

Dementia-friendly communities: what now? next?

Ideas from a Memory-Friendly Neighbourhoods break-out session



On Monday 2nd June 2014, 45 of the leading thinkers, strategists and practitioners in dementia-friendly communities came together at the Scottish Universities Insight Institute in Glasgow to exchange knowledge and ideas about their work. Invited by the Memory-Friendly Neighbourhoods team, participants came from across Scotland, the UK, Europe and North America. They were from a range of backgrounds, including academia, policy and practice. Three participants had dementia.

There were two interactive activities on the day, interspersed with short presentations from invited speakers. This brief report summarises the outcomes from the second of the interactive activities in which participants were asked five key questions about the current evidence and resource base on dementia-friendly communities, gaps in knowledge, and ways to make the process inclusive of everyone. The informal, carousel-type exercise took place over an hour, with participants working in multi-disciplinary groups of six - eight people. The questions were posted on flipcharts, with each group spending a maximum of ten minutes at each chart discussing and noting down answers. Listed here are the collective responses from the five groups...

What resources are already out there?

- Dementia Services Development Centre – website has resources and materials, also offers courses
- National Autistic Society (we discussed the links and commonalities between experiences of dementia and of autism)
- British Standards Institute
- Age Friendly Cities Guide – Manchester/ World Health Organization
- Alzheimer's café's
- Alzheimer Scotland toolkit for DFC's (and other online materials)
- People with dementia and carers are a resource in research and active engagement
- Alzheimer Australia website includes videos modelling good practice for different professions such as bus drivers
- Scottish Promoting Excellence, Knowledge and Skills Framework – 'informed about dementia' DVD
- Act on Alzheimer's (Minnesota) website resources
- Joseph Rowntree Trust 'Dementia Without Walls' programme
- Local Government Association 'Toolkit for dementia friendly communities'
- Alzheimer Society: 'Building dementia friendly communities: a priority for everyone'
- Elizabeth Burton and Lynne Mitchell's research 'neighbourhoods for life'

Memory-Friendly Neighbourhoods (MFN) is an interdisciplinary collaboration between research centres at the Universities of Stirling and Edinburgh. Funded by the Scottish Universities Insight Institute (SUII), the programme is supported by the Centre for Dementia Research at the University of Linköping, Alzheimer Scotland, Anderson Bell Christie Architects and Architecture and Design Scotland. For further information and resources, visit www.memoryfriendly.org.uk

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What resources are already out there? (continued...)

- Using social media, such as LinkedIn for dialogue, Facebook for wider information etc.
- Community asset mapping (John Knight)
- Architecture and Design Scotland – urbanism
- Leading Age (Continuing care providers in the US)
- Age Creativity (website for those working with people with dementia)
- Designing Streets (Scotland) Manual for streets (1&2) (England)
- International Federation on Ageing
- European Association for Ageing People (AGE)

What resources exist for guiding the design of dementia-friendly homes?

- Dementia Services Development Centre
- Stirling Dementia Care Village – currently being built
- Kings Fund – Enhancing the Healing Environment materials
- Dementia Action Alliance website
- Alzheimer Knowledge Exchange Ontario (online community of practice on design and dementia)
- Pozzoni Architects
- Gardening for Good
- Department of Health National Minimum Standards
- National Housing Federation (Dementia and Housing)
- Eden Alternative Green House project
- Hogewey Project outside of Amsterdam (Weesp) dementia village
- France, Switzerland and Austria are starting dementia-friendly holiday locations
- Dementia friendly B&B's e.g. in Dunblane
- Work underway by RIBA with architecture organisations
- AGE UK advice on home adaptations
- BS 9266 Access – General Needs Housing Lifetime Homes BS 8300-2009
- Joost van Hoof's work
- Forums for sharing experiences

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What are the gaps in knowledge that need more research...?

- Disseminating findings and translating findings into practice and business action (how do people take up information that is out there and put it into practice?)
- Making financial benefits clear to funders
- How to rigorously evaluate interventions
- What are the economics of DFC's? How to make a business case
- Processes of evaluation and demonstrating impact for MFN work
- Social inequalities in living with dementia
- Understanding co-morbidity, and how dementia exists alongside learning disability or sensory impairment
- Cross-cultural research
- Impact of outdoor space at end of life
- More empirical research is needed on the physical environment
- What navigation strategies are used by people with dementia?
- Toolkit to benchmark 'where am I on the age or dementia-friendly continuum?'
- People's fear about dementia and its impact on their attitude to people with dementia
- Impact of dementia on LGBT people
- Loss of acquired language
- Role of technology in everyday life (impact on social change; intuitive devices)
- The different expectations of younger people with dementia
- Learning through international comparisons
- How do people with different types of dementia interact with their community
- What are the different factors that stop people doing things for themselves? (biologically, chemical, physiological, psychological)

How do we make dementia-friendly neighbourhoods sympathetic to the needs and preferences of diverse groups?

- Begin by knowing where people are – demographic mapping
- Expand talk of community beyond physical neighbourhoods – communities of interest are important too
- Ensure the voices of people with dementia are represented in the media
- Find good sponsors who serve a diverse population (e.g. banks)
- There needs to be ways for people with dementia to connect with specific communities – e.g. links between dementia services and the LGBT community
- Education and awareness – start at school
- Promote interaction and participation between diverse groups on a daily basis
- Empower minoritised groups...(!)
- Don't assume all BME communities have similar needs

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How do we make dementia-friendly neighbourhoods sympathetic to the needs and preferences of diverse groups? (continued...)

- Localise decision-making
- The public sector should support different groups to do what they think best (community commissioning of services, housing etc.)
- Bring together different groups with a common purpose (such as regeneration of public spaces/parks) (co-locate and tessellate)
- Use different media for communication – e.g. creative and arts-based approaches
- Recognise differing contexts such as cultural differences in attitudes to healthcare and medicine
- Create virtual communities where particular groups are geographically dispersed
- Would it help to have a spokesperson for different groups or perspectives?
- Create safe/neutral spaces for people to meet if these don't exist – create diverse spaces so there are different uses and different areas as well as common areas

How can we support people with dementia in remote, rural locations?

- Who is we?
- Do not assume but ask...
- Understand the distinctiveness of location/context
- Build on existing community connectedness
(is there greater familiarity? Less privacy? Sources of resilience)
- Listen first to people with dementia themselves
- Community-wide support rather than targeting individuals
- Potential of assistive technology (e.g. GPS, telehealth) and social media
- Use local communication channels such as village blogs, newsletters and befriending services
- 'Village agents' as being piloted in Somerset (trained volunteers to be 'eyes and ears')
- Importance of peripatetic health and social care workers
- Transport! Local taxi firms are important
- Design buildings that relate to the environment and local history
- Build on local industry
- Recognise the role of informal networks
- We need to avoid binary thinking of rural/urban as if the two are polarised
- Provide catalysts (finance, education)

Please note that the text reproduced here is exactly what was written on our flip charts, by our participants, on the day of our event (2nd June 2014). The names of organisations and reports etc. have not been checked. We apologise for any inaccuracies.

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