Plenary one: Creating dementia-friendly communities – the role of housing providers

Speakers:
Karishma Chandaria, Dementia Friendly Communities Programme Manager, Alzheimer’s Society

Dr Karim Saad, Regional Clinical Lead for Dementia, NHS West Midlands
Creating dementia-friendly communities

Karishma Chandaria, Alzheimer’s Society
Dementia: A national challenge

- 75% of the public do not think society is geared up to deal with dementia

- 61% of people with dementia think that their community doesn't understand

- 58% of the public think that people with dementia have a bad quality of life.
A dementia-friendly Britain

alzheimers.org.uk
Prime Minister’s Challenge on Dementia

- New diagnosis ambition
- CQUIN rewards for hospitals
- Alzheimer’s Society Dementia Friends
- Investments in research
Dementia-friendly communities: Gaining momentum

- Over 50 communities have committed to becoming dementia friendly
- 35 Dementia Action Alliances
- Schools driving intergenerational change
- Business, services and organisations taking up the challenge.
Loneliness and dementia

62% of people with dementia living alone feel lonely

38% of people with dementia feel lonely

24% of over 55s have felt lonely in the last month

alzheimers.org.uk
Building dementia-friendly communities: A priority for everyone
Dementia-friendly communities

What did we find?

Only 47% of survey respondents feel a part of their community.

When asked what they have had to stop doing, people said:

- 28% getting out of the house
- 22% exercise
- 16% transport
- 23% shopping
- 9% have had to give up everything
The opportunity for change

33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.

74% think supporting people to be a part of the community would help reduce stigma.

40% think everyone has a role to play to support people with dementia in their community.

47% think that dementia-friendly areas would be nicer places for everyone to live.

3% think that people with dementia don’t have anything to offer their communities.

Source: YouGov
Empowering people with dementia to have high aspirations, confidence and know they can contribute

Becoming dementia friendly means:

- Shaping communities around the views of people with dementia and their carers
- Ensuring early diagnosis, personalised and integrated care is the norm
- Maintaining independence by delivering community-based solutions
- Appropriate transport
- Challenging stigma and building awareness
- Befrienders helping people with dementia engage in community life
- Businesses and services that respond to customers with dementia
- Ensuring that activities include people with dementia
- Easy to navigate physical environments

alzheimers.org.uk
Housing supporting Dementia-friendly communities:

- Home truths - Housing services and support for people with dementia

- Dementia: Finding Housing Solutions

- Housing Learning and Improvement Network findings
What needs to change?

- Recognition that housing and housing services are effective mechanisms of supporting people with dementia in the community

- Housing schemes need to be integrated with health and social care services and involved in the local community

- People with dementia and their carers should have access to information on housing options, services and sources of funding adaptations
For more information please email myself karishma.chandaria@alzheimers.org.uk or dementiafriendlycommunities@alzheimers.org.uk
800,000 people with dementia (PwD) in UK

Greatest health concern for people over 55!

44% PwD receive a diagnosis

33% of people with dementia said they lost friends following a diagnosis

2/3 PwD live in the community while 1/3 live in a care home

400,000 Care Home residents

80% of people living in care homes have a form of dementia or cognitive impairment

Inappropriate prescriptions for antipsychotics halved between 2008 and 2011

1000 AP prescriptions x 12 weeks = 10 Deaths + 18 CVAs + 58-94 Falls

Hospital LOS longer! More likely to be discharged into a care home

Karim Saad  Dementia & Housing 14/11/13
Are Housing Providers Prepared?

- 300 associations surveyed, 88 respondents, 88% had a dementia strategy in place
- Most didn't consider a separate dementia strategy to be necessary because of the size of their organisation
- 48% don't have an older people's strategy in place
- 59% said they did not intend to put one in place

Housing groups have a mental block when it comes to dementia!

David Hucker; Guardian Professional Thursday 22 August 2013
Current themes in Dementia

- Awareness at its highest: *the decade of dementia?*
- Diagnosis rates: *local ambitions*
- Early v Timely diagnosis: *benefits v harm*
- Ongoing care and support: *outcome based commissioning*
- Dementia rarely travels alone: *comorbidities*
- Dementia is a Long term condition: *role of primary care*
- Dementia awareness & education
- Population screening v active case detection
- Prevention, wellbeing and resilience
- Research: *biomedical & psychosocial*
National Dementia Strategy

Early diagnosis and intervention in primary care

Dementia in the General Hospital

Dementia in Care homes

Reduction of antipsychotics

Support for carers

9 Outcomes statements
People with dementia should be able to say...

- I was diagnosed early
- Those around me and looking after me are well supported
- I can enjoy life
- I understand, so I make good decisions and provide for future decision making
- I am treated with dignity and respect
- I feel part of a community and I'm inspired to give something back
- I get the treatment and support which are best for my dementia, and my life
- I know what I can do to help myself and who else can help me
- I am confident my end of life wishes will be respected. I can expect a good death
Key challenges

Improvements in health and care

2/3 to have a diagnosis by 2015
Dementia Friendly Hospitals
Dementia Care & Support Compact

Raising awareness and supporting dementia friendly communities

Dementia Friends
50 cities, towns & villages
Dementia Schools Pioneer Programme
National Awareness Campaign

Better research

MRC
NIHR
ESRC (prevention)
Closing the diagnosis gap
West Midlands

2012 National average 44.2% (32% - 67%)

Up to 56% of people with dementia did not have a formal diagnosis.
1. Should be available to all citizens who require it at a stage when people first notice changes in cognitive function;

2. Decreasing fear and stigma about dementia are necessary precursors for increasing the numbers of people coming forward for diagnosis;

3. The rights and wishes of the person with suspected dementia should be paramount in engaging with the assessment process used to achieve a diagnosis;

4. Giving and receiving a diagnosis of dementia is a key intervention in the complex adjustment process to living with dementia. The needs of the person and their family/significant others are central to assessment, diagnosis and post-diagnostic interventions.

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Chart 1.4. Time between first noticing symptoms and receiving a diagnosis of Alzheimer's disease (2005)

<table>
<thead>
<tr>
<th>Country</th>
<th>Average number of months</th>
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<tbody>
<tr>
<td>UK</td>
<td>20</td>
</tr>
<tr>
<td>France</td>
<td>15</td>
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<tr>
<td>Poland</td>
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<td>Spain</td>
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</tr>
<tr>
<td>Italy</td>
<td>8</td>
</tr>
<tr>
<td>Germany</td>
<td>5</td>
</tr>
<tr>
<td>Total</td>
<td>80</td>
</tr>
</tbody>
</table>


Chart 4.3. Views on who is most likely to recognise early symptoms of Alzheimer's disease in potential patients (2009)

Percentage of respondents

GP | Family member

Spain | Italy | Germany | France | UK

A FUTURE STATE OF MIND

Nida Broughton, Nigel Keohane and Ryan Shouthouse
1. People worried about possible dementia can discuss their concerns, and options of seeking a diagnosis, with someone with knowledge and expertise.

2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

7. People with dementia live in housing that meets their specific needs.

8. People with dementia have opportunities, with their carers, to participate in and influence the design, planning, evaluation and delivery of services.

9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

10. People with dementia are enabled, with the involvement of their carers, and develop their involvement in and contribution to their community.
Principles of Smart Ageing

Nutrition

Cognitive Stimulation

Social Connectedness

Physical Exercise

Ryuta Kawashima
Smart Ageing International Research Center
IDAC, Tohoku University
Sendai JAPAN

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Is this the Lancet study we’ve been waiting for?

A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II

Fiona E Matthews, Antony Arthur, Linda E Barnes, John Bond, Carol Jagger, Louise Robinson, Carol Brayne, on behalf of the Medical Research Council Cognitive Function and Ageing Collaboration

Figure 1: CFAS I and CFAS II age-specific dementia prevalence.

CFAS = Cognitive Function and Ageing Study.

Figure 2: Estimated dementia prevalence in the UK in 2011, by sex and local authority.
Dementia Friendly Communities

- Robert Bosch Foundation (Confetti in the Head), 2010
- Integration
- Visible posters and banners
- Training: police, banks, shops
- Activities: cultural and sports
- Bistros and restaurants
- People with dementia speak for themselves to define their needs are and place in society
- Creativity in austere times

"I'm still the same person"

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Environment, Design & Dementia

Enhancing the Healing Environment
Whole System Demonstrator Programme

*Telehealth & Telecare*

- 15% reduction in A&E visits
- 20% reduction in emergency admissions
- 14% reduction in elective admissions
- 14% reduction in bed days and
- 8% reduction in tariff costs
- 45% reduction in mortality rates
http://www.livingwellwithdementia.com

>> Buddi

>> Dementia Dog

>> Grouple

>> Ode

>> Trading Times

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Misconceptions

Dementia inevitable part of ageing
Nothing can be done

Raising Awareness

Dementia Friends http://www.dementiafriends.org.uk/
Doctors http://www.safeprescriber.org/
Nurses & Social Workers http://www.worcester.ac.uk/discover/dementia-education-training.html
Higher Education http://vimeo.com/75533303

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Redesigning an unbalanced pathway

INTEGRATION
QUALITY
Personalisation

STIGMA WELLBEING AWARENESS EARLY DETECTION COMPASSION
POOR OUTCOMES

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Integrated Dementia Pathway

Dementia Pathway Coordinator

TIMELY ACCURATE DIAGNOSIS

Diagnosis
- GP Assessment & Referral
- Memory Assessment
- Multidisciplinary Workforce
- Expert Diagnosis & Interventions
- Information & Self Help, Assistive Technology, IAPT, Carer support, Direct Payments, Advanced Care Planning, Genetic Counselling, Dentistry, Hearing & Sight checks

Looking to the future
- Information
- Research

ONGOING INTEGRATED CARE

- Dementia Friendly Prescribing
- Dementia Friendly Hospitals / A&E
- Integrated CMHT
- Cognitive Stimulation
- Reablement / Intermediate Care
- Home Treatment / Crisis Intervention
- Psychological Services
- Younger Onset Dementia & ARBD
- Appropriate Home & Respite Care
- Quality Residential/Nursing care
- End-of-Life care
- Bereavement

Specialist Dementia Service

Patient, Carer & Public Engagement

PUBLIC DOMAIN

1- Promote Wellbeing & Resilience
2- Awareness starts in school
3- Dementia Friendly Communities

SCN, PHE, HEE, AHSNs, ADASS, LAs, HWBs, Royal Colleges, 3rd Sector

Other Long Term Conditions

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What Next?

• Values: Asset based - *What is Strong not What is Wrong!*
• Emphasis: Smart Ageing, Wellbeing & Resilience
• Workforce: Improved awareness and timely skilled interventions
• Quality Assurance: Building Capacity and Capability
• Creating Compassionate Communities – *Only communities can address loneliness!* 
• Dementia Friendly Partnerships: Service users, Carers, Industry, Museums, Schools, Universities, Clinicians, 3rd Sector, Minority Groups, Commissioners, LAs, Public Health, HWBs, etc....
• Profile: showcasing & rewarding innovation
West Midlands SCN Dementia Priorities

1. Supporting prevention and timely diagnosis for people with dementia and ensuring appropriate support before and after diagnosis
2. Improving the experience of care for people diagnosed with dementia
3. Improving the experience of end of life care for people with dementia and their carers
Next SCN Meeting

Dementia Diagnosis & Care
21 November 2013

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