledges
- Annual work programme
- Overall aim is to help Liverpool become a dementia-friendly city
DAA in Liverpool: how we are organised

• 4 sub groups:
  community engagement and education
  diversity
  transport
  SURF

• Co-ordinating group of chairs, city council, CCG, Alzeimers Society, Merseycare meets monthly

• Groups report to co-ordinating group

• Full DAA meets quarterly
Dementia Action Liverpool

• Not for profit limited company
• Three directors – LDAA chair, vice-chair + SURF representative
• Identical aims as LDAA
• Provides business functions for LDAA
• Bank account, contracts
• No paid staff
Housing and LDAA

- Seminar 2016 to explore design – by invitation
- Followed up with ‘Doing Dementia Design’ national conference 2017
- 193 attendees
- Explored design of internal and external built environment and how to improve inclusiveness
Doing Dementia Design

• Importance of involving people with dementia and carers in decisions about their homes

• Significance of individual capacities and changing needs – adaptability of spaces

• Relationship of regulation, guidance and standards to design practice – how to influence change

• Importance of education and awareness-raising for maintenance and construction staff

• Confirmed crucial role of housing organisations as providers and as strategic partners
Housing and LDAA

• Brought housing providers together to consider outputs from the conference
• Decided to run local conference exploring policy and practice for people and places – development and management of homes
• Sector took ownership, organised conference
• 9 RSLs contributed as sponsors
Meanwhile...

- Dementia Action Liverpool commissioned to refresh Liverpool’s joint dementia strategy
- Wide membership beyond health and social care
- Conference provided opportunity to contribute housing perspectives
- People with dementia and carers involved as speakers and participants
- Metro mayor invited – confirmed commitment to dementia friendly city region
What did the conference tell us?

• Importance of ‘home’ for people with dementia and carers
• Specialist provision is important e.g. extra care housing can provide a real alternative to residential care – but ...
• RSLs need to improve responses to people with dementia and carers in general needs housing
• Information about housing options and how to access it are variable
• Awareness and training in dementia for staff need to be bespoke
• Private rented sector – beyond radar & remains a challenge
What next?

• Ensure housing included in refreshed dementia strategy as part of solution
• Establish housing group in LDAA
• Sector led
• Co-design solutions with SURF members
• Promote Dementia and Housing Charter
• Follow up opportunities within Liverpool City Region
• Maintain the momentum!
Thank You!
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