‘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

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1 Aims, scope and methods of the review

A scoping review of the literature relating to people with dementia living in extra care housing, also known as ‘housing with care’ and ‘very sheltered housing’, was commissioned by the Housing and Dementia Research Consortium (HDRC, see Appendix One for further information) in November 2008 with funding from the Joseph Rowntree Foundation.

The purpose of the review was to take stock of what research evidence exists in order (i) to inform policy and practice through summarising what has been shown to be effective or ineffective, and (ii) to highlight areas where there are notable gaps in the knowledge base and further research is needed.

Key aims were to identify recent published and grey literature relating to people with dementia living in extra care housing with a focus on evidence relating to the following elements:

- Design and use of the built environment
- Facilities, furnishings and equipment
- Care, support and therapeutic services
- Organisation and management
- Outcomes in relation to health, wellbeing, policy and cost.

Published and unpublished literature from 1999 to March 2009 was identified through searches of a wide range of databases, journals and relevant websites, and through consultation with academics, researchers and practitioners in the field. 123 references were finally included in the review.

Inclusion criteria

Studies were included in the review if they focused on, or 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.

This included ‘Assisted Living’ (AL) studies from the United States1 as long as at least some of the residents included in the study met the above criteria. Most of the newer, purpose-built assisted living facilities consist solely of self-contained apartments2. Many participants of American AL research studies include tenants from both apartments and more communal style living.

It should be noted that findings from American studies will be generalisable to the UK to varying degrees due to differences for example in legal, welfare, eligibility, and cultural aspects (which also in fact vary from state to state within the USA).

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1 AL of all types has the same ethos and guiding principles as extra care
Also included were findings from some key research studies that were not carried out specifically in an extra care environment but which nevertheless have direct relevance to it, such as the design and furnishing of the built environment.

2 Overview of Findings

2.1 Overall Messages

Findings from studies relating to people with dementia in extra care accommodation consistently highlight the importance of person-centred care, developing staffs’ knowledge and expertise in dementia, partnership working and joint working.

2.2 The Availability of Research Evidence

In the UK there have been very few studies to date of extra care housing (ECH) which focus on tenants who have dementia. A number of case studies and evaluations of single schemes were identified, and just one longitudinal study. These studies are largely descriptive and, due to their nature, lack scientific rigour and generalisability. They also tend not to collect information regarding specific characteristics, experiences and outcomes for people with dementia themselves. Nevertheless they provide valuable information which together has formed a small body of evidence from which certain inferences can be drawn and hypotheses formed.

A number of research studies currently in progress in the UK have been identified and are detailed in Appendix Two.

The vast majority of research evidence relating to people with dementia in extra care settings originates from the United States of America (commonly known there as apartment-style assisted living). The number of research studies in the US has increased rapidly over the last decade and many longitudinal studies have been conducted as well as several major multi-site, multi-state studies. However, despite there being a large number of studies which include people with dementia living in ‘apartment style’ assisted living facilities, many of these also include residents from non-apartment ‘assisted living’ and residential care settings and do not present results broken down by accommodation type.

2.3 Is Extra Care an Appropriate Living Solution for People with Dementia?

There is mounting evidence that people with dementia living in ECH generally have a good quality of life although studies consistently show that some tenants with dementia can be at risk of loneliness, social isolation and discrimination.

It is apparent that extra care can be an effective alternative to residential care, and can delay or prevent moves to nursing care. Whatismore, many people with
dementia have been supported in extra care through to the end of their lives. However, enabling all tenants, with or without dementia, to remain in place through to the end of their lives in extra care housing is not usually possible.

Common factors found by many studies that influence whether people with dementia are required to move from extra care to alternative accommodation and care solutions are:

- ‘challenging behaviours’ and their impact on staff and other tenants;
- difficulties in providing the necessary levels and flexibility of care in response to increasing care needs;
- availability of resources, including increasing demand for carers time;
- the level of community nursing services available to tenants;
- targets for dependency mixes, and maximum numbers of high-dependency tenants, that can be cared for in schemes;
- the availability of places in other facilities;
- the willingness of funders to pay for increasing levels of care for individuals;
- choices and preferences of tenants and their families.

Extra care is able to offer some people with dementia an alternative, more independent lifestyle than is possible in a care home. Independence is a key concept of ECH and certainly appears to be an achievable goal for those with early to moderate stages of dementia. As dementia and/or other conditions worsen, the need for care and support increases and with that the ability to live independently inevitably diminishes. At this stage, aspects such as choice, self-determination and quality of life will prevail.

It is clear from current evidence that having people with dementia living in extra care schemes it can be:

- intensive in terms of staff time
- possible to effectively manage common behaviours such as incontinence, anger and distress
- difficult to manage other types of behaviours which are detrimental for other tenants (e.g. disruptive, disconcerting, worrying, annoying)

and requires:

- flexibility and responsiveness in care and support
- innovative and insightful approaches
- staff to have a positive attitude, and good understanding, about dementia and about each individual with dementia
- a stimulating environment including social activities
- effective management of symptoms such as incontinence
- effective management of common behaviours, such as anger, that distress or harm caregivers and neighbours.

There is strong evidence and general agreement that it is not appropriate for people to enter extra care when they already have advanced dementia.
2.4 Increasing Positive Outcomes for People with Dementia Living in Extra Care

There is strong evidence that important aspects that contribute to quality of life for people with dementia living in extra care settings are:

- maximisation of dignity and independence
- individualised activities and experiences that bring pleasure and a sense of accomplishment (there is some evidence that this may even delay functional decline)
- effective communication
- meaningful social interactions
- ability to maintain meaningful relationships
- person-centred care
- freedom from pain and discomfort
- the ability to age in place
- the appropriateness, layout and appearance of the physical environment
- access to health care and palliative care when needed.

Key organisational and operational aspects that are shown to effectively enhance to quality of life for people with dementia living in extra care settings are:

- specialist dementia expertise
- specialised activities
- strong partnership and joint working, and integrated strategies between social care, health and housing
- well-trained, well-supervised and empowered staff
- procedures to address behavioural symptoms
- individualised assessment and case work
- strong management and leadership
- the availability of support from the wider locality (e.g. social services, community nursing and other health services)
- simple and robust assistive technology which is integral to service and care planning.

2.5 Key Gaps in the Evidence Base

The importance of creating a much larger, robust research evidence base applicable to people with dementia in extra care housing in order to be able to determine its current benefits, limitations and future potential is all too apparent. Studies are urgently needed to provide specific information regarding how different processes and structures result in specific outcomes in various subpopulations of people with dementia.

In order to vastly improve the robustness of UK research evidence, a lot more research activity is needed including large scale, multi-site studies. It is also essential that relevant knowledge from other settings, spheres and disciplines is transferred, to avoid unnecessary duplication, investment and delay. Areas where there are important gaps in evidence include,
• integrated versus specialist-dementia models
• provision of end-of-life care
• knowledge about outcomes for different types of individuals with dementia in relation to the key variables of extra care settings, such as the design of the building and the environment, the organisation of care, medication management, delivering health care, recruiting and training staff, and the management of transitions to and from schemes
• studies that address fundamental issues, such as eating, drinking, sleeping, pain management, incontinence management, socialisation, and staff communication with tenants with dementia
• comparisons of extra care housing with available alternatives.

In addition, there is a pressing need for studies that address how best to implement research findings in practice.

2.6 Perceived Priorities for Research

Surveys and professional stakeholder events have determined the following as priorities for the generation of research evidence:

- tenants' characteristics, needs, preferences, experiences and decision-making processes
- service capacity in extra care
- costs and benefits of housing and service models
- staffing strategies
- specialised services for residents with dementia
- cost and financing
- resident outcomes
- family involvement in resident care
- transitions to and from extra care
- assistive technology
- design of the built environment
- effective change management
- implementation of research findings.

2.7 Key Recommendations for Research

A substantial amount of research activity is needed in order to produce the quality, depth and breadth of evidence needed which will help guide commissioners to be able purchase effective buildings, environments and services, and help managers and practitioners provide effective environments, care and support.

Large programmes of co-ordinated research studies carried out in the USA (such as the Alzheimer’s Association Campaign for Quality Residential Care (CQRC), the Collaborative Studies of Long-Term Care (CSLTC), and the Maryland Assisted Living Study (MD-AL)) are useful models.

To enable the creation of an empirically based extra care and dementia literature, and to allow for effective comparisons to be made across studies (whether large or small scale) there needs to be:

a) more standardisation in the way variables are measured, and
b) more rigour and consensus in the reporting of,

- participant characteristics such as age, type and severity of dementia, whether dementia was pre- or post-move in, and the nature and incidence of co-morbidities
- extra care housing characteristics, including scheme design and facilities and the range and flexibility of care provision
- sampling, time frames, and measures used.

It is paramount that the input and active involvement of people with dementia at all stages of the research process is addressed.
3 Key Findings by Topic Area

3.1 What is Extra Care?

**Messages from Current Evidence**

- The terminology used for extra care type settings in the UK and internationally varies enormously, as do the definitions for each term. Common terms are ‘housing with care’, and ‘assisted living’ (AL) which is widely used in the USA.

- There is a huge variety of types of extra care housing, with differences occurring in the design and layout of buildings, the internal and external environment, the services and facilities provided, etc.

- Professionals rate the three most important features of extra care as: ‘flexible care’, ‘self-contained dwellings’ and a ‘homely feel to the building’.

- The assisted living concept in the USA incorporates the same principles as extra care including: the promotion of independence, choice, privacy and dignity; minimisation of need to move to another setting; the provision of tailored, flexible and person-centred support services. Like extra care housing, many assisted living facilities (particularly the newer-builds) consist of apartment-style, self-contained accommodation with communal shared living areas.

**Identified Evidence Gaps**

- There needs to be greater standardisation of terminology and definitions relating to extra care, and in the description of the differing elements of extra care housing schemes including the building(s), services, facilities, policies and organisational practices.

3.2 Prevalence of Dementia in Extra Care Settings

**Messages from Current Evidence**

- Older people moving into extra care have much less physical and mental impairment than those moving into care or nursing homes.

- Some tenants living in extra care settings are very frail and have serious multiple long term health conditions as well as dementia.

- Research studies by Housing 21 and Hanover suggest that around a quarter of extra care housing residents have some level of dementia. Other studies indicate there are very wide variations in prevalence of dementia with some schemes having few cases and others having many.
Identified Evidence Gaps

- Researchers need to carry out better designed and executed studies with replicable methodologies so that unbiased and generalised findings are produced.
- Housing and care research studies with older people tend not to present findings broken down by those with dementia and those without.

3.3 Suitability of Extra Care for People with Dementia - Overview of UK Studies

Messages from Current Evidence

- Extra care is meeting the needs and providing a good quality of life for many people with dementia, enabling them to live in a community setting and retain their independence as long as possible.
- The ability to promote and retain a person’s ‘independence’, a core concept of extra care, decreases as dementia and other health and care needs increase.
- The ability of extra care to support people with high needs depends on the availability of local services (such as community nursing) which in turn depends on local practices and national strategies for older people’s services.
- People with dementia living in extra care schemes and retirement villages can be a cause of stress and anxiety for other residents.

Identified Evidence Gaps

- There are very few research studies in the UK focusing on extra care housing for people with dementia.
- It is very common for housing studies generally to exclude people with dementia as participants.
- Robust studies are particularly needed to fully evaluate outcomes for people with dementia including quality of life and health.
- In order to improve the usefulness, robustness and generalisability of research findings, well-designed studies are needed involving
  (a) larger sample sizes
  (b) multiple sites
  (c) longitudinal studies.
- There are no comparative studies in the UK of extra care housing with available alternatives (the current Evaluation of the Extra Care Housing Funding Initiative will be comparing outcomes and costs with those for people who have moved into residential homes).
3.4 Suitability of Extra Care for People with Dementia - Overview of USA Studies that Encompass Apartment Style ALFs

Messages from Current Evidence

- Priority targets for change should be characteristics relating to staff and the environment, rather than characteristics of residents with dementia themselves.
- A key aspect impacting on overall quality of life is person-centred care.
- Improved training and deployment of staff can increase quality of life for residents.
- There is no one component that would encapsulate a definition of "good" AL care.
- There is a need for improvement in assessment and care in both assisted living and nursing home settings.
- Policy and practice should not focus narrowly on any one area of care, or restrict the type of care; diversity should be encouraged to accommodate individual preferences.

Identified Evidence Gaps

- Research in quality-of-life assessment and care in assisted living and nursing homes is still in its infancy.
- Large and longitudinal studies are needed, "using admissions cohorts and monitoring quality of life and determining the components of care that relate to quality of life from the moment their influence begins" (Zimmerman, 2005).
- More randomised controlled trials\(^3\) are needed where they are feasible and appropriate,

  "Randomization of residents is not feasible if staff are part of the treatment because any training or intervention staff use will likely affect how they care for all residents. In addition, an intervention for one … resident may affect another, who might be serving as a control. Therefore, randomization may need to be conducted at the facility level rather than at the individual level. … it may be difficult to find accessible and comparable controls" (Tilly and Reed, 2008).

In the USA, randomised trials have been carried out to investigate the effectiveness of mental health interventions, falls prevention programs, and training programs for staff within assisted living.

\(^3\) This methodology generates the most robust evidence.
More qualitative research studies are also needed. These are extremely valuable in generating information helping to answer 'how' and 'why' research questions. Research is required to generate evidence on processes as well as outcomes.

Sample size limitations restrict the ability to conduct complex model testing, and the cross-sectional nature of much of the data impedes causal inferences.

To enable effective comparisons to be made across studies, there needs to be more rigour and consensus in reporting of,

- respondent characteristics such as age, type and severity of dementia, whether dementia was pre- or post-move in, and co-morbidities
- extra care housing characteristics including scheme design and facilities, and the range and flexibility of care provision
- sampling, time frames, and measures used,

as well as more standardisation in the way variables are measured.

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

Study designs should be inclusive of people with dementia themselves. Current challenges include designing research that respects residents’ own definitions of quality and honours their dignity and, “to find meaningful and appropriate ways to ask questions of people with dementia; and to measure, with reasonable reliability and validity, their responses to care and treatments” (Hyde et al., 2007).

Studies pulling together learning and relevant findings from other settings that would inform,
- policy and practice
- new research studies and their interpretation.

The focus of research, policy, and providers needs to shift from silos and competing interests to common issues that cut across settings. E.g. recruitment and retention of care workers is a problem for all long-term care settings including extra care, nursing homes and home care.
4 Key Findings by Theme

4.1 Activities

Messages from Current Evidence

- Activities have the potential to improve quality of life, delay functional decline, and increase length of tenancy for people with dementia in extra care settings.
- Having opportunities for social interaction, a choice of a range of activities, and a choice to be involved or not, are all important.
- Many people with dementia appreciate, and can greatly benefit from, taking part in everyday household routine tasks, such as preparing for meals and cleaning activities.
- The use of formal activities programs using individualised assessment and casework approaches looks promising.

Identified Evidence Gaps

- More studies are needed of activities programming specific to extra care for people with dementia including the processes and effectiveness of activities programming that are both dementia-specific and for more general populations that includes people who have dementia.
- Further longitudinal research is needed to understand how engagement in activities may affect functional decline.
- A long term, multi-site, controlled evaluation of the Enriched Opportunities Programme is needed to determine its effectiveness in supporting people with dementia, increasing good quality of life, and reducing the likelihood of moving on to a nursing or care home.
4.2 Assistive Technology

Messages from Current Evidence

- Assistive technology has many benefits for people with dementia in extra care e.g. in terms of increasing security, independence and quality of life, and reducing risks.
- AT appears to be an under-used resource in many schemes.
- Installation costs can deter residents from making use of AT in their flats.
- It is essential that residents and staff are given information about what is available and how to use it.
- Residents should have the facility to deactivate automatic systems such as movement activated lighting and bed occupancy sensors 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.

Identified Evidence Gaps

- Research studies are needed that focus on the outcomes of assistive technology for people with dementia in different models of extra care (the main focus of studies to date had been safety requirements and residential care). “There is an urgent need to investigate the value of technology for quality of life and independent living of people with dementia” (Topo, 2007).
- How AT can be better utilised in extra care schemes.
- The role of telecare and other assistive technologies, their usefulness and acceptability to residents, and impact on staffing requirements.
4.3 Comparisons with Other Types of Settings and Care

Messages from Current Evidence

► Extra care expands the range of choices available for older people and for providers.

► Extra care can provide a feasible alternative to residential care for people with even moderate to severe dementia.

► Factors that can negatively influence the ability of extra care schemes to provide an alternative to residential care include the need to maintain dependency mix balances, and a lack of resources and care staff capacity.

► Studies from the USA have found that,
  - compared to nursing homes, ALFs have fewer residents with cognitive impairment, and those with dementia have fewer comorbidities, but there is a higher incidence of behavioural issues
  - different facilities appear to be catering for different types of resident needs
  - boundaries between nursing and residential homes and assisted living are over time beginning to blur.

Identified Evidence Gaps

► Studies are needed to investigate the suitability, costs and benefits of extra care compared with different settings, looking at how different services and service combinations met the needs of people with dementia at various stages of the condition (considered high priority for research in a recent HLIN survey).

4.4 Cost Effectiveness

Messages from Current Evidence

► Evidence about the cost-effectiveness of extra care generally is sparse and contradictory.

► Findings from single case or evaluation studies include:
  - an extra care scheme for couples where one partner has dementia was less expensive for most couples than home, residential or nursing care;
  - one scheme was offering “significant advantages” for tenants compared to the alternatives with (a) little or no extra cost to Adult Social Care for those who would otherwise have been in residential care, but (b) greater cost for those who would have otherwise remained in their former homes.
**Identified Evidence Gaps**

Studies are required to investigate,

- The cost effectiveness of housing with care compared to other alternatives looking at who (agencies and individuals) bears the range of costs involved.

- The cost-effectiveness of different models and approaches to supporting a good quality of life for people with dementia in extra care.

There is a need for a template for assessing the cost-effectiveness of specific services which,

- enables transparent comparison and benchmarking
- factors in qualitative outcomes for individuals, such as quality of life, benefits to carers, and enabling couples to stay together.

**4.5 Design of the Built Environment**

**Messages from Current Evidence**

- Key aspects of successful extra care schemes are (i) specialist design for dementia, and (ii) having adequate space within flats and within the building as a whole.

- Important design priorities that assist vision and wayfinding in dementia care environments are lighting, signposting, the use of colour, the use of colour contrast, and the use of artwork and memorabilia.

- The physical environment has a wide range of impacts on outcomes for tenants, staff and visitors.

- Pleasant, homely and easy to understand environments which offer opportunities for residents to improve their functioning can increase independence, mobility and encourage food and fluid intake.

- There are pros and cons regarding the size of buildings. Larger schemes can be disorientating and confusing for tenants but are more likely to be able to provide a wider range of amenities and facilities.

- The ‘housing’ element of extra care is as important as the care aspect.

- There is emerging evidence from small-scale UK studies that,

  - adequate spaces for gatherings of both large and small tenant groups should be provided
  - apartments should be equipped with baths as well as showers
  - schemes should appear welcoming to relatives and friends
  - couples generally dislike small ‘two’ bedroom flats which have one combined bedroom/living area.
Identified Evidence Gaps

“Evidence-based design is moving forward, and we must do everything possible to base our design decisions on hard data or plausible theories, and to test theories by measuring the outcomes associated with our design interventions.” (Brawley, 2006).

- There needs to be rigorous testing of current design guidelines, the majority of which do not have a robust evidence base.

- What impact do specific aspects of design and the living environment, such as the effects of colour, size, ‘homeliness’ and cultural sensitivity, have on outcomes for people with dementia? There is a relatively large body of work on physical assisted living settings, but most of this literature does not identity the precise aspects of the setting, nor relate them to outcomes for specific residents.

- Current design guidelines relating to visuoperception need refinement as most are very general.

  “Current ones make no distinction between specific visual requirements for different types and stages of dementia or perceptual ranges. For example, the existing design principle of ‘use of objects for orientation in preference to colour’ could be conceptually extended to describe the best uses of specific classes of objects and the best uses of colour/s.” (Jones and Van der Eerden, 2008).

- Post-occupancy evaluations,

  “Conspicuously absent from the literature are references to ‘post-occupancy evaluations’ of completed and occupied care homes … about how and why certain aspects may not be ‘working as expected’ “ (Jones and Van der Eerden, 2008).

- Studies investigating how to optimise links and relationships of tenants with dementia with the wider community.

- Evaluations of models of extra care housing are needed that specifically address needs in rural areas, through services that include outreach and use of community transport.

- Multi-disciplinary research yielding useful implications for practice. For example,

  “The application of healthy lighting requires multidisciplinary knowledge, including photobiology, perception, color preference, vision, lighting technology, optics, design, arts, human health, and more. Once the underlying scientific principles of healthy lighting application are understood, the physical application is relatively simple. Lighting hardware and software are already commonly available, low-cost, and user-friendly” (Smith et al., 2004).
4.6 End of Life in Extra Care

Messages from Current Evidence

► A UK longitudinal multi-scheme study found that 62% of the people with dementia who died over the study period died in hospital after having been admitted a few days previously due to sudden illness.

► Studies in the USA have found,
- the quality of care and palliative care for people with dementia who are dying in RC-AL settings is comparable to nursing homes
- hospice care is widely used, although could be initiated earlier and more gradually
- there are still high rates of physical restraint and sedative use in all long-term care settings but people in RC-AL facilities are restrained less often
- RC-AL residents with dementia tend to have more skin ulcers and poorer hygiene care than the residents without dementia.

► Communication and advance planning for care are central to delivering quality end of life care.

► Also crucial are person-centred approaches, the involvement of the family in decision-making as early as possible, and knowledge about how to assess needs and manage symptoms.

Identified Evidence Gaps

► In the USA, across all settings, end of life research generally has been primarily descriptive and used small samples.

► There have been no studies in the UK of end-of-life care for people with dementia in extra care.

► Research is needed to assess the effect of access to health care and palliative care on unnecessary moves.

► Case-specific research is needed to investigate the appropriateness of higher reported rates of sedative use among persons with dementia.
## 4.7 Home for Life / Length of Tenancy

### Messages from Current Evidence

- Many people with dementia are supported in extra care through to the end of their lives.

- The jury is still out on extra care providing a ‘home for life’ in all circumstances, indeed, “it might be more appropriate to adopt the term ‘prolonged residence’” (IPC, 2007).

- Common reasons for people with dementia having to move out of extra care (and assisted living facilities) include,
  - behaviours that challenge and the impact these have on staff and other tenants
  - difficulties in providing the necessary levels and flexibility of care for increasing care needs
  - needing to meet targets for dependency mixes and the maximum numbers of high-dependency tenants that can be cared for in schemes
  - the availability of placements in other facilities
  - the unwillingness of funders to pay for increasing levels of care for individuals
  - the choices and preferences of tenants and their families.

- Factors contributing to schemes being successful in providing a home for life include,
  - the ability for care and support to be flexible, responsive and adapted around the individual
  - services provided from outside the extra care schemes
  - a move in before dementia is too advanced
  - availability of specialist facilities
  - accessible design features.

- An American multi-site longitudinal study including apartment style ALFs found that,
  - managing tenant decline is vital for successful ageing in place
  - the management of decline needs to be coordinated between the facility, tenant and families
  - a key component was family support (this came mostly from daughters, often on a daily basis, including washing and dressing, paying bills, managed medications, and providing encouragement).

- It must be clear from the outset what an extra care scheme is intending to achieve and for whom. For example, whether it aims to be an alternative to a care home and a home for life and, if so, how increasing care needs are to be addressed.

- Regulatory requirements for admission and retention (which vary significantly by state) have a large influence on whether assisted living facilities can provide a home for life for residents.
**Identified Evidence Gaps**

- More research is needed to determine the capacity of extra care to accommodate people with differing levels and types of dementia.

  Studies should include investigations of issues relating to,
  - the skills and training of staff
  - communal dimensions of extra care and their relation to the well being of all residents
  - dependency mixes
  - the ability of schemes to maintain a balance of fit and frail residents
  - the design of buildings and the environment
  - the appropriate use of technologies.

- Further investigation is needed of the reasons why people with dementia move out of extra care and where they move to, and how these compare to similar data regarding residents without dementia.

- The impacts of ageing in place on residents, family, and staff.

- The role of family, significant others, and friends.

- Reasons for move-in and move-out decisions, and “under what circumstances should people be expected to move on to different forms of care provision, and who decides?” (Croucher et al., 2006).

- Mechanisms for supporting autonomy.

- The provision of appropriate health care including medication management.

- Factors associated with acuity levels, length of stay, health, and quality-of-life outcomes.

- The hypothesis that the detection and treatment of dementia might delay discharge from assisted living / extra care should be tested in randomised trials.
4.8 Integration v. Dementia-Specialist Models

An *integration* extra care model accommodates people with dementia in flats alongside all other tenants. This is in contrast to *dementia-specialist* models of which there are two main types,

(i) a dementia cluster (sometimes referred to as a specialist dementia care unit) accommodates tenants with dementia in flats within a separate self-contained area of the extra care scheme, such as a wing or floor of the building
(ii) a dementia-specialist scheme where only people with dementia live.

**Messages from Current Evidence**

- Integration schemes offer benefits for people with dementia, through additional opportunities for stimulation, social integration and support from other residents, but can at the same time be unpopular and problematic for other residents.
- The advantages integration offers those with dementia diminishes over time as their cognitive impairment increases.
- Specialist models appear to be liked by residents and their families.
- People in early stages of dementia may be unwilling to move into a specialist unit.
- There are some indications that specialist approaches may,
  - be able to sustain people longer in an independent setting
  - be better able to support people with dementia over the full course of their illness
  - be able to better manage behaviours associated with dementia
  - be able to better equip staff with appropriate specialist knowledge and skills.
- A US study found that operators of dementia-specialist assisted living and residential care settings preferred to be licensed as a residential care facility because the assisted living facilities required single occupancy, private bathrooms and kitchenettes which were considered, “neither cost-effective nor desirable for residents with dementia.”
- Messages from other settings: most research on Special Care Units in nursing homes has found that living in a specialised facility in itself does not appear to lead to better outcomes.

**Identified Evidence Gaps**

- A high priority for attention is the generation of evidence regarding the effectiveness of integration and of the different types of dementia-specialist models in terms of,
  - mixing ‘fit’ with ‘frail’ and/or dementia and non-dementia tenants
  - quality of life and other key outcomes for all tenants
  - length of tenancy
• financial cost to individuals and organisations
• housing, care and support services provided
• management of behaviours associated with dementia
• staff training, specialist knowledge and skills
• staff recruitment and retention.

▶ Large scale, multi-site studies are needed with balanced samples of housing types in order to be able to draw conclusions about the respective advantages or disadvantages of the different models of accommodation.

▶ There is a need for a template to aid the comparison of the different models.

4.9 Impact of Care, Services and Facilities

Messages from Current Evidence

▶ Core concepts underpinning extra care (such as the promotion of independence, choice, and flexibility) are being achieved and are well-regarded by tenants, families and other stakeholders.

▶ Person-centered care is key to improving aggregate quality of life for tenants, and gives job satisfaction for staff.

▶ On average, having dementia increases the amount of care tenants require.

▶ Having well-trained staff is vital for the provision of good care for people with dementia.

▶ Distress and behavioural symptoms are minimised, and quality of life is higher, where staff know their residents, are well-trained, and have positive attitudes and communication styles with tenants.

▶ American and UK studies have shown that pain is under-recognised, under-assessed professionally, and under-treated.

▶ Dementia is under-diagnosed and care staff tend not to be aware of the benefits of obtaining diagnosis and treatment.

▶ Involvement of the family in contributing to the provision of care and decision-making is very important, although some families can be risk-averse.

▶ Individually tailored programs can be successful in reducing both the number of falls and injury following a fall. The focus of falls interventions and strategies needs to be on environmental change and staff compliance, particularly where tenants with moderate to severe dementia are concerned.

▶ There is a need to provide culturally aware services for people with dementia from minority ethnic groups.

4 The Evolve research project led by Judith Torrington (School of Architecture, University of Sheffield) is currently developing an assessment tool for the evaluation of the design of older people’s extra care housing, due to be completed September 2010 (PSSRU, 2007).
Appropriate design features and services for people with dementia and with additional needs such as hearing and visual impairments are required.

Facilities incorporated into schemes, such as restaurants, cafes, shops and hairdressers, can provide good opportunities for social engagement. Restaurants are well liked by residents and families, although some feel they can lead to tenants losing key independence skills more quickly.

**Identified Evidence Gaps**

- Despite there being a large amount of literature on interventions to help improve the quality of care and environments for people with dementia there are limitations regarding the scope and quality of the available research,
  - most has been carried out in nursing facilities (although findings are likely to be applicable in other types of settings) and much of this needs to be replicated, and new types of research initiated, in extra care settings
  - the majority of research articles do not specify the type or severity of dementia of participants.

- There is a need for well-designed evaluations in extra care housing / assisted living facilities in order to determine what works regarding interventions for people with dementia to improve their care and quality of life.

- Studies are needed that address fundamental issues such as eating, drinking, sleeping issues, pain management, incontinence management, socialisation, and staff communication with residents with dementia (in contrast there is a fairly large body of research literature relating to behavioural health interventions, especially ones to treat aggression and agitation behaviours).

- Models of staffing and staff supervision and mentoring should be tested to determine how best to configure staffing for effective care for those with varying severity of dementia.

- “Effectiveness of different care interventions with individuals who have dementia” was considered high priority for research in a recent HLIN survey (Garwood, 2007).

- The role of extra care in addressing the future housing and care needs of older people from black and minority ethnic communities.

- The impact that increasing numbers of care staff from different ethnic minority groups and/or whose first language is not English has on residents, staff, and managing organisations. (e.g. particular communication difficulties, differences in attitudes towards ageing, older people, death and dying).
4.10 Prevalence and Management of Psychosocial and Behavioural Symptoms

Messages from Current Evidence

- Many ECH schemes are managing psychosocial and behavioural symptoms of dementia. Certain types of behaviours can be very challenging to manage, and can be more disruptive to other residents, and more resource-intensive for the scheme.

- Available evidence relating to the use of psychosocial approaches for managing dementia-associated neuropsychiatric symptoms indicates the following are effective:
  - behaviour management therapies
  - specific types of caregiver and residential care staff education
  - cognitive stimulation.

- Person-centered care, incorporating careful assessments, care planning, and individualised interventions, are likely to be successful in managing unsafe walking about.

Identified Evidence Gaps

- Effective strategies and techniques to manage psychosocial and behavioural symptoms of people with dementia in extra care settings.

- There is insufficient research evidence to explain fully why and when walking about occurs. Future research should incorporate a clearer definition of walking about (previously commonly referred to as ‘wandering’), specific target population(s), focused interventions and better control conditions.

- There are few intervention studies addressing ‘walking about’ which have robust methodology. “Much more research is urgently needed to determine the causes of wandering and interventions to prevent unsafe wandering.” (Tilly and Reed, 2008).

- Effective alert mechanisms for alarm systems in extra care schemes as an alternative to the traditional ‘pull cord’ system which can be problematic for tenants who have dementia.
### 4.11 Service Delivery / Management / Organisation

#### Messages from Current Evidence

- **Success factors are:**
  - Availability of flexible person-centred care and support
  - Appropriate levels of staff time
  - Continuity in care
  - Well trained staff
  - Positive attitude from care staff
  - Strong coordination and partnership working using a structured approach
  - Joint support and joint care plans
  - Having an appropriate balance of dependency needs
  - Effective strategies and management of behavioural symptoms
  - Environments that are enabling for people with dementia
  - Flexibility of services (rather than the model of service provision).

- Evaluations consistently show that care staff and scheme managers are in need of more dementia-specialist training and knowledge sharing/transfer opportunities.

- Scheme managers and administrators are pivotal figures in decisions relating to transition timing and care. Factors influencing retention or transfer of residents include the scheme culture, family member involvement in decision making, and/or care.

#### Identified Evidence Gaps

- Comparisons of differing approaches to care in extra care / assisted living settings.

- What determines moving into and out of extra care:
  - What guidelines are used
  - Where do residents move from and where do they go?

- How different organisational structure, management and staffing models in extra care affect outcomes for service users with and without dementia (considered a high priority for research in a recent HLIN survey).

- The impact of increasing staff awareness of signs of dementia and understanding of nonverbal cues.

- Which organisational and management characteristics and approaches foster effective staff–resident interactions and the implementation of successful practices.

- Models of staffing and staff training, supervision and mentoring should be tested to determine how to best configure staffing for effective care for those with varying severity of dementia.
Factors affecting staff recruitment and retention.

How characteristics of setting and service affect resident outcomes (adjusting for resident characteristics), such as

a. Death in a scheme
b. Move out to nursing homes or other forms of care
c. Physical health and functioning
d. Social functioning
e. Psychological well-being
f. Satisfaction with care, housing, with the extra care community
g. How different aspects of the setting or the care differentially affect different outcomes.

Investigation of the best ways to make care as flexible as possible in order to minimise the need to move on, and whether there are legitimate limits to this flexibility.

Impacts of regulation on services provided and experience of tenants.

Tools and techniques suitable for assessing quality of life outcomes for people with dementia to,

- provide guidance on collection of statistical information
- provide methodology to review outcomes for various stakeholders along a range of parameters, e.g. health and social care and costs
- assess soft/qualitative outcomes for individual service users
- be dementia specific
- be developed in conjunction with people with dementia or older people in general.

“Development of a standardised ‘outcome-focused’ person centred monitoring and evaluation tool would assist with national and local benchmarking across provision/projects” (Garwood, 2007).

Tenure choices.
4.12 Quality of Life and Well Being

Messages from Current Evidence

► Quality is a multifaceted and subjective concept.

► Factors shown to enhance quality of life and well being include,
  - effective partnership working
  - person-centred care
  - continuity of care (therefore a solid staff base)
  - flexibility of care and support
  - individualised assessment and case work
  - effective management and leadership
  - specialist dementia expertise
  - staff training and staff attitudes
  - the culture of the scheme
  - opportunities to take part in a range of activities and occupations
  - support provided by families.

► People living with dementia in extra care settings can be at risk of loneliness, social isolation and discrimination. Recent studies in the USA have shown that there is strong intolerance of residents with dementia in RC-AL.

► Discrimination and social isolation can be reduced through Information and awareness raising about dementia with tenants and families, and through person-centred approaches and tenant empowerment.

► Staff and organisations need to be more proactive in enabling people with dementia to join in with social activities.

Identified Evidence Gaps

► Further investigation of resident and environmental factors that influence satisfaction and quality of life in extra care, the predictive power of these factors over time, and the effects of interventions that target these factors.

► More studies addressing issues regarding resident empowerment, consultation and participation.

► Comparisons with people with dementia living in other settings of specific measures of health such as the number of falls and prevalence of depression.

► How ‘stigmas’ associated with dementia and other characteristics (such as age and health) can be better understood and combated in extra care settings.

► Studies responding to diversity, such as black, minority and ethnic communities.

► Tools for assessing outcomes where residents have communication difficulties.
5 References


Institute of Public Care (2007) Raising the stakes - extra care housing report literature review. Institute of Public Care.


Appendix One:

the Housing and Dementia Research Consortium (HDRC)

The HDRC was set up in 2008 by four leading providers of housing with care: Housing 21, Hanover, Anchor and the MHA. It currently has membership of around 100 individuals and organisations. The idea of the Consortium came about as a platform for collaborative working from which interested parties can work together to develop robust evidence on dementia care and extra care housing in order to influence policy and practice in the UK. It was recognised that commissioners and practitioners have a significant need for evidence which provides specific information regarding how extra care processes and structures result in specific outcomes in the various subpopulations of residents with dementia.

The primary aims of the HDRC are to:

- Shape the agenda of research into housing with care, to ensure its relevance and usefulness to housing providers and people with dementia;
- Work together to have greater weight when applying for research funding;
- Deliver more ambitious large-scale, multi-site, multi-provider research; and
- Share our findings from in-house research and evaluations.
Appendix Two: Studies Currently in Progress Relating to Extra Care for Older People

The following research studies are currently in progress. Although not dementia-specific, findings and outputs are likely to be useful for, and relevant to, people with dementia.

Evaluation of the Extra Care Housing Funding Initiative
(Darton et al., PSSRU, University of Kent)

The PSSRU has been commissioned by the Department of Health to carry out an evaluation of 19 new-build schemes for older people funded in the first two rounds of the Extra Care Housing Funding Initiative (ECHFI).

The research study is monitoring the development of the schemes, tracking long-term outcomes both for the schemes and the residents and will compare outcomes and costs with those for people who have moved into residential homes. The study is collecting information relating to demographics and care needs, tracking residents' experiences and health over time, and gathering residents' expectations and experiences.

Evaluation of the design of older people’s extra care housing: development and testing of an assessment tool
(Judith Torrington, School of Architecture, University of Sheffield)
Completion date September 2010.

This study is building on an existing evaluation tool, the Sheffield Care Environment Assessment Matrix (SCEAM), previously developed for residential care homes. The new tool (named EVOLVE) is designed to be used at all stages in the life-cycle of a building, from inception to evaluation after tenants have moved in, and will take account of the views of extra care building tenants and users, providers, commissioners and architects (PSSRU, 2007).

The tool will,
i) describe the range of extra care housing
ii) quantify the experience of the people living and working there
iii) identify environmental features that are associated with higher quality of life.

Evaluation of Pocklington Place (an extra care scheme for people with sight-loss)
(Darton et al., PSSRU, University of Kent)

Pocklington Place is a new extra care scheme in Northfield, Birmingham provided specifically for people with sight loss over the age of 55. The scheme, owned by Midland Heart Housing Association and managed by Thomas Pocklington Trust, comprises 64 one- and two-bedroom apartments and communal facilities including a restaurant, large communal lounge, hairdresser, shop, activities room, launderette and IT suite.
The evaluation study is focusing on how well extra care may support people with sight loss and meet their aspirations for independence and support.

Evaluation of Pocklington Rise (an extra care scheme for people with sight-loss)
(Darton et al., PSSRU, University of Kent)

Pocklington Rise is a new purpose-built extra care scheme just outside Plymouth, designed and managed specifically for people with sight loss and complex needs. The scheme is owned and managed by Thomas Pocklington Trust and comprises one- and two-bedroom apartments and communal facilities. The site also contains 14 self contained flats managed by Anchor Housing.

The Longitudinal Study of Ageing in a Retirement Community (LARC)
(Miriam Bernard et al., Research Institute for Life Course Studies, Keele)
Phase 1: 2006 – 2009

This longitudinal study is exploring the development of Denham Garden Village, a new Anchor Trust purpose-built retirement community in South Buckinghamshire. The integrated care and housing scheme for people aged 55 and with over 326 residential properties and many communal amenities and facilities.

There are four research questions underpinning the study:

- How, in the absence of a care home, will the care needs of residents be met both now and in the future?
- What will the potential impact of dementia and other types of disability be and how can these best be managed over time?
- What are residents’ attitudes to living in a mixed tenure development?
- What are the wider policy and practice implications of this type of care and accommodation?

(Source http://www.keele.ac.uk/research/lcs/membership/docs/RI%20'Annual%20Review%202005-07.pdf)

On-going study of Hartfields retirement village
(Karen Croucher, Centre for Housing Policy, University of York)

This study is exploring how the concept and lessons learned from other extra care schemes have been re-worked and taken forward to inform the development of Hartfields, the new JRF retirement village in Hartlepool. Key aims are to:

1) Track and analyse major decisions and developments in the planning and implementation of Hartfields.
2) Describe and analyse any barriers, challenges and constraints encountered, and the strategies deployed to overcome these.
3) Explore how the concept of a retirement village has moved on from the earlier development at Hartrigg Oaks, and how research evidence, and experience gained at Hartrigg Oaks, has informed the Hartfields development.
4) Explore baseline expectations of key stakeholders including partner agencies, staff, and residents.