Charlotte Cook
Winckworth Sherwood

Housing - Rising to the Dementia Challenge
DAA and the Dementia Statements
DAA Background

* Sarah Tilsed – Campaigns & Partnerships Manager
* DAA formed in 2010
* 41 national organisations and people affected by dementia
* Created and signed up to the National Dementia Declaration
* Each member commits with an Action Plan
* Local and National DAA are separate
* New National DAA website soon

@Dementia_Action

#DementiaAction
What does the DAA Secretariat do?

We exist to bring together national organisations to connect, share best practice and take practical action on dementia.

The DAA:

* Runs events
* Meets with members
* Has a variety of comms channels
* Runs campaigns
  Dementia Words Matter
The ‘I’ Statements

1. I have personal choice and control or influence over decisions about me

2. I know that services are designed around me and my needs

3. I have support that helps me live my life

4. I have the knowledge and know-how to get what I need

5. I live in an enabling and supportive environment where I feel valued and understood

6. I have a sense of belonging and of being a valued part of family, community and civic life

7. I know there is research going on which delivers a better life for me now and hope for the future
The Dementia (‘We’) Statements

* In 2016 Alzheimer’s Society led a consultation on behalf of the DAA

* Groups and events took place

* Over 80 people with dementia and carers contributing

* Key themes were identified: identity, care, community, carers and research

* A revised set of statements were created: Dementia or ‘We’ Statements

* In April 2017, the Statements were endorsed by the Dementia Programme Board that monitors the Challenge on Dementia 2020
We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.
We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

@Dementia_Action
#DementiaAction
www.dementiacao.org.uk
We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.
We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.
We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.
Significance

The person with dementia is at the centre of these statements

They represent everyone living with any type of dementia

The “we” encompasses people with dementia, their carers, their families, and everyone else affected by dementia

Enshrined in:
* Equality Act
* Mental Capacity legislation
* Health and care legislation
* International Human Rights law

@Dementia_Action
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www.dementiaaction.org.uk
How can YOU use the Dementia Statements?

* Everyone can implement these - they are not rocket science!

* Enshrined in basic human rights

* All staff to have a copy and be aware

* Commissioners should have it as part of their contract

* Housing sector: “We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness”.

@Dementia_Action
#DementiaAction
www.dementiaction.org.uk
Helpful information

Statements
www.dementiaaction.org.uk/nationaldementiadeclaration

Dementia Words Matter
www.dementiaaction.org.uk/dementiawords

Challenge on Dementia 2020

Contact me sarah.tilsed@alzheimers.org.uk
Housing and the dementia 2020 challenge

Gavin Terry
Policy Manager
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Housing and Dementia
‘By 2020 we would like to see an increased number of people with dementia being able to live longer in their own homes when it is in their interests to do so, with a greater focus on independent living.’

Prime Minister’s challenge on dementia, 2020
People with dementia should be supported to live independently in their own homes for as long as they are comfortable and safe to do so

- Adaptation of accommodation
- Exploring housing options
- Social care to preserve independent living
- Support for initiatives that help people stay independent and healthy
Housing

- Increase to the budget of the Disabled Facilities Grant by 2019
- Exploring assistive technology as well as other options for supporting people with dementia
- Continued support of the Health and Housing Memorandum of Understanding, in particular equipping the workforce to provide integrated care
What the DH said it would do

- Work with the Dementia and Housing working group to raise the profile of housing, and highlight and promote good practice
- Work with Sitra, the Association for Dementia Studies at the University of Worcester and the Housing Learning and Improvement Network to deliver specialised training
- Work closely with the Life Story Network to focus on older people and people with dementia who live in social housing
What the DH said it would do

- Safe and appealing green spaces, building dementia-friendly streets and ensuring people can access new GP services using digital technology
- Technology and assistive technology to enable people to live independently for longer
Review of the PMC 2020

- Taking place in 2018
- Focus on the 18 key commitments set out in the Roadmaps to Delivery
- Housing *not* included
- Phase 1 Stocktake undertaken with key delivery partners – current progress
- Reporting in summer 2018
- Potential to look at other activity and beyond 2020?
Alzheimer’s Society actions

Turning Up the Volume: unheard voices of people with dementia

Dementia – the true cost: Fixing the care crisis

Fix Dementia Care Homecare

alzheimers.org.uk/fixedementiahomecare
Thank you

Gavin Terry
Policy Manager
The impact of dementia on Black, Asian and Minority ethnic communities in the UK

David Truswell
Chair, Dementia Alliance for Culture & Ethnicity
Common cultural issues in accessing services for Black, Asian and minority ethnic communities

- An anxiety about stigma in their own community group regarding dementia that leads people living with dementia to withdraw from their community
- A feeling of community isolation by carers
- A fear of experiencing discrimination or lack of understanding from mainstream dementia services that makes people reluctant to seek help
- A lack of information on dementia that feels relevant for people’s own personal circumstances
- A belief that dementia is a natural part of ageing and nothing can be done
- Language and cultural practices that impact on day to day care and support
Common service challenges

• Diagnostic materials not appropriate
• Lack of appropriate reminiscence materials and materials for social interventions
• Unfamiliar with working with family group rather than just an individual
• Unfamiliar with working with an interpreter
• Lack of information on community resources
• Pharmacology and ethnicity interactions unknown
• Pharmacology and traditional medicine interactions unknown
• Dying matters
The individual impact

FindingPatience
Contact details

www.demace.com
Vanessa Pritchard-Wilkes
Housing & Care 21

Housing - Rising to the Dementia Challenge
Dementia-Friendly Housing Charter

Housing – Rising to the dementia challenge
14th June 2018
Vision and scope of the charter

- Engage wide range of stakeholders
  Increase awareness of the contribution of housing to the challenges posed by dementia

- Provide relevant resources and examples of good practice

- Aimed at the full range of professionals working in the housing sector

- Designed to help all professionals support people living with dementia in their homes and facilitate consistency and good practice
Bringing together existing resources and research

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
The three pillars and stakeholders

Stakeholders across:
• Designing and building
• Managing and supporting
• Modifying and adapting
<table>
<thead>
<tr>
<th>Commitment Statements</th>
<th>People</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Commitments to People</strong></td>
<td></td>
</tr>
<tr>
<td>There is a lack of understanding by staff of the different needs of people with dementia and associated stigma</td>
<td>Appoint a Dementia lead in the organisation to provide leadership, promote dementia awareness and keep staff up to date with resources</td>
</tr>
<tr>
<td>There are negative reactions from residents and/or communities towards people living with dementia</td>
<td>Increase awareness through the <a href="#">Dementia Friends</a> initiative</td>
</tr>
<tr>
<td></td>
<td>Address <a href="#">negative language</a> and perception and promote more positive messages about living with dementia</td>
</tr>
</tbody>
</table>
Why sign up to the charter?

- Demonstrate leadership within the sector by proactively addressing the societal challenges posed by an increasing incidence of dementia
- Increase awareness of how dementia and its challenges affect the services and products which an organisation offers
- Ensure that the needs of customers are met in a consistent and appropriate manner
- Create an organisation in which customers feel comfortable discussing their needs
- Be perceived by partners as dementia-friendly which may enhance reputation
Committing to the charter

- Download the charter and register on Alzheimer’s website
- Deliver the commitments specific to your stakeholder group within a set, individually determined and planned time-frame
- Identify a senior member of staff to champion the initiative
- Report on progress and outcomes of the identified commitment statements
Thank you

Vanessa Pritchard-Wilkes

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@VanessaHC21
140,000 Customers
66,000 Homes
Board agreed to commission report about becoming a dementia friendly organisation

2015 – Report published and wins an international dementia award

2016 – Housing and dementia project commences

2017 – Project extended for a second year

2018 – Project formally ends, external evaluation due and dementia becomes BAU at Guinness
Customers are more tolerant of ‘odd’ behaviour

Risks to sustaining tenancies are reduced

**Finding:** Progress has been made in raising awareness among customers and this has increased the likelihood of customers with dementia receiving the support they need to continue to live independently.

There is an opportunity to roll out this awareness raising across all customer groups, including new customers.
Contractors and non-care staff have been included in the training.

Additional external training has been accessed.

**Finding:** Before the project, staff awareness of dementia came mainly from direct experience at work (at Guinness or elsewhere) and/or through personal experience. Although care staff have supported people with dementia for many years, they did not necessarily have the breadth of knowledge and confidence to consistently apply best practice. The investment of training resources reflects the priority given to this aspect of the service and alternative channels for learning make it more likely that staff will access training.
DEEP guides are used in all communication formats

Accessible information booklets are available

Finding: Guinness has made effective use of external sources such as Dementia Connect rather than developing its own information hub, as originally envisaged when the project started. The ability to search by postcode for local services on the Connect website means staff and customers can see what is available. The link to Dementia Connect on the Guinness website needs to be more prominent. The use of DEEP guides allows staff to benefit from work done elsewhere on effective communication. Regular items on the GRID have maintained staff awareness related to dementia.
Awareness has made these services more **flexible and tailored**

**Local groups** offering a range of activities

**Finding:** customers living with dementia have been supported to access a range of appropriate services. Through its approach Guinness has brokered a range of bespoke forms of support to be established that support and enhance the lives of customers living with dementia.
Pre-work visits and repairs prioritised

Better recognition in behavioural changes

Finding: The flagging system has made a difference where customers have been identified and consented to be flagged. In order to be of wider benefit many more customers with dementia would need to be covered. Based on modelling by Guinness of the likely prevalence of dementia among customers (in the region of 300-350 in housing for older people and 350-450 in general needs) the current number flagged is a small percentage of the estimated number of customers living with dementia.
Digital noticeboards reducing the need for written material

Dementia day clocks to improve sleep patterns

Finding: It is early days in developing assistive technology specifically for dementia however Guinness has made significant progress in trialling a range of solutions, several of which can be rolled out where resources allow. The interface of digital applications with internal data systems needs to be considered early on to identify potential security risks.
Finding: The design guide is an important tool for staff involved in development and estates as well as those responsible for flagging up repairs requirement. It is making a tangible difference to adopting a dementia friendly approach to both new development and repairs work. The total estate owned by Guinness is large and the process of making changes to existing stock through cyclical maintenance and planned refurbishment will take time.
Housing & Dementia | other findings

- Clear evidence of cultural change

Dementia is a day to day topic

New structures and roles = better support
Dementia and the Disabled Facilities Grant

Housing & Care 21 14th June 2018

National Body for Home Improvement Agencies
Improving Delivery of the Disabled Facilities Grant
2020 Dementia Challenge

- Reduce Stigma
- Raise Awareness
- Support Independence
- Raise Rate of Diagnosis
- Reduce Crisis Points

- 18 Priorities for 2018
- Builds on 2012 achievements
- Mixes Public Health, research, awareness & social action & commitments to co-production

Role for housing in:
- Joined up working
- Workforce awareness & training
- Creating dementia friendly health & care settings incl. Home
- Within wider integration & transformation of health & care
The Scale of the Challenge

- 850,000 people in the UK
- Age is a risk factor – >½ over 85 yr olds experience cognitive changes
- 70% have another medical condition or disability
- Two-thirds of those with dementia live in their own ordinary homes
  - 85% of them prefer to remain in there.
- People with Dementia experience the pressures on acute care disproportionately:
  - Spending 4.2 million days in hospital 2015-16, up from 3.5 million in 2009-10
  - many will have been admitted to hospital from their own homes but do not return there.
  - They are likely to stay 25% longer
  - They twice as likely to be readmitted
  - 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

- In our Communities
  - 2/3 of costs is borne by people with dementia & carers £17.4B
  - Ageism, stigma & lack of capacity affects service provision & access
DFG Targeting

Primary Impairment

Aids & Adaptations

- Information & Advice Deficit
- Workforce Challenges: OTs & surveyors
  - Lack of bespoke training & CPD
  - Design principles established in acute settings
- Stairlifts & Level Access Showers
- ICES business model
- Weak evidence base
  - What works to improve resilience at home
  - DFG referrals prompted by crisis
Glimmers of Hope

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
Glimmers of Hope

Dementia Dwelling Grants - Worcs

- 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
Siobhan Moore
Housing & Care 21

Housing - Rising to the Dementia Challenge
Designing Enabling Environments

Siobhan Moore
Head of Development
Housing and Care 21
Not Only but Also.............

- Sensory impairment
- Physical & ambulatory conditions
- Embrace inclusive design principles
- Simple changes
Colour, Contrast and Lighting

- **Colour and Contrast**
  - Easy identification of important areas e.g. bathrooms & toilets
  - Helps orientation e.g. ‘I live on the green corridor’
  - Helps depth perception

- **Lighting**
  - Maximise natural light
  - LEDs
Wayfinding - 1

Signs

- Remove unnecessary signs

- Ensure remainder are clear (including recognisable symbols)
Wayfinding - 2

• Artwork
  – Use to theme corridors e.g. ‘I live on the steam train, film star, ships corridor’
  – Outside lifts to help identify floor level e.g. ‘my floor has the red chest of drawers/ large pottery jar/tartan chairs, view of ‘The Green, 1964’ etc. beside the lift,’
Wayfinding - 3

External

- Clearly identified entrances and exits – contrast doors and/or frames
- Use pathways with resting areas
- Sensory planting
- Personalise own front door – memory box/milk shelf
Thank you for listening

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Conrad Quast
Edmund Williams Architects

Housing - Rising to the Dementia Challenge
RISING TO THE DEMENTIA CHALLENGE

THE ROLE OF THE ARCHITECT

Edmund Williams Architects
1. INTRODUCTION

Question:
How can the architect achieve dementia friendly design and how can we change the environment for the better?

- Design Considerations

- Designing: from large to small (a brief introduction)

- Summary
2. DESIGN CONSIDERATIONS

What is it that makes designing for dementia special?

**Perception**
- Changes in Perception/ vision -> Daylight to all spaces
- Changes of sense of time -> View to outside

**Movement / Orientation**
- Orientation and choices
- Dead end corridors -> Meaningful spaces
- Restriction vs. movement
- Connecting to the external space

**Social interaction vs. privacy**
- Small groups of flats per corridor
- Risk of isolation vs. risk of intrusion
- Communal spaces for meeting the neighbours
3. DESIGNING – FROM LARGE TO SMALL
MASTERPLANNING

• Create recognisable places

• Create sense of direction and space within an urban setting

• Easy wayfinding within a larger development

• Easy identifiable houses

*Example from Lichtenberg, Berlin*
3. DESIGNING—FROM LARGE TO SMALL PLANNING

The House

- Individuality of the house
- Grouping of flats
- Easy wayfinding within the house
- Daylight to all spaces (where possible)
- Create communal spaces / meeting spaces outside of private areas
- Sense of security and safety
- Good lighting!
3. DESIGNING– FROM LARGE TO SMALL PLANNING

The Landscape / Outdoors

• Create user friendly landscapes: easy access, easy wayfinding (circular routes) and lots of resting spaces

• Create gardens away from traffic where possible

• Good supervision creates a sense of safety and security

• Easy access to outdoor spaces (if possible at all floors)

• Planting: Avoid poisonous and thorny plants!

• Good lighting!

Example from specialist housing project
3. DESIGNING – FROM LARGE TO SMALL

DETAILED DESIGN

The House

• Avoid contrasts in floor material

• Use contrasting material between floors and walls

• Groups of flats (streets)

• Identity of corridors and individual flats

• Wayfinding: supporting signage

• Meeting spaces

• Outdoor spaces

• Good lighting!

Example from specialist dementia housing project
3. DESIGNING– FROM LARGE TO SMALL
DETAILED DESIGN

The Garden
• Level access

• No contrasts in flooring material for paths

• Resting spaces: include seating where ever possible

• Include easy signage

• Where possible include raised planters and activity areas / communal spaces

• The garden shed and access to WCs

• Good lighting!

Example from specialist dementia housing project
3. DESIGNING— FROM LARGE TO SMALL
DETAILED DESIGN

The Flat / The Dwelling

• Easy identifiable front door

• Wayfinding: easy to find rooms; avoid multiple corridors; coloured doors

• Floors and walls

• Storage: easy to find; enough storage to put ‘that old table’ away...

• Access to outdoors: balconies and patios

• Kitchen: Induction hobs, kitchen cabinet doors in clear Perspex

• Signage for individual rooms (especially Bath/WC)

• Good lighting!

Example from specialist dementia housing project
4. SUMMARY

IS IT POSSIBLE TO CREATE FLATS AND Dwellings THAT ARE DEMENTIA FRIENDLY AND FUTURE PROOF?
• YES!

DOES THIS IMPACT ON OTHER RESIDENTS?
• No. Most of the design considerations can be applied easily without having a negative impact on people not living with dementia. In fact all of the proposed solutions do benefit everybody – it is inclusive design.

HOW TO DO IT?
• Ask your architect to include dementia friendly design from the beginning of a project (be that new build or refurbishment) – or ask us to help you...

THANK YOU FOR LISTENING!
Housing - Rising to the Dementia Challenge

#dementiachallenge  #housing  Sli.do: E146