Key messages from research: findings from the recent review by the Housing and Dementia Research Consortium

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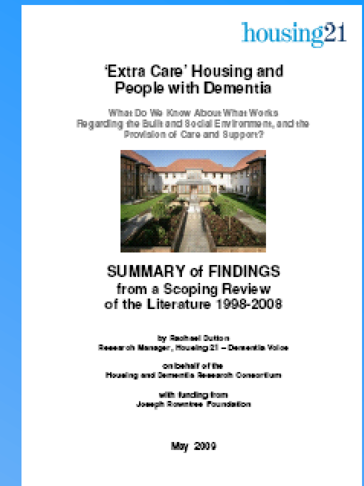
Where the Review Came From

Commissioned by the Housing and Dementia Research Consortium*, funded by the JRF.



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'Extra Care' Housing and People with Dementia

What Do We Know About What Works Regarding the Built and Social Environment, and the Provision of Care and Support?

SUMMARY of FINDINGS from a Scoping Review of the Literature 1998-2008

by Rachael Dutton
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on behalf of the
Housing and Dementia Research Consortium

with funding from
Joseph Rowntree Foundation

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* HDRC set up by four leading providers of ECH: Housing 21, Hanover, Anchor and the MHA.

Recognised commissioners and practitioners have significant need for evidence regarding how extra care processes and structures result in specific outcomes.

Platform for collaborative working – development of robust evidence - influence policy and practice in the UK.

Aims of the Scoping Review

- Identify published and grey literature from 1999 onwards relating to designing
  (a) the built and social environment, and
  (b) care and support services,
  to meet the needs of people with dementia in extra care housing
- Review and summarise the research evidence
- Identify gaps in research evidence.

Terminology

ECH aka

- Housing with Care
- Very Sheltered Housing
- Assisted Living
- Retirement Villages
- etc

Inclusion Criteria

Studies were included in the review if they focused on, or closely related to:

people with dementia or memory loss who are living in a self-contained unit (including a bedroom, bathroom, living area and kitchen) within a complex providing flexible person-centred care services with an ethos of homeliness, choice, independence, privacy, and minimising the need to move.

1,000s > 323 > 123.

Extent of Evidence

Vast majority of research from USA

Many longitudinal, several multisite studies

However many studies of apartment style ‘assisted living’ facilities also include residents from non-apartment ‘assisted living’ and residential care settings.

In the UK, there are a number of small qualitative studies including evaluations of single schemes, and just one longitudinal study.

Some key messages …

Prevalence of Dementia in UK ECH

- Research studies by Housing 21 and Hanover suggest around ¼ of ECH residents have some level of dementia.

  Other studies indicate very wide variations in prevalence - some have few cases, others have many.

- Some tenants in ECH are very frail and have serious multiple long term health conditions + dementia.

Appropriate environment for PWD? Quality of Life? Home for Life?

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Overall positive messages. Generally ECH is

- meeting needs
- providing a good QOL
- retaining independence
- enabling living in a community setting for longer.

However, PWD in extra care schemes can

- be intensive in terms of staff time
- cause of stress and anxiety for other residents
- be at risk of loneliness, social isolation and discrimination.

There are challenges and ‘tipping points’.

Appropriate environment for PWD? Quality of Life? Home for Life?

Not home for life for all, not just for those with dementia.

Ability to support people with high needs

- availability of local services
- local practices and national strategies for older people's services.

Common Factors that Cause Tenancies to End

- difficulties in providing the necessary levels and flexibility of care
- availability of resources
- the level of community nursing services available
- targets for dependency mixes
- the willingness of funders to pay for increasing levels of care
- choice and preferences of tenants / families
- ‘challenging behaviours’ …

Managing Common Behaviours

Evidence from UK studies:

Possible to effectively manage common behaviours such as

- incontinence
- anger
- distress.

Difficult to manage other types of behaviours which are detrimental for other tenants e.g. disruptive, disconcerting, worrying, annoying.

Increasing Lengths of Tenancy for PWD - Research Evidence

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Enablers

- flexibility and responsiveness in care and support
- innovative, insightful approaches
- staff ⟶ positive attitude and good understanding
- effective management of symptoms
- effective management of common behaviours
- involvement of family and friends
- appropriate and stimulating environment.

Important Aspects Linked to QOL for People with Dementia in ECH

Strong evidence:

- maximisation of dignity and independence
- individualised activities and experiences → pleasure and sense of accomplishment
- effective communication
- meaningful social interactions
- ability to maintain meaningful relationships
- person-centred care
- freedom from pain and discomfort
- the ability to age in place
- access to health care and palliative care when needed
- the appropriateness, layout and appearance of the physical environment.

Success Requires

- well-trained, well supervised and empowered staff
- person-centred care and effective communication
- specialist dementia expertise
- specialised activities
- strong partnership working
- strong management and leadership
- support from wider locality
- good building and environment design
- simple and robust AT.

Design of Environment

Housing' element can be as important as the care aspect.

Physical environment has wide range of impacts on outcomes for tenants, staff and visitors.

E.g. for tenants it can

- improve sleep, orientation and way finding
- reduce aggression and disruptive behaviour
- increase physical activity , social interaction, privacy and control, resident safety
- reduce falls, infection, 'walking around' and unsafe exiting.

Design of Environment

Pleasant, homely and easy to understand environment with opportunities for tenants to use/improve their functioning can increase independence, mobility and encourage food and fluid intake.

Important design priorities to assist way finding:

lighting,
signposting,
colour,
colour contrast,
artwork and
memorabilia.

Design of Environment

Emerging evidence from small-scale ECH UK studies,

- apartments should be equipped with baths not just showers
- schemes should appear welcoming to relatives and friends
- couples generally dislike small 'two' bedroom flats which have one combined bedroom/living area.

Key aspects of successful EC schemes

(i) specialist design for needs of tenants including those with dementia

(ii) having adequate space within flats, and within the building as a whole.

Design of Environment

Size of buildings

- Larger schemes can be disorientating and confusing.
- More likely to be able to provide a wider range of amenities and facilities.

Design of Environment

Integration Models

- Integration offers benefits for PWD.
- Can be unpopular / problematic for other tenants.
- Advantages PWD diminish over time as cognitive impairment increases.

Specialisation Models

- Specialist models appear to be liked by tenants and families.
- Some indications that specialist approaches may be better able to,
  - sustain people longer in an independent setting
  - support PWD over the full course of their illness
  - manage associated behaviours
  - equip staff with appropriate specialist knowledge and skills.
- People in early stages may be unwilling to move into a specialist unit.

Design of Environment

Lots of design guidelines, recommendations and examples of good practice. Much is anecdotal and “little is certain” (Fleming et al., 2009), lit. review of design of physical environments for PWD.

However, findings from studies to date support ‘consensus of views’ on principles for dementia specific design (Marshall, 2001):

- compensate for disability
- maximise independence, reinforce personal identity, and enhance self esteem/confidence
- demonstrate care for staff
- be understandable and easy to orientate around
- welcome relatives and the local community, and
- control and balance stimuli.

Design of Environment

Fleming et al. (2009) current evidence strongly supports the use of,

- unobtrusive safety features
- a variety of spaces, including single rooms
- the enhancement of visual access, and
- the optimisation of levels of stimulation.

Assistive Technology

- AT many benefits for PWD in extra care e.g. increasing security, independence and quality of life, and reducing risks.
- Appears an under-used resource in many schemes.
- Installation costs can deter residents from making use of AT.
- Essential that tenants and staff are given information about what is available and how to use it.
- Tenants should have facility to deactivate automatic systems if they desire.
- Thorough research and careful planning as an integral part of service and care development is required from early stages.
- Technology used should be simple and robust.

Example of Guideline / Checklist (not ECH specific)

Dementia Design Guidelines - Home and Community Care
(Hodges, et al., University of Sydney, Nov 2007)
http://www.homemods.info/files/Dementia_Design_Guidelines_2ndEd%20Nov_2007.pdf

Guidelines * based on research evidence *
Contains a checklist

1. SUPPORT INDEPENDENCE, AUTONOMY AND CONTROL
2. SUPPORT FUNCTIONALITY THROUGH MEANINGFUL ACTIVITY
3. PROVIDE AN ATMOSPHERE THAT IS SOOTHING, PLEASANT AND NON-THREATENING
4. HIGHLIGHT HELPFUL STIMULI AND PROVIDE ORIENTATION CUES
5. REDUCE EXTRANEOUS STIMULI
6. PROVIDE FOR WANDERING
7. BE HIGHLY NEGOTIABLE
8. BE SAFE AND SECURE
9. MEET THE NEEDS OF STAFF.

Key Gaps Research Evidence

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Large scale, multi-site studies are needed.

Important gaps include:

- segregated versus integrated living
- provision of end-of-life care
- which types and designs of ECH work most effectively for which types of individuals with dementia
- well-designed studies focusing on what works to improve care and QOL
- studies that address fundamental issues as eating, drinking, sleeping issue, pain management, incontinence management, socialisation, and staff communication with tenants with dementia
- comparisons of effectiveness of different ways of achieving outcomes i.e. the organisation of care, alternative ways of managing medications, delivering health care, recruiting and training staff.

Very few studies address how best to implement research findings into practice.

The Literature Review

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Extra Care' Housing and People with Dementia:
A scoping Review of the Literature 1998 - 2008

- Commissioned by the HDRC
- Funded by the Joseph Rowntree Foundation.

Main report and summary available from

- http://www.housing21.co.uk/corporate-information/housing-21-dementia-voice/research/
- http://www.dhcarenetworks.org.uk/IndependentLivingChoices/Housing/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&child=5844