

VERSION 1.7

‘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?



A Scoping Review of the Literature 1998-2008

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on behalf of the
Housing and Dementia Research Consortium

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1 Summary

1.1 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) 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Published and unpublished literature from 1999 onwards was identified through searches of a wide range of databases, journals and relevant websites, and through consultation with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.

1.2 Key Findings

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.

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.

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.

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.

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.

Key Gaps in the Evidence Base

In the UK there are very few studies of extra care housing that have produced evidence relating to tenants with dementia. In order to vastly improve the knowledge base and the quality of current research evidence, well designed large scale, multi-site studies are needed in the UK. The majority of the existing research evidence is from the USA but even there it is recognised that the knowledge base is still far too small and an aggressive research agenda is required. Robust studies are particularly needed to fully evaluate outcomes for people with dementia living in extra care, including quality of life and health.

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
- costs and benefits of housing and service models
- studies that address fundamental issues such as eating, drinking, sleeping issue, pain management, incontinence management, socialisation, and staff communication with tenants with dementia
- comparisons of extra care housing with available alternatives.

Critically, studies are urgently needed to address how best to implement research findings into practice.

1.3 Recommendations

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.

2 Acknowledgements

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3 Introduction

3.1 Why This Review Was Commissioned

This scoping review of the literature relating to extra care housing and people with dementia was commissioned by the Housing and Dementia Research Consortium (HDRC) and funded by the Joseph Rowntree Foundation (JRF).

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.

Following feedback received at a stakeholder consultation event, one of the first priority areas identified for action was to find out what we already know. What evidence already exists in the field of extra care for people with dementia, and where are the key gaps in evidence?

3.2 Relevance to the New National Dementia Strategy

'Living Well With Dementia: a National Dementia Strategy' was published by the Department of Health in February 2009 (DH, 2009). The overall aim of the strategy was to improve dementia services across three vital areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The strategy, based on research evidence and wide consultation, identified 17 key objectives. This scoping review contributes directly to two of these:

- Objective 16: *A clear picture of research evidence and needs,*

"Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled. "

- Objective 10: *Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers,*

"The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence

emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.”

3.3 Extra Care Housing

Extra Care Housing is a model of housing that combines independent housing with flexible levels of care. There is a wide variety of types of extra care housing, along with many definitions and terminologies among which ‘housing with care’, ‘very sheltered housing’, and ‘assisted living’ are widely used. The Department of Health’s Housing Learning and Information Network (HLIN) describe extra care as a concept that covers a range of specialist housing models incorporating particular design features and guiding principles. Key features include:

- self-contained accommodation, usually flats or bungalows
- tenants have a legal right to occupy the property
- the provision of individualised packages of care which are flexible and adapt to changing needs
- catering facilities providing meals
- care staff and support available round the clock
- communal facilities including, for example, lounge(s), restaurant, communal kitchen, and hairdresser.

(e.g. King, 2004; Croucher et al., 2007; and EAC, 2008).

3.4 Dementia

Dementia is an umbrella term relating to a significant intellectual decline or cognitive impairment that persists over time. A condition may be classed as a type of dementia if the following criteria are met:

- a. “It must cause decline in at least two of the following four essential cognitive functions:
 - i. memory;
 - ii. ability to generate coherent speech or understand spoken or written language;
 - iii. capacity to plan, make sound judgments and carry out complex tasks; and
 - iv. ability to process and interpret visual information.
- b. The decline must be severe enough to interfere with day-to-day life”,

Stevens (2008).

The most common type of dementia is Alzheimer’s disease which accounts for around 69% of all cases. Other types of dementia include:

- Vascular dementia
- Mixed dementia
- Dementia with Lewy bodies
- Frontotemporal dementia

- Dementia due to Parkinson's disease
- Dementia due to Creutzfeldt-Jakob disease.

3.5 Aims and Scope of the Review

This is a scoping review of the research evidence base carried out within parameters as defined in the Methods section below. The key aims were to:

- Identify recent published and grey literature 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 (otherwise known as housing with care or very sheltered housing)
- Review and summarise the research evidence
- Identify gaps in research evidence.

The focus of the review was to find evidence relating to a number of elements pertinent to housing with care for people with dementia, namely :

- 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.

The literature relating to design of buildings and environments, and care and support services, relevant to people with dementia in extra care housing covers many academic disciplines and is voluminous. Clear study criteria and boundaries were therefore established.

In addition, the review was carried out in a short time-scale of two months. The information in this report therefore focuses on research evidence (and gaps) sourced from existing relevant literature reviews, key research studies, any unpublished documents identified, and relevant studies published in the last three years.

3.6 Terminology used in the report

This document predominantly uses the terms '**extra care housing**' to describe establishments which provide independent housing along with flexible levels of care (see section 4.2 for a more detailed definition).

The term '**scheme**' is generally used to describe an extra care housing establishment otherwise known as '**court**').

The terms '**tenant**' and '**resident**' are used inter-changeably to refer to people living in extra care housing settings.

Acronyms used are listed in the Glossary (see section 9).

4 Methods

The approach to this scoping review of the literature was carried out according to established methods (e.g. Arksey and O'Malley, 2005) which do not include evaluating the methodological quality of studies.

The search strategy focused on finding:

- most up-to-date findings, particularly literature and systematic reviews
- publications no earlier than 1999 through to March 2009
- formal published UK research
- international published research, especially from the USA and Australia
- evaluative information from government, commissioners and providers of housing and dementia projects
- unpublished research, evaluations and literature relating to housing and dementia, mostly from housing and care providers.

4.1 Identifying relevant literature

A range of different search strategies was used.

- 1) A list of relevant search terms was drawn up initially and added to during the process of uncovering literature. Search terms included:

extra care, housing with care, very sheltered housing, assisted living, care housing, continuing care retirement communities, retirement housing, dementia, cognitive impairment, cognitively impaired, memory loss, and Alzheimer's disease.

Search terms were entered into relevant scientific and academic electronic databases and web-based search engines including:

Applied Social Sciences Index and Abstracts (ASSIA), Dogpile (a meta search engine), Google Scholar, Health Management Information Consortium (HMIC), IngentaConnect, Medline, PsychINFO, Science Direct, Sociological Abstracts and Social Services Abstracts (CSA), and Zetoc.

- 2) Manual searches of specific pertinent websites were carried out including:

Alzheimer's Australia, Alzheimer's Europe, Alzheimer's Society, Bradford Dementia Group, Community Care, Housing LIN, PSSRU, Social Care Online (part of the Social Care Institute for Excellence (SCIE)), Society Today (part of the Economic and Social Research Council (ESRC)), Joseph Rowntree Foundation (JRF), and the National Centre for Independent Living (NCIL).

- 3) Emails were sent out to members of the Housing LIN and the Housing and Dementia Research Consortium, and to councils and housing with care providers requesting information about any evaluations which organisations may have undertaken relating to extra care housing and people with dementia.
- 4) Networking.

All types of materials were considered including academic papers, reports, articles, books, and powerpoint presentations, both published and unpublished (grey) literature, and international (but limited to the English language).

4.2 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).

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.

4.3 Analysis

Identification of Themes and Key Findings

Relevant data were extracted from the identified literature, classified into non-mutually exclusive categories, and analysed thematically using 'narrative synthesis' which included describing the characteristics of research studies, their key findings and implications.

Identification of Evidence Gaps

Gaps in the evidence base were identified by:

- (a) extracting those highlighted in research papers and reports
- (b) an analysis of the evidence collated during the process of the literature review.

¹ AL of all types has the same ethos and guiding principles as extra care

² http://en.wikipedia.org/wiki/Assisted_living [Accessed 10 November 2008]

5 Results of the Literature Search

A large number of references and materials (over 2,000) pertaining to extra care housing and people with dementia were identified. The 323 which met the inclusion criteria were collected. 123 references were finally included in the review.

5.1 Range and Type of Research Evidence Identified

A wide variety of study designs was identified. A few were longitudinal, multisite studies but the vast majority, particularly in the UK, were small qualitative studies including evaluations of single extra care schemes.

Section 5.1 presents some of the key publications from which evidence has been extracted for this report. It shows:

- the type of study (e.g. literature review or evaluation study)
- the main focus of the study whether,
 - extra care(/assisted living), or housing more generally
 - people with dementia, or older people generally, including those with dementia
- UK or international.

5.1.1 Key Studies Identified

TYPE	MAIN FOCUS OF STUDY	UK OR INTERNATIONAL	TITLE OF ARTICLE OR REPORT, AUTHOR(S), AIMS, AND METHODOLOGY IN BRIEF
Literature review	EXTRA CARE for people with DEMENTIA	UK	None
“	EXTRA CARE / assisted living for people with DEMENTIA	International	<ol style="list-style-type: none"> 1. Dementia and Assisted Living (Hyde et al., 2007) An overview of what is known about dementia services in assisted living settings and suggestions of areas for future research. Searches were undertaken of Medline, the Journals of Gerontology, and The Gerontologist. Identified publications were reviewed and findings are organised into 10 topic areas. 2. Evidence on intervention to improve quality of care for residents with dementia in nursing and assisted living facilities (Tilly and Reed, 2004) A comprehensive literature review which critiques the evidence on interventions designed to improve dementia care in nursing and assisted living facilities.

Literature review	EXTRA CARE for OLDER PEOPLE	UK	<ol style="list-style-type: none"> 1. <i>Housing with Care for Later Life: a literature review (Croucher et al., 2006)</i> A scoping review of relevant literature published between January 1985 and June 2004 on models of extra care housing for later life. 2. <i>Raising the Stakes (Institute of Public Care, 2007)</i> A comprehensive review of available evidence relating to extra care housing which focused on, “primary research, service evaluations and learning papers that have been written about the topic of housing with care.” It aimed to, <ul style="list-style-type: none"> • Identify a number of assumptions that are made about extra care • Test whether there is sufficient evidence to support such claims • Identify gaps in that evidence • Identify what seem to be the critical success factors in delivery of Extra Care Housing”. 3. <i>Making the Case for Retirement Villages (Croucher, 2006)</i> A review of the evidence relating to retirement villages. 4. <i>The Essential Ingredients of Extra Care (Hanson et al., 2006)</i> Comprised a literature review and email survey of membership of the Housing LIN³.
“	HOUSING for people with DEMENTIA	UK	<ol style="list-style-type: none"> 1. <i>Housing and Dementia Care – a scoping review of the literature (O’Malley and Croucher, 2005)</i> “A scoping study designed to describe the evidence base with regard to housing provision for elderly people with dementia with the aim of identifying gaps in existing knowledge covers studies of housing and accommodation in relation to dementia that have been published in the UK since the early 1980s, although we draw on limited aspects of overseas research to illuminate issues missing from the UK research agenda”. The review include three ‘very sheltered’ studies.
Studies involving multiple schemes	EXTRA CARE for people with DEMENTIA	UK	<ol style="list-style-type: none"> 1. <i>Opening Doors to Independence (Vallely et al., 2006)</i> A longitudinal study which tracked tenants with dementia in all Housing 21 extra care schemes over a three year period. Methodology included collecting views and opinions of people with dementia themselves.

³ The Housing Learning and Improvement Network (HLIN) <http://networks.csip.org.uk/IndependentLivingChoices/Housing/>

<p>Studies involving multiple schemes</p>			<p>2. <i>Incidence and Management of Dementia In Hanover Extra Care (Baker, 2003)</i> An unpublished report of two surveys carried out in 2002 looking at how extra care housing can support people with dementia. Based on data from 21 extra care schemes</p>
<p>“</p>	<p>EXTRA CARE / assisted living for people with DEMENTIA</p>	<p>International</p>	<p>1. <i>The Collaborative Studies of Long-Term Care (various)</i> The Collaborative Studies of Long-Term Care (CSLTC) was set up in 1997 and the research carried out has made a significant contribution to what is known about quality of life, its correlates in long-term care, and the improvement of care for people with dementia in assisted living and nursing home settings.</p> <p>2. <i>The Maryland Assisted Living Study (MD-AL)</i> “is the first direct-evaluation study designed specifically to examine dementia in the AL setting and the effects of dementia on resident outcomes, including length of residence.” (Rao et al., 2008). Maryland Assisted Living Study (MDAL), an epidemiologic study of psychiatric disorders in AL. A stratified, random sample of 198 residents of 22 AL facilities in central Maryland was evaluated using a number of cognitive, behavioral, general health, and functional assessments</p> <p>Effect of Dementia and Treatment of Dementia on Time to Discharge from Assisted Living Facilities: The Maryland Assisted Living Study (Constantine et al., 2007) This Maryland Assisted Living Study (MD-AL) is the first direct-evaluation study designed specifically to examine the effects of dementia in assisted living facilities (ALFs) on resident outcomes including length of stay. The study was a prospective cohort study with a stratified random sample of 198 residents living in twenty-two ALFs in central Maryland, followed for an average of 18 months.</p> <p>3. <i>The Alzheimer’s Association Campaign for Quality Residential Care (e.g. Reed and Tilly, 2008)</i> This is a nationwide initiative aiming to enhance quality of life for people with dementia in nursing homes and assisted living residences by improving the care they receive. Publications have included literature reviews and evidence-based person centred practice recommendations.</p> <p>4. <i>Managing Decline in Assisted Living: The Key to Aging in Place (Ball et al., 2004)</i> This was the first longitudinal study to examine in depth the process of ageing in place in ALFs. Tenants were tracked in five ALFs over a one year period. The researchers</p>

			<p>carried out participant observation, interviews with providers, residents, and residents' families, and reviewed records.</p>
Studies involving multiple schemes	EXTRA CARE for OLDER PEOPLE	UK	<p>1. Comparative evaluation of models of housing with care for later life (Croucher et al., 2007) A longitudinal study of seven different housing with care schemes including one 'village' style scheme, operated by a range of provider organisations in different locations. The study focused on three aspects:</p> <ul style="list-style-type: none"> - what makes schemes distinctive - services and resources - how different needs for housing, care and support are balanced. <p>2. Evaluation of the Extra Care Housing Funding Initiative: Summary of Initial Findings (Darton et al., 2008). The PSSRU is currently carrying out an evaluation of the development of 19 new-build schemes for older people funded in the first two rounds of the ECHFI. This first phase report presents findings from information collected from the eight schemes that had opened in 2006 and 2007 in local authority areas of: Bradford, Brighton & Hove, East Riding, Enfield, Havering, Northamptonshire, Peterborough and West Sussex.</p> <p>The study methodology includes the collection of demographic and care need information, tracking residents' experiences and health over time, and gathering residents' expectations and experiences. "A particular feature of the study is to compare costs and outcomes with those for residents moving into care homes. The aim is to collect information on the characteristics of residents of extra care schemes in a way that allows comparisons to be made with the results of previous studies PSSRU has undertaken of care homes and their residents."</p>
Studies involving one scheme	EXTRA CARE for people with DEMENTIA	UK	<p>1. Fred Tibble Court, an evaluation (Institute of Public Care, 2005) An evaluation of a specialist Hanover extra care scheme for people with dementia in Dagenham, Essex focusing on the following research questions,</p> <ul style="list-style-type: none"> • Is the scheme attracting the "right" population? • Is the scheme performing to an acceptable standard? • Does the scheme deliver a reasonable quality of life for its residents?

Studies involving one scheme		<p>2. <i>A Report on the Evaluation of Moor Allerton Care Centre (Cantley and Cook, 2006)</i> The Moor Allerton Care Centre was established by the MHA Care Group (MHA) in 2004. It is a purpose built housing with care and day care facility for older people including those with dementia.</p> <ul style="list-style-type: none"> * <i>Yew Tree Court</i> providing 45 units of housing with care (28 two-bedroomed) * <i>Rosewood Court</i> providing 20 one-bedroom units of housing with dementia care, which can be occupied by a single person, or a couple * <i>Bay Tree Resource Centre</i> offering day care for up to 20 people per day. <p>The evaluation was undertaken by Dementia North, the regional dementia services development centre. The evaluation aimed to describe and assess the first year of operation of the new Centre; to make recommendations to MHA in relation to any areas for improvement and development; and, to inform future evaluation and research in this field.</p> <p>3. <i>The Standards We Expect : Moor Allerton (De Montford University, 2007, unpublished)</i> A study looking at person-centred approaches, outcomes of life history work, carer support groups, different communication, complementary therapies, and staff training.</p> <p>4. <i>Stanton Lodge (Jevons, 2008)</i> An unpublished evaluation report of a study of the first 30 months in the life of a unique MHA retirement housing and care scheme providing, “self-contained purpose built apartments for couples where one person has dementia. This will enable couples to stay together while gaining access to the best possible support”. The scheme has fourteen one and two bedroom apartments. . The evaluation aimed to:</p> <ul style="list-style-type: none"> - “assess the extent to which this model of housing with care provides a supportive and cost-effective way for couples to stay together when one partner has dementia AND - assist MHA to decide whether or not to replicate this scheme elsewhere, and if so what variations to make in new schemes.” <p>The study analysed documents and records, carried out interviews with tenants (who had the capacity to participate) and close relatives, and those closely associated with the schemes setting up and operation.</p>
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			<p>5. Duddon Mews Extra Care Scheme for People with Mental Health Problems and Physical Frailty in Cumbria (Garwood, 2008) “Duddon Mews is a 14-unit extra care scheme in the small town of Millom in Cumbria which opened in April 2005 .. The scheme caters primarily for older people with mental health problems (most with dementia), but also frail older people ... The case study is based on documents provided by the partners and interviews with staff from each. The reflections on the scheme combine what one or more interviewees reported and the author’s own observations.”</p>
<p>Studies involving one scheme</p>	<p>EXTRA CARE for OLDER PEOPLE</p>	<p>UK</p>	<p>1. Housing and care for older people: life in an English purpose-built retirement village (Bernard et al., 2007) A three-year study of the Berryhill retirement village which opened in 1998 in Stoke-on-Trent, Staffordshire developed by the ExtraCare Charitable Trust and Touchstone Housing Association. “A multi-method, participative action research design was adopted, with several different but related approaches to the collection of data and information, including: informal participant observation for three years; diary-keeping by certain residents ; a series of participation groups and annual community conferences; individual and group interviews with key people; three waves of structured questionnaires to residents (administered every Spring), and self-completion questionnaires to family, friends and some staff.”</p> <p>2. Living at Hartrigg Oaks (Croucher et al., 2003) A study of residents’ views of Hartrigg Oaks, a Continuing Care Retirement Community developed by the Joseph Rowntree Housing Trust. in York comprising 152 bungalows clustered around a central complex containing shared facilities including a library, cafe and restaurant. There is also a residential care home named ‘The Oaks’. Qualitative and quantitative methods were used in the study including two postal surveys of all residents, face-to-face interviews (only with those able to give informed consent) and discussion groups.</p>

6 Results – Research Evidence

The evidence identified during the review of the literature related to a number of main categories (not mutually exclusive). These form the subheadings of this results section.

6.1 *What is Extra Care?*

Terminology, Definitions and Essential Ingredients

MESSAGES FROM CURRENT EVIDENCE – WHAT IS EXTRA CARE?

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- ▶ 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.
-

6.1.1 Terminology

The concept of extra care housing is not alone in having a wide range of terms and definitions associated with it. The variety of terms used for housing in general for older people is very confusing, and this is not only the case in the UK. Writing in the American ‘*Housing Options for Older People, a Guide for Making Housing Decisions*’, Robinson (2007) states that often there is no standard “vocabulary” to clearly distinguish one housing type from another.

During the process of this review, terms used for housing options akin, very similar to, or incorporating extra care included:

- Accommodation with care
- Aging / ageing in place
- Assisted care living
- Assisted housing
- Assisted living (common in the USA)
- Close care
- Clustered housing-care

- Congregate care apartments
- Continuing care retirement communities
- EasyLiving
- Housing plus services
- Housing with care
- Independent apartment living options
- Independent living
- Independent senior housing
- Multi-unit housing with services
- Residential care apartment complexes (RCAC) (common in the USA)
- Retirement communities
- Retirement housing
- Retirement villages
- Service co-ordinated housing
- Senior collective housing
- Supported independent accommodation
- Supportive housing
- Total care living
- Very sheltered housing.

6.1.2 Definitions of Extra Care Housing

The CSIP toolkit (CSIP, 2006) identifies three key principles that underpin extra care housing,

- the promotion of independence,
- empowerment, and
- accessibility.

The toolkit explains that understanding definitions of extra care is more than semantics. It states that clarity is needed around the meaning of 'extra care' in terms of,

“furthering its development, being clear about its regulation and conveying a clear image to the general public, older people and the range of professionals who may be involved in its development or in the provision of services.”

Cox (2007) explains that different types of extra care are still evolving and that current varieties include:

- Continuing care communities and retirement villages
- Remodelled sheltered housing or care homes
- Purpose built schemes, with or without community resources
- Housing that is 'linked' to a care home
- Specialised housing grouped in a wing or cluster of a larger development
- Core and cluster - central core building, dispersed housing units (co-located or 'virtual' across a locality)
- Small independent living houses - with shared living space.

A generalised definition of extra care housing is described in section 3.3 (see page 10). For an in depth discussion of definitions, models and typologies see Croucher et al. (2006) who, having reviewed the UK and international literature relating to housing with care for later life, concluded,

“There are various definitional problems, and very few schemes are exactly alike, although a number of common features emerge, notably a focus on a ‘homely’ rather than institutional environment and services that promote independence and autonomy.”

Similarities with Assisted living

Assisted Living (AL) has been used in the USA to describe a wide variety of residential facilities for older people that,

- (a) provide personal care in activities of daily living and
- (b) are able to respond to unscheduled needs for assistance, unless they are licensed as a nursing home (Zimmerman et al., 2005).

Similar to ‘extra care’ in the UK, there are numerous definitions of ‘Assisted Living’ in the USA. Core principles proposed by the *Assisted Living Workgroup* for assisted living facilities (ALFs) are highly similar to those described for extra care (ALW, 2003),

- “1) To create a residential environment that actively supports and promotes each resident’s quality of life, right to privacy, choice, dignity, and independence as defined by that resident.
- 2) To offer quality supportive services, individualized for each resident and developed collaboratively with the assisted living residency.
- 3) To provide resident-centered services with an emphasis on the particular needs of the individual and his/her choice of lifestyle incorporating creativity, variety, and innovation.
- 4) To support the resident’s decision-making control to the maximum extent possible.
- 5) To foster a social climate that allows the resident to develop and maintain relationships within the ALR and in community-at-large.
- 6) To make full consumer disclosure, including what services will be offered and their associated costs, before move in and throughout the resident’s stay.
- 7) To minimize the need to move.
- 8) To foster a culture that provides a quality environment for the residents, families, staff, volunteers, and community-at-large.”

Many ALFs offer self-contained accommodation for residents. Most of the newer, purpose-built ALFs consist of self-contained apartments⁴.

⁴ http://en.wikipedia.org/wiki/Assisted_living [Accessed 10 November 2008]

6.1.3 The Essential Ingredients of Extra Care

Hanson et al. (2006) carried out a review of the literature to identify what the essential features are for extra care. A proposed checklist was drawn up with a feature being added only if it was mentioned in several publications. The authors then carried out an email survey amongst the membership of the Housing LIN⁵ in spring 2006 to determine the relative importance of each of the twenty-five identified features. 137 respondents rated the proposed essential ingredients on a five point Likert Scale.

There was strong agreement about the three highest ranking features: 1) 'flexible care', 2) 'self-contained dwellings', and 3) a 'homely feel to the building'. However some of the middle ranking features such as a communal lounge, kitchen and dining room, guest room, assisted bathrooms and laundry room, produced opposing importance ratings.

The table below presents the features as ranked in order of importance by survey respondents:

Rank of Importance	Extra Care Feature
1	Flexible care, responsive to tenants' fluctuating care needs
2	Self contained dwellings. Control of one's own front door.
3	Living at home, not in a home. A 'homely' feel.
4	Premises that are wheelchair accessible throughout
5	Lifts to upper floors so that the whole scheme is 'visitable'
6	24 hour support on site for those who need it
7	Flexible design to adapt to changing needs of tenants
8	Providing a culturally sensitive mode of service delivery
9	Smart and assistive technology for independent living, including social alarm / intercom
10	Rebuilding tenants' skills for independent living.
11	On-site support staff who assist tenants with daily chores
12	Communal lounge to promote social activities
13	Scheme manager to co-ordinate care and support teams
14	Assisted bathrooms for use by frail tenants
15	Communal dining room where tenants can share meals
16	Activity room for use by tenants and local community
17	Well being facilities - hairdresser, gym, chiropody etc
18	Balanced community, that mixes abilities and types of tenure
19	Guest room available for tenants' friends and family to stay
20	Communal (commercial) kitchen to serve a fresh mid-day meal on site
21	Communal laundry room for the tenants' use
22	Activity coordinator to organise tenants' social activities
23	Consulting room for visiting health / care professionals
24	Lively locality. Scheme located in a well-established neighbourhood
25	Day Centre incorporated in the scheme to boost social life

⁵ The Housing Learning and Improvement Network (Housing LIN)
<http://networks.csip.org.uk/IndependentLivingChoices/Housing/>

**EVIDENCE GAPS IDENTIFIED – WHAT IS EXTRA CARE?
TERMINOLOGY, DEFINITIONS AND ESSENTIAL INGREDIENTS**

- ▶ 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.
-

6.2 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.
-

A survey of Hanover extra care schemes⁶ carried out in 2002 found that 9% of residents had a diagnosis of dementia, and a further 15% were believed to have dementia (11% mild, 3% moderate, 0.4% severe), a total of around 27% (Baker, 2003).

A similar figure was found from a Housing 21 survey of scheme managers⁷ which was carried out in 2008 which indicated that 22% of extra care residents have been diagnosed with, or were believed to have, dementia (Vallelly, 2009).

Respondents to the Raising the Stakes Survey carried out by the Institute of Public Care (IPC, 2007) indicated that 23% of current extra care residents had dementia prior to entry.

Brooker et al.'s study (2008) of ten ExtraCare Charitable Trust schemes and villages⁸ found very large variations in prevalence of dementia. The schemes were situated in the Midlands and North West of England and ranged in size from 45 to 320 residents. Results showed that the larger schemes had only small percentages of people with dementia (as determined by the Mini Mental State Examination instrument) in some cases just 5% of residents. In the older smaller schemes percentages were much

⁶ data received from 21 extra care schemes with 758 residents

⁷ based on data received from 29 extra care schemes with 1337 residents

⁸ over 1,000 participants in all

higher, an average of around 30%, with the highest being 47%. Over half of the respondents had moderate or severe cognitive impairment, a much higher number of people than were believed to have dementia, or had received a formal diagnosis of dementia. Interestingly, “neither the dementia or non-dementia diagnoses seemed to be related to size of home or time since opening. It was presumably a reflection of local arrangements between each facility, local GP’s and specialist services.”

Initial findings from the *Evaluation of the Extra Care Housing Funding Initiative* (Darton et al., 2008) states that,

“It would appear that most schemes prefer to admit residents with lower levels of physical and mental impairment than is common in care homes. This reflects both policies of prevention and supporting independence as mixed communities can provide mutual support.”

“Those who moved into extra care had much less physical and mental impairment and required much less support than those who moved into care homes. Just under 30 per cent of those who moved into extra care had moderate or more severe levels of dependence, compared with two-thirds of those moving into a care home providing personal care. A very small proportion (4 per cent) who moved into extra care were severely mentally impaired, compared with 39 per cent of those moving into a care home providing personal care.”

Studies conducted in the USA report similar findings. Golant’s review of six national studies (Golant, 2004) determined,

“ALFs are currently serving older residents who require less nursing care and who are less functionally and cognitively impaired than those found in nursing homes. The more restrictive admitting and discharge criteria of a substantial share of ALFs guarantee their less frail occupant profile. This is, however, an extraordinarily diverse shelter and care alternative, and very frail older persons with serious chronic health problems can be found in ALFs.”

**EVIDENCE GAPS IDENTIFIED –
PREVALENCE OF DEMENITA IN EXTRA CARE SETTINGS**

- ▶ 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.

6.3 Overview of UK Studies Suitability of Extra Care for People with Dementia

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MESSAGES FROM CURRENT EVIDENCE (UK STUDIES) – SUITABILITY OF EXTRA CARE FOR PEOPLE WITH DEMENTIA

- ▶ 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.
-

At the time when O'Malley and Croucher carried out their *Housing and Dementia Care Scoping Review of the Literature* (O'Malley and Croucher, 2005) there were only three studies relating to 'very sheltered housing' that were appropriate to include in the review. Since then, several UK studies focusing on people with dementia in extra care housing have been carried out. An unpublished evaluation carried out in 2004 was also identified by this review. All the studies identified are evaluations of single schemes, apart from '*Opening Doors to Independence*' which was a multi-site longitudinal study of people with dementia living in Housing 21 extra care schemes (Vallely et al., 2006), and an unpublished report of Hanover extra care schemes looking at the incidence and management of dementia (Baker, 2003).

The studies generally report positive findings in terms of quality of life for people with dementia. They provide some valuable evidence and indications of what is working and ways in which improvements could be made. A brief overview of their findings is presented below (in chronological order by type), with more detail included under the sectioned themes in this report.

6.3.1 UK Single Scheme Extra Care Studies Focusing on People with Dementia

(i) Portland House (Scott, 2004)

 *Evaluation of a specialist dementia scheme*

Portland House in St Helen's is a specialist MHA 'extra care' scheme for eight people with dementia *although tenants' flats do not have their own kitchens* and meals are provided in a communal restaurant. An evaluation of Portland House (Scott, 2004)

concluded that the scheme was, “offering a very good service to its tenants”, providing a good quality of life with benefits including social inclusion, improved skills, flexible person centred care, and promotion of activity and stimulation. The study reported that some of the tenants would have moved into a care home had it not been for Portland House.

(ii) Fred Tibble Court (Institute of Public Care, 2005)

📁 Evaluation of a specialist dementia scheme

The evaluation of Fred Tibble Court, a specialist Hanover extra care scheme for people with dementia in Dagenham (Essex), carried out by the Institute of Public Care (IPC, 2005) showed that the building, accommodation and care were generally well-received and effective.

Some of the key conclusions from the evaluation were:

- the scheme reaches acceptable standards across a range of measures including building design, the use of assistive technology, support to managers and staff, and a rehabilitative focus
- the scheme is designed to give opportunities for social interaction
- residents have a reasonable quality of life
- most residents feel safe, respected and supported by staff
- experience of families is generally positive.

Some area for improvement were found to be:

- almost one third of residents expressed feelings of loneliness and felt that staff did not spend enough time talking to them
- there is a need to increase resident involvement in care planning
- ways of reducing the impact of staff shortages
- further development of ways to involve residents in the running of the scheme
- further development of involvement with the wider community
- more focus during assessment on strengths of residents
- partnership working needs to build upon a more structured approach because current success of partnership between managers relies on personalities involved.

(iii) More Allerton Care Centre

📁 Two evaluations of a facility including a specialist dementia scheme

(1) (Cantley and Cook, 2006)

More Allerton is an MHA facility in Leeds incorporating two extra care schemes and a day centre. One of the schemes, Rosewood Court, is a specialist scheme for people with dementia providing 20 one-bedroom units of housing with dementia care which can be occupied by a single person or a couple. The overall conclusion from the 2006 evaluation by researchers from the Bradford Dementia Group was that,

“the Centre performs well in relation to the model and philosophy set out ... Underpinning its high standards are a strong value base, good management, a strong commitment to staff support and development, and a high quality environment.” (Cantley and Cook, 2006).

(2) (De Montfort University, 2007, unpublished)

This study concluded that because the service is relatively new it is yet uncertain who benefits from living in such units and what support they need.

(iv) Stanton Lodge (Jevons, 2008, unpublished)

✉ Evaluation of a specialist dementia scheme for couples

MHA’s Stanton Lodge is a unique new extra care scheme providing self-contained apartments for couples where one person has dementia. The model of care and support offered enabling couples to stay together is a major attraction of the scheme for residents. Jevons (2008) concluded that Stanton Lodge is proving of particular value for couples where both partners have high care needs, and is able to accommodate a variety of high care needs as well as dementia. The quality of life for all the residents with dementia was considered to be good or excellent and better than previous circumstances. For partners without dementia, the majority felt their quality of life was good or excellent but around one third felt theirs was medium or poor.

“For couples where the importance of continuing to live together outweighs other considerations, Stanton Lodge provides a comfortable, supporting and effective means of achieving that goal.”

The evaluation found that for couples who wanted to continue living together during the dementia of one partner, “traditional residential or nursing home care not only fails to meet this objective, but in most cases is more expensive than support at Stanton Lodge over the lifetime of both partners”. Overall costs to residents of living at Stanton Lodge were found to depend on many variables such as the future life durations of each partner, the care needs of each partner, and the extent to which the couple are able to obtain public funding to support the care.

(v) Duddon Mews (Garwood, 2008)

✉ Evaluation of a specialist scheme for people with mental health conditions

Duddon Mews is a Home Group 14 unit extra care scheme in the small town of Millom in Cumbria for people with mental health conditions and physical frailty. Most of the residents have dementia. Findings from Garwood’s (2008) case study, which also drew on a previous initial evaluation of the scheme, included,

- the scheme is successfully meeting the needs of people with dementia and supporting their independence
- high quality person-centred service has resulted in very positive feedback from all stakeholders with tenants having a high level of choice and control
- the housing and housing related-support service is efficient and effective (within defined limits).

Findings also indicated that the service objectives drawn up in the Service Specification are being met resulting in:

1. avoidance of unnecessary admission to hospital
2. avoidance of preventable or premature admission to long term residential or nursing home care
3. maximising potential by working to maintain skills as far as possible and provide support
4. support for the transition from hospital to home
5. an alternative option to residential care where appropriate and assessed care needs can be met
6. user-focused inter-agency working
7. assist informal carers with day to day requirements of caring for service user.

6.3.2 UK Multiple Extra Care Scheme Studies Focusing on People with Dementia

(i) Incidence and Management of Dementia in Hanover Extra Care (Baker, 2003)

📁 Surveys carried out in multiple schemes, focus on tenants with dementia only

Two surveys were carried out to determine the incidence of dementia in Hanover extra care schemes, to find out how the effects of dementia are managed in schemes looking at the balance the quality of life of residents with and without dementia, and to assess scheme managers' current abilities to work with dementia.

The study found that scheme managers were managing dementia well in many respects and there were a lot of examples of considerable good practice. The main recommendations for improvements were: further training, guidance and support for scheme managers; changes to some management practices such as striving to ensure allocations maintain the promoting independence character of extra care; and changes to certain design features.

(ii) Opening Doors to Independence - Housing 21 extra care schemes (Vallelly et al., 2006)

📁 Evaluation multiple schemes, tenants with dementia only

A key study, 'Opening Doors to Independence' study (Vallelly et al., 2006), tracked tenants with dementia in fifteen Housing 21 extra care schemes over a three year period. Importantly the research methodology included collecting views and opinions of people with dementia themselves.

The findings from the 'Opening Doors' study suggest overall that extra care is working for the majority of people with dementia, extending their independent lives in a community setting for around as long as people without cognitive impairment, and is providing a good quality of life. The study concluded that most of the extra care schemes in the study were operating as a replacement for residential care, and in most cases the extra care is effective as an alternative to residential care for people with dementia.

6.3.3 UK Studies Including Findings Regarding People with Dementia Living in Extra Care

Since O'Malley and Croucher's *Housing and Dementia Care Scoping Review of the Literature* (O'Malley and Croucher, 2005) there have been new studies and reviews focusing on older people in general that include some notable findings regarding people with dementia in extra care (presented in chronological order below).

(i) *Housing with care for later life: a literature review* (Croucher et al., 2006)

📁 Literature review, older people

This literature review of extra care for later life concluded that the evidence base supports the notion that extra care housing promotes independence and achieves high levels of resident satisfaction, but messages pertaining to key areas of interest are less clear.

(ii) *The Essential Ingredients of Extra Care* (Hanson et al., 2006)

📁 Based on a literature review and a survey, older people

See section 6.1.3. above.

(iii) *Making the Case for Retirement Villages* (Croucher, 2006)

📁 Review of evidence, older people

Croucher's review of the evidence relating to retirement villages found evidence that such villages have many benefits including: increasing choice in living arrangements; offering decent age appropriate housing; playing a role in maintaining and promoting health; and providing opportunities for community services to be delivered more effectively and efficiently. However they found examples from studies showing that residents with dementia present particular challenges, including causing anxiety and distress to other residents.

(iv) *Comparative Study of Models of Housing with Care in Later Life* (Croucher et al., 2007)

📁 Evaluation of multiple schemes, older people

This was a longitudinal study of seven housing with care schemes which found,

“tensions around the capacity of housing with care to accommodate individuals who have high-level care needs and still remain true to the concept of promoting ‘independence’ in later life.”

The ability for an extra care scheme to be able to provide appropriate care depends heavily not only on the capacity of the scheme itself, but on other local services such as community nursing, to be able to provide required services,

“Housing with care schemes cannot exist in isolation, but need to be embedded in wider national and local strategies for older people's services.”

(v) *Housing and Care for Older People: Life in an English Purpose-Built Retirement Village* (Bernard et al., 2007)

✉ Longitudinal study, older people

A three-year study of the Berryhill retirement village in Stoke-on-Trent found that there were issues with cognitively impaired residents living among those without cognitive impairment. For example, staff and residents found the 'walking around' behaviour of some residents with dementia hard to cope with.

(vi) *Raising the Stakes, Promoting Extra Care Housing* (Institute of Public Care, 2007)

✉ Literature review, older people

The *Raising the Stakes* project included a comprehensive review of available evidence relating to extra care housing including primary research and service evaluations as well as learning papers written about extra care, plus a survey of extra care scheme managers from 19 different organisations.

For older people generally (not specifically people with dementia) the project concluded, based on the evidence available, that extra care housing:

does

- improve the health and well being of occupants or the capacity to sustain health
- improve the quality of life of its occupants
- enable the continued involvement of family carers
- provide a realistic alternative to care home admission

is able to, but not in all cases,

- provide a home for life for its occupants
- reduce social isolation of older people and encourage active engagement and involvement
- reduce or maintain levels of need for formal support and health services, reduce hospital admission and speed up early discharge

may (but not enough evidence sources existed)

- improve staff recruitment and retention and impact positively on the local market
- offer a sustainable return on investment for commissioners.

(vi) *Evaluation of the Extra Care Housing Funding Initiative: Summary of Initial Findings* (Darton et al., 2008)

✉ Current evaluation of multiple schemes, older people

Findings from an investigation of the first eight new-build Extra Care Housing Funding Initiative schemes included,

- all eight schemes aimed to support older people with dementia

- none of them specified that they would be using a dementia-specialist model.
- one scheme was aiming to be a centre of excellence for dementia in the local area
- some of the bids described that the schemes would incorporate good practice design features, including security systems and orientation prompts, in order to support the needs of people with dementia.

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EVIDENCE GAPS IDENTIFIED (UK STUDIES) – GENERAL OVERVIEW

- ▶ 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).
- ▶ Reports of user perceptions of extra care and dementia care services are extremely rare.

6.4 Overview of USA Studies that Encompass Apartment Style ALFs Suitability of Extra Care for People with Dementia

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MESSAGES FROM CURRENT EVIDENCE – SUITABILITY OF EXTRA CARE FOR PEOPLE WITH DEMENTIA (OVERVIEW OF USA STUDIES)

- ▶ 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.
-

There has been a great expansion in research activity relating to assisted living (AL) for people with dementia in the USA over the past few years, including some very large, methodologically sound, studies, such as national and multi-state longitudinal studies (Kane et al., 2007).

Caution is needed in applying these findings to UK populations and settings, particularly because there can be large differences in many variables including culture, aspirations, laws, and regulations (generalisability can also be problematic *within* the USA as large differences also exist between states). Croucher et al. (2006) noted that comparisons with the UK context can be problematic given the minimal provision in the USA for people on low incomes.

Nevertheless, it is evident that there are many commonalities between findings which have been generated to date from the small number of extra care studies in the UK and the much larger number of assisted living studies in the USA. This suggests that overall key messages from assisted living research can have useful and valuable application to UK extra care settings.

An overview of some of the key studies is presented below. Detailed findings from these and other studies are included in the themed findings sections of the report.

(i) The Collaborative Studies of Long-Term Care (CS-LTC)

 *Research Programme, multiple schemes, people with dementia*

The Collaborative Studies of Long-Term Care (CS-LTC) was set up in 1997 and the research carried out to date has made a significant contribution to what is known about quality of life, its correlates in long-term care, and the improvement of care for people with dementia in assisted living and nursing home settings,

“the CS-LTC was initiated in response to the proliferation of RC/AL facilities, to address the paucity of information regarding the needs of their residents and the care that they receive, especially in light of the great diversity among these facilities.”

The CS-LTC has carried out a series of multistate projects with nearly 5,000 residents in around 350 AL facilities and nursing homes. The work has taken community-based participatory research approach in order to maximise its application to practice and policy.

Research papers based on data collected from the studies include,

- ***How Good Is Assisted Living? Findings and implications from an outcomes study (Zimmerman et al., 2005)***

“No single component defines “good” AL care. Predictors and outcomes are inconsistent, and effect sizes are small. Therefore, practice and policy should not focus narrowly on any one area or restrict the type of care—this being welcome news that supports diversity to accommodate individual preferences.”

- ***Dementia Care and Quality of Life in Assisted Living and Nursing Homes (Zimmerman et al., 2005)***

“Change in quality of life was better in facilities that used a specialized worker approach, trained more staff in more domains central to dementia care, and encouraged activity participation.”

- ***Obtaining Evidence to Inform Practice and Policy (Zimmerman et al., 2008)***

An overview of the ‘*Dementia Care Project*’ conducted in partnership with the Alzheimer’s Association which identified key quality care domains for people with dementia in assisted living and nursing home settings: resident pain, depression, behaviour, activity involvement, food and fluid intake, mobility, and overall (aggregate) quality of life. It highlighted the importance of staff training and care relating to the identified domains, as well as family involvement.

(ii) The Alzheimer’s Association Campaign for Quality Residential Care (CQRC)

 *Research Initiative, multiple schemes, people with dementia*

The Alzheimer’s Association Campaign for Quality Residential Care (CQRC) is, “a nationwide initiative designed to enhance quality of life for people with dementia in nursing homes and assisted living residences by improving the care they receive”.

Literature reviews commissioned by the Alzheimer’s Association as part of this initiative include,

- ***Evidence on Interventions to Improve Quality of Care for Residents with Dementia in Nursing and Assisted Living Facilities (Tilly and Reed, 2004)***
- ***Falls, Wandering, and Physical Restraints: Interventions for Residents with Dementia in Assisted Living and Nursing Homes (Tilly and Reed, 2006)***

The CQRC have developed a set of evidence-based person centred practice recommendations for assisted living and nursing homes (Reed and Tilly, 2008) relating to advocacy, training, activities and care provision designed to help people better deliver high-quality dementia care.

All of the outputs from the CQRC have been derived by:

1. using the best available high quality research evidence.
2. translating the evidence by developing consensus across key stakeholders to foster commitment and collaboration.
3. targeting specific care areas to maximise impact.
4. using a multi-level approach to encourage change across the various influences on quality.

The key overall finding from this work is,

“staff and environmental characteristics should be priority targets for change, rather than individual resident characteristics.”

(iii) Dementia and Assisted Living (Hyde et al., 2007)

📁 Literature review, people with dementia

Hyde et al. (2007) carried out a literature review to ascertain what is known about dementia services in assisted living settings. They undertook searches of Medline, the Journals of Gerontology, and The Gerontologist, and collected other relevant publications widely referenced in the literature.

They describe the demographic characteristics of cognitively impaired residents in assisted living in the USA, the services they receive, and process and structural aspects in both specialised dementia units and integrated assisted living settings.

EVIDENCE GAPS IDENTIFIED – OVERVIEW, INTERNATIONAL

- ▶ 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 trials⁹ 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.

- ▶ 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.

⁹ This methodology generates the most robust evidence.

6.5 THEMES

6.5.1 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.
-

In their '*Housing with care for later life: a literature review*' Croucher et al. (2006) reported consistent examples from various settings of people not being able to take part in social activities because of their impairments.

In the USA, Kuhn et al.'s study of people with dementia in ten ALFs (2002) found that there were few structured activities being run, and there was little variety in activities that were offered to, or engaged in, by residents.

Tighe et al.'s (2007) activity participation study involving 198 residents¹⁰ found that higher levels of activity were associated with longer retention in the ALFs, and that the effect appeared to be independent of other potentially confounding factors including dementia, general health, and mobility. They conclude that this evidence is, "consistent with the hypothesis that engagement in activities delays functional decline" (Tighe et al., 2007).

In the UK, Vallely et al. (2006) found the more effective extra care schemes were those providing accessible and welcoming opportunities for stimulating activities and social interaction including facilities for communal dining and involvement in preparation, planning and buying of meals. Activities were received positively by people with dementia.

Regnier (2002) advocates that residents, especially those with dementia, are usually more comfortable taking part in normal everyday household activities such as preparing food, laying the table, cleaning up after meals, etc. Such activities have often taken up a large part of a person's day. Running a 'life skills' program with people with dementia who like household tasks can be an effective therapeutic approach.

¹⁰ Part of the Maryland Assisted Living Study (MDAL)

Activity sessions were found to be more enjoyable and effective at Moor Allerton when run for dementia and non-dementia tenants separately (Cantley and Cook, 2006). However, a 'segregation effect' may have accounted for, or contributed to this, as the Moor Allerton site has two extra care schemes, one specifically for people with dementia.

In the studies reviewed by Croucher et al. (2006), a consistent view from tenants was the importance of not being forced to take part in activities and social events if they did not want to. Evidence shows that differences in needs and preferences mean that it is important to involve tenants in the design of activities.

Garwood (2008) recommended that there should be opportunities for tenants to engage in meaningful activity at community and group levels as well as on a one-to-one basis.

Brooker and Woolley (2006) report on the initial evaluation of a new model for working with people with dementia, the '*Enriched Opportunities Programme*' (EOP). This was developed by the Bradford Dementia Group and the Extracare Charitable Trust with the aim to,

“provide a practical way of working that could ensure that people with mental health problems including dementia can lead happy and fulfilled lives within extra care without having to move into nursing home care if their mental or physical health status deteriorates”.

The EOP is based around the following five elements working together:

1. Specialist expertise
2. Individualised assessment and casework
3. Activity and occupation
4. Staff training
5. Management and leadership.

The evaluation involved an extra care housing scheme with apartments for 86 tenants and three dementia specialist nursing homes. 25 tenants who were identified as being vulnerable to exclusion because of dementia (diagnosed or otherwise), other mental health conditions or significant communication difficulties took part.

Overall, findings were very positive and demonstrated that it is possible to increase levels of well-being and diversity of activity for people living with dementia in extra care housing. It was clear that, “a casework model of setting and working towards fulfilling personal goals with tenants in extra care housing works well with many vulnerable tenants”.

EVIDENCE GAPS IDENTIFIED - ACTIVITIES

- ▶ 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.
-

6.5.2 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.
 - ▶ It 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.
-

Evidence of Benefits of AT in Extra Care

There are pockets of evidence indicating that assistive technology can improve security, reduce risks, increase independence, lengthen tenancy, and improve quality of life for people with dementia living in extra care.

A literature review of technology and the needs of people with dementia and family caregivers carried out by Topo (2007) concluded that the limited evidence available does suggest that technology has potential in helping to support people with dementia.

Evidence of benefits of AT for older people in general living in extra care include its contribution to people's sense of security (for example through being able to call for help in an emergency) and recognition by older people that it is a preventative measure (Alladice, 2005).

Positive outcomes were identified in a recent evaluation of an enabling 'Smart Flat' for people with dementia in an extra care scheme:

“It is clear from the monitoring that the installation had a beneficial impact on his behaviour. It is felt that the evaluation does provide evidence that the enabling smart technology can have a real benefit to the security of users, and indirectly improve quality of life through such aspects as improving continence, independence and improved sleep.”
Evans, Orpwood et al. (2007).

The Use of AT in Extra Care

Vallelly et al.'s (2006) longitudinal study of people with dementia living in Housing 21 extra care schemes found that the benefits of appropriate use of assistive technology (e.g. to help compensate for physical and cognitive impairments, counteract isolation, monitor risk, and promote safety) were well understood by staff, relatives, and senior local health and social care managers. However, the study found, “only three examples where assistive technology was being used, in spite of Housing 21's investment in hardwiring when schemes were first built.”

The recent evaluation of the Stanton Lodge extra care scheme for people with dementia and their partners also found that little use was being made of the assistive technology. It had either been forgotten or disregarded as the cost of installation is incurred by residents and these may appear excessive compared to its benefit. Jevons (2008) recommended that ways need to be found to reduce the installation charges, and that AT needs to be actively promoted. The evaluation of Fred Tibble Court also found there was a need more information to be given to residents about what is available (IPC, 2005).

The Stanton Lodge evaluation (Jevons, 2008) also found that most residents valued the movement activated lighting but some did not and it was recommended that a manual override should be fitted to enable those lights to revert to ordinary mode if desired. Likewise, feedback received during the Portland House evaluation advised,

“only bed and light sensors should be fitted as standard with other systems only installed if a particular risk was identified.”

Vallelly et al (2006) recommended that greater use should be made of electronic assistive technology to support residents with dementia, “in the context of well developed, person centred risk assessment and management processes”. Cahill et al., (2007) agree it is essential that technology is viewed as part of service and care.

In terms of assistive technology in extra care for older people in general, Croucher et al.'s (2007) comparative evaluation of models of extra care housing found that the amount of technology that residents are comfortable using is a key aspect. The overriding message was to keep the technology simple and robust. Likewise, the case study report of Duddon Mews extra care scheme Garwood (2008) warned that installed equipment will be under-used if a one-size-fits-all approach is adopted and if programming is complicated. The author recommends that, when deciding on assistive technology for extra care schemes, research and thorough planning is needed to ensure optimum usage and benefit.

EVIDENCE GAPS IDENTIFIED – ASSISTIVE TECHNOLOGY

- ▶ 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.
-

6.5.3 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.
-

Extra Care as an Alternative to Care Homes

In areas where extra care schemes are available, the current evidence indicates that it is able to offer people an alternative to residential care, and that it can provide a positive alternative and replace residential care for some people even with moderate to severe dementia (Poole, 2006; Henwood, 2007).

Garwood (2008) estimated that, at the time of the case study, without the Duddon Mews extra care scheme,

- one tenant would be in a nursing home,
- four or more would be in residential care.

The scheme, “therefore clearly is an alternative to residential care for some people, but as a mix of needs and dependencies is targeted, and some people move on to residential care, it could not be seen as a complete replacement for residential care.” (Garwood, 2008).

The *Opening Doors to Independence* longitudinal study of Housing 21 extra care schemes noted that that frailty levels in extra care increased over the study period to the point where most residents were at the ‘high dependency’ level which meant that,

“The courts participating in this research were all primarily operating as a replacement for residential care.”

Nevertheless, studies show that for some people a move from extra care to a nursing or residential home is unavoidable, or indeed preferred. The *Raising the Stakes, Promoting Extra Care Housing* literature review concluded,

“Extra Care does not present a total alternative to care homes, but increases choice for older people themselves and for care providers” (IPC, 2007).

Croucher et al., (2006) suggest that the reasons for some extra care schemes being found not to be a realistic alternative to a care home include,

- a lack of schemes nationally,
- a lack of capacity in all forms of care staff,
- the requirement to ensure a stable balance of dependency levels within the schemes.

USA Assisted Living Compared with Nursing Homes

Doraiswamy et al. (2002) in Hyde et al. (2007) found that around one third of both assisted living and nursing home residents with dementia have three or four comorbid conditions. However, far more residents in assisted living have none, or one or two coexisting conditions, and nearly three times as many nursing home residents have more than five comorbidities.

In their paper ‘*Assisted Living and Nursing Homes: Apples and Oranges?*’ Zimmerman et al. (2003) point out that there are,

- fewer people in ALFs have cognitive impairment than those in nursing homes
- more incidences of behaviour that challenges in assisted living/residential care than in nursing homes.

The authors suggest that, over time, overall RC/AL and NH populations are becoming increasingly similar. They note that dependency-mixes differ across different types of RC/AL facilities due to a variety of factors including variations in admission and discharge policies, and the matching of facilities resources and policies to resident needs. Difficulties with activities of daily living (ADL), and cognitive and behavioural impairments, are highest in facilities that,

- are for-profit
- are less than five years old
- have more lenient admission policies, provide less privacy, and less resident control (“all areas seemingly consistent with the realities of a more impaired population”).

Weisman et al. (2004) studied ‘*Differences in Dementia Services and Settings Across Place Types and Regions*’. They explored the range of services and settings available to people with dementia in five Wisconsin counties in three different place types: (i) nursing homes, (ii) community-based residential facilities, and (iii) independent senior housing. The authors reported some surprising findings:

- Some apartment-style assisted living facilities are providing administration of intravenous fluids and intravenous medication (“these services seem to go beyond the scope defined by the American Health Care Association as typical of what assisted-living facilities currently provide”).
- Many apartment-style assisted living housing did not offer behaviour management services for people with dementia
- In terms of institutional characteristics, nursing homes compared favourably with regard to features such as smaller dining rooms and day rooms, secure outdoor areas, therapeutic kitchens, and controlled use of radio and TV. They were less favourable however with other features such as fluorescent lighting, call systems, and radios and TVs.

The authors make the same point as Zimmerman et al. (2003) that housing and dementia care continues to transform rapidly, with boundaries between different types and settings beginning to blur.

Overall

Croucher (2008) advocates that,

“housing with care is not a panacea for all older people’s housing, care and support needs, and the needs for alternative provision should be addressed.”

EVIDENCE GAPS IDENTIFIED – COMPARISONS WITH OTHER TYPES OF SETTINGS

- ▶ 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).
-

6.5.4 Cost Effectiveness

MESSAGES FROM CURRENT EVIDENCE - COST EFFECTIVENESS

- ▶ 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.

For older people in general, Croucher et al.’s (2006) literature review of housing with care for later life concluded that there is not yet enough evidence to be able to determine whether extra care housing is a more expensive alternative than residential care or home care. What is more, Henwood (2007) noted that the little evidence there is available relating to cost-effectiveness and extra care housing is contradictory.

A recent study carried out by Bäumker et al. (2008) assessed as accurately as possible the comparative costs before and after residents moved in to Rowanberries, a new extra-care housing scheme in Bradford. Overall costs were found to rise by an average of £90 a week as a result of moving into Rowanberries but residents experienced better social care outcomes and quality of life and reported fewer unmet needs. The cost increases were largely due to higher costs of accommodation, social care and support, however health care and informal care costs were found to fall. The authors concluded that some methodological challenges need to be overcome to allow a comprehensive evaluation of the cost-effectiveness of extra-care housing to take place.

Regarding costs to the individual, the CSIP (2006) extra care housing toolkit states that it appears that older people on low incomes living in extra care, “are left with considerable more personal allowance after meeting housing and care costs.”

Very little research evidence exists regarding the cost effectiveness for people with dementia living in extra care, although there are some interesting indicative findings from some of the small evaluation studies.

The longitudinal study by Housing 21 (Vallelly et al., 2006) showed that the average number of hours of care for some tenants with dementia in extra care schemes declined over the study period. Garwood’s case study of Duddon Mews (Garwood, 2008) determined that the specialist extra care scheme,

“clearly offers significant advantages over the alternatives for its residents. This applies at little or no extra cost to Adult Social Care for those who would otherwise be in residential care, but at greater cost

for those who would otherwise be in their own dispersed homes. Whilst more costly for Adult Social Care than standard domiciliary care in the community, it could be argued that those living at Duddon Mews are enjoying a better quality of life and benefitting from earlier recognition of signs of ill-health and greater safety and security. These in turn may be prolonging good health and well-being and delaying the need for residential care. It is difficult to prove this preventative effect. “

Garwood (2008) concluded that if the scheme had been slightly larger (twenty units instead of fourteen) economies of scale would have meant that care funding would have been more cost-effective but the scheme would have still been able to retain its homely feel.

The evaluation of Stanton Lodge (Jevons, 2008) found that, for couples wanting to live together through the dementia of one partner, Stanton Lodge was less expensive in most cases than home, residential or nursing care. Jevons explains costs are dependent on a number of variables including the future life duration of each partner, their care needs, and eligibility for public funding. However, in general it looks likely over a couple's lifetime that:

- Stanton Lodge is less expensive than remaining at home where,
 - care at night or 24 hours surveillance is needed
 - the care partner has high needs
 - the care partner dies first
 - both survive for similar lengths of time;
- Stanton Lodge is more expensive than remaining at home where,
 - the partner with dementia dies after only a short time in the scheme
 - the care partner has few care needs.

EVIDENCE GAPS IDENTIFIED – COST EFFECTIVENESS

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.
-

6.5.5 Design of the Built Environment

MESSAGES FROM CURRENT EVIDENCE – DESIGN OF THE BUILT ENVIRONMENT

- ▶ 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.

There are a lot of guidelines, recommendations and examples of good practice relating to the design of buildings and living environments for people with dementia. However, much of the information is anecdotal and, although it might be helpful, is not proven (Smith et al, 2004).

Fleming et al.'s recent literature review of the design of physical environments for people with dementia concluded that little is certain (Fleming et al., 2009). The authors state that findings from studies existing to date support the previously published 'consensus of views' on principles for designing dementia specific facilities (Marshall, 2001) which concluded that care accommodation for older people living with dementia should:

- 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.

Fleming et al. (2009) also conclude that the currently available evidence also 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.

In the context of extra care housing, it appears that sensory and cognitive impairments are not very well understood or addressed in design terms (Croucher, 2008). In their study of various extra care schemes, Croucher et al. (2007) found,

“the focus of design appears to be on wheelchair access; however, other types of disability, for example sensory and cognitive impairments, appear generally to be less well understood or addressed in design terms. Individual dwellings also need to be designed with thought given to future adaptation or installation of aids and equipment, and with thought towards how well the spaces within individual dwellings will allow carers to assist residents.”

Baker (2003) highlighted the importance of having a communal room or space which is suitable for relatives and friends to meet should they wish. Likewise, Evans and Vallely (2007a) in their literature review of *'Best Practice in Promoting Social Well-Being in Extra Care Housing'* concluded that features that are welcoming for friends and relatives should be incorporated.

Homely and pleasant environments that provide opportunities for tenants to improve their functioning and walk around with minimal risk, have been shown to lead more independence in daily activities Tilly and Reed (2008a).

The layout and design of a scheme can impact on tenants' social well-being (Evans and Vallely, 2007b). Chimes (2007) also noted in his design features for older people with dementia literature review that there were evident positive correlations between built design features and quality of life. He cautioned however,

“it is difficult to establish categorically that it is the design features that improve well-being in most cases. Other factors, such as the social environment and philosophy of care that are difficult or impossible to extrapolate may be influencing outcomes.”

The extra care housing literature review, *Raising the Stakes* (IPC, 2007), determined that evidence exists for the following success factors,

- adequate space in schemes, and in each unit
- design being closely aligned to address the needs of the scheme's population, including specialist design for dementia.

This is endorsed by findings from Hanson et al.'s (2006) extra care survey among professionals which asked what factors contributed to successful extra care schemes. Recurrent comments from respondents included,

- use good design and ensure individual apartments have plenty of space
- design schemes to be dementia-friendly throughout, and suitable for people with sensory impairments and other disabilities
- build new schemes to 'Lifetime Homes' standards
- a safe and secure environment.

Joseph's review of the literature (Joseph, 2006) looked at the relationship of physical environmental factors to resident and staff outcomes in a range of different types of long-term-care settings. Key findings were that the physical environment has an impact on outcomes for residents, their family, and staff in terms of,

- (i) resident quality of life,
- (ii) resident safety, and
- (ii) staff stress.

He identified several studies which showed that different aspects of the physical environment can have direct impact on quality of life in a wide variety of ways including,

- improved sleep
- improved orientation and wayfinding
- reduced aggression and disruptive behaviour
- increased social interaction
- increased privacy and control
- improved links to the familiar
- increased physical activity
- increased resident safety
- reduced falls
- reduced infection
- reduced 'walking around' and unsafe exiting.

In their longitudinal comparative study of seven housing with care schemes (not focused on people with dementia) Croucher et al., (2007) reached the conclusion that no one particular model stood out as being more effective although they found that making judgements about comparative effectiveness was difficult due to wide variances in design and circumstances including size, location, provider organisation, eligibility criteria, and partnerships. They felt however that larger schemes in the study had more opportunities to provide a wider range of non-care related amenities and facilities for residents. Larger schemes can also have their drawbacks. Bernard et al.(2007) found that the large size of the building at Berryhill, and the similarity of its various corridors, could be disorientating and confusing.

Messages from Single UK Evaluation Studies of Extra Care

The evaluation of Portland House (Scott, 2004) found it was advantageous to have two small dining areas attached to two kitchens to serve four tenants each, and that replacing cupboard doors with see-through ones would help the tenants to locate equipment in the kitchens.

Cantley and Cook's 2006 evaluation of Moor Allerton (an MHA extra care site in Leeds) found that there was, "consensus that all three units in the Centre are well designed, comfortable, clean and homely" and that, "dementia-friendly design

features ... are a positive feature” although the length of the corridors (a design compromise due to constraints of the site) was problematic for some tenants.

Recommended improvements for the dementia-specialist extra care scheme were to have,

- shorter corridors
- no ‘dead ends’
- better visual access to communal areas
- provision of two-bedroom flats for couples
- larger kitchen on each floor, where tenants and staff could cook meals together (the tenants with dementia were found to make little use of their own kitchens).

Tenants were generally very positive about the quality and facilities of their flats at Moor Allerton. To further increase satisfaction, Cantley and Cook (2006) recommended that tenants should have the option of having a flat with a bath as well as a shower. This is reinforced by findings from the evaluation of the MHA’s new Stanton Lodge extra care scheme for couples where one has dementia (Jevons, 2008) where the ‘wet room’ style shower rooms within individual apartments are widely disliked by residents who preferred instead to use the baths in the shared bathrooms.

In the case study of Duddon Mews, an extra care scheme for people with mental health conditions and physical frailty, Garwood (2008) found that positive features included,

- the small size of the scheme (fourteen properties) which, “facilitates a warm friendly atmosphere and tailored personalised service provision. It is also small enough to aid orientation and feels very homely”
- bed occupancy sensors, which were useful for some tenants
- the attractive, secure garden which provided a safe area for tenants to walk or sit down as well as opportunities to take part in gardening activities.

Some drawbacks and improvements identified regarding design included,

- although having smaller communal lounge and dining areas can create a more homely feel, it can be restrictive in terms of community life if they are too small for all tenants to meet together at once
- flats which had no proper cooking facilities (e.g. have mircrowaves only), particularly where there are no communal cooking facilities, reduce tenants’ choice and opportunities to (re-)gain independence
- the lack of a communal toilet meant that tenants and their visitors have to return to their flats when using the communal areas
- the staff office needs to be large enough to accommodate all necessary staff and ideally another private space should be available for private meetings, or for staff to be able to have a break.

The Stanton Lodge evaluation (Jevons, 2008) found that tenants liked the common areas and grounds of the extra care scheme and they were generally satisfied with the design of their flats and the fittings. Those showing most satisfied lived in a one bedroom flat, or a large two bedroom flat. The smaller two bedroom flats which had a combined bedroom and living area were generally disliked. Residents were more likely to feel satisfied with their particular flat if they visited it prior to occupation and made the ‘choice’ themselves.

Regarding the isolated location of the scheme there were mixed views, but most residents and their relatives did express a preference for a site which had easier walking access to local facilities.

Stanton Lodge has two lounges which are both used for informal gatherings and formal activities. These were liked by tenants as spaces where small numbers could meet together. However, as other studies have found, tenants did not like the fact that there was nowhere big enough for all from the scheme to meet together at one time.

Orientalional and VisuoPerceptual Considerations

People with dementia often experience a number of changes in visual abilities including difficulties with depth perception (e.g. 'visual cliffing', a misinterpretation of colour as difference in depth), contrast sensibility (making it difficult to identify objects against a similar colour background), glare, and visual misinterpretations such as illusions (misinterpretations of common objects) (e.g. Warner, 2000; Bakker, 2003).

Strategies likely to enhance orientation and way finding in buildings generally include the use of distinguishing colours, landmarks and signage. For example, Nolan et al. (2002) evaluated the effect of using portrait-like photographs and personal memorabilia as orientation cues outside residents rooms in a nursing home. They found that average success in room finding increased by 45%. Environmental modifications that make the environment easy to understand have been shown to help with residents' basic physiological needs (Tilly and Reed, 2008a).

Jones and Van der Eerden's paper (2008) provides insights from several fields in considering visuoperceptual requirements for specialist dementia care environments in the UK. They reported that the body of literature regarding the design of optimal dementia care environments is growing rapidly in the UK and elsewhere, but it is still a young field. Currently evidence suggests that important design priorities that assist vision are lighting, signposting, the use of colour, the use of colour contrast, and the use of artwork and memorabilia.

Memory boxes are becoming a popular wayfinding tool in extra care. Brawley (2006) comments on the widespread use of memory boxes in dementia care settings as an aid for cueing. She points out however that there is little research or evidence to show that they have such an effect, and that,

"Many are too small, poorly lit, or filled with items that hold no special significance for the resident. Using identical items beside each door diminishes the usefulness of the memory box as a distinctive cue."

The effect of colour is highly complex and people's perceptions and responses will vary depending on aspects such as location, age, condition, physiology, culture, and personal experiences. Scientific research on the use of colour in health, care and housing settings is very limited and there is still little understanding of what effect colours have, and how (Smith et al., 2004).

Other studies have shown that improving lighting in homes of people with dementia can have wide-ranging effects including improvements in appetite, health, and self-confidence, and decreased incidence of loneliness, temper, anxiety and falls (e.g.

LaGarce, 2002; Joseph, 2006). Smith et al. (2004) note that, “it is important to combine the visual stimulation from healthy lighting with other sensory stimulations—aroma, sound, and touch—and synchronize all of them with the human biological clock”.

EVIDENCE GAPS IDENTIFIED – DESIGN OF THE BUILT ENVIRONMENT

“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 identify 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).

6.5.6 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.
-

In the *'Opening Doors to Independence'* study of Housing 21 extra care schemes, 21 residents with dementia died over the period of the study (Vallelly et al., 2006). Most of these (62%) died in hospital having been admitted a few days previously due to sudden illness. 90% of those who died had dementia and other health conditions when they had moved in to extra care.

A service improvement project designed to enhance dignity and choice in end of life care was carried out and evaluated in three Housing 21 extra care schemes (Easterbrook and Vallelly, 2008). Based on the findings, the authors conclude that, "a 'one size fits all' model is not appropriate". Their recommendations for improving end of life care in extra care housing schemes included:

- Ensure specialist support can be accessed for people with dementia so that choices can be communicated and recognised.
- The issue of end of life care should be incorporated into existing policies and practices. A simple question, for example, could be included in existing care and support plans.
- Begin with what is straight forward and feasible in the local context.
- Strive to ensure that both the housing and care providers are at the same stage regarding their approaches to personalising support.
- Provide opportunities for tenants and their families to discuss and record their wishes, but questions or forms should not be compulsory.

In an American study, Sloane et al. (2008b) investigated¹¹ the experiences and potential unmet need of persons who die in long-term care settings, including assisted living facilities. The results suggested that the overall quality of care for people dying in long-term-care settings does not noticeably differ if a person has dementia (Engel et al. (2006) reported similar findings). Within the RC-AL settings however, residents with dementia tended to have more skin ulcers and poorer hygiene care than the residents without dementia.

Irrespective of setting, no differences were found between deceased persons with and without dementia in terms of,

- pain (although this was slightly higher among persons with dementia, but not significantly)
- psychosocial status
- family involvement
- advance care planning
- most life prolonging interventions
- and hospice use.

Across all settings, when compared to residents without dementia, residents with dementia who were dying were found to,

- have less shortness of breath
- receive more physical restraints and sedative medication
- use emergency services less frequently on the day they died
- be less likely to die in a hospital.

In the RC-AL facilities, the overall quality of palliative care for people with dementia in was found to be comparable to that in nursing homes. In addition, those dying with dementia in RC-AL facilities tended to be,

- restrained less often
- have emergency services called more often on the day of death
- and have family more satisfied with physician communication.

The authors commented that the high rates of physical restraint and sedative use identified among persons with dementia were troublesome findings. In contrast, the high rates of hospice service use in both the RC-AL settings (65%) and nursing homes (55%) were,

“particularly refreshing, as this indicates a marked trend upward from the virtual non-use by persons with dementia reported by Hanrahan and Luchins in 1995 and the lower rates that we identified 5 years prior to the current study.”

They questioned whether hospice services were called in early enough for people with dementia, a major issue for quality end of life dementia care emphasised in the clinical practice guidelines developed by the National Consensus Project for Quality Palliative Care (National Consensus Project, 2004).

¹¹ The authors conducted afterdeath interviews with staff who had cared for 581 people (422 of whom had dementia) who had been receiving terminal care in USA nursing homes or RC/AL settings. They also carried out interviews with family caregivers for 293 decedents.

Tilly and Fok (2007) interviewed physicians, researchers, social workers, nurses and other experts involved in provision of end of life care to people with dementia in assisted living and nursing home settings. They found strong agreement among the experts regarding,

(a) the key characteristics of good end of life care for residents with dementia:

- communication and advance planning for care
- person-centered approaches
- involvement of families as early as possible in decisions about care for their loved ones.

(b) what providers must know:

- about the residents and their lives before acquiring dementia
- how to communicate with residents
- how to assess needs and manage symptoms at the end of life
- how to educate families about dementia as a terminal condition and about what they should expect as a person draws closer to death.

EVIDENCE GAPS IDENTIFIED – END OF LIFE

- ▶ 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.
-

6.5.7 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.

Can Extra Care Be a Home for Life?

Research evidence to date suggests that, while extra care is providing a home for life for a large number of people with dementia, not all needs can be met by all schemes, and there are many examples of cases where symptoms and/or effects of dementia cannot be managed by staff, and in some cases cannot be tolerated by other tenants. Inability to support people with advanced dementia is usually due to capacity and availability of services and balancing their needs with the needs of other tenants.

This is reflected in the 2006 *‘Wanless Social Care Review – Housing Options for Older People’*,

“Despite the various benefits, for a proportion of residents, extra care housing cannot provide a home for life, and a final move into residential care may become inevitable. Although extra care housing normally has 24-hour onsite care, it does not provide the same level of support as the care home model, which is designed specifically for people who have unpredictable and continuous need – particularly people with severe dementia” (Poole, 2006).

The Impact of Dementia

The three year longitudinal study of people with dementia living in Housing 21 extra care schemes demonstrated that tenants with dementia are able to live independently nearly as long as those without dementia, suggesting that, “dementia alone does not have a negative impact on a person’s potential to live independently in extra care housing” (Vallelly et al., 2006). The study found that extra care schemes were providing a ‘home for life’ for around half of their tenants who had dementia, despite them typically having high dependency needs, other health conditions as well as dementia, and being 85 years or older when they moved in.

Reasons for People with Dementia Having to Move Out

The survey carried out as part of the ‘Raising the Stakes’ study in 2007 revealed that 86% of extra care scheme managers felt their schemes were able to support ‘high levels of care and support needs’. However, 77% felt they were unable to support ‘high levels of dementia’ and the same proportion felt they were unable to support ‘nursing care needs’.

The ‘Living at Hartrigg Oaks’ evaluation (Croucher et al., 2003) found that tenants with severe dementia were cared for off site in NHS specialist dementia facilities. The authors questioned the capacity of current services to care for people with more severe dementia and highlighted that to do so would have, “implications for the ambience, management and costs of living at Hartrigg Oaks”.

The *Opening Doors* study of tenants with dementia in Housing 21 extra care schemes (Vallelly et al., 2006) determined that, of the tenancies that came to an end during the three year study, around half moved out and most of these moved into nursing homes. Reasons for tenants with dementia having to leave extra care

schemes were identified as: risk, 'challenging behaviours', distress, and conflict with staff and other residents. Worsening dementia was a factor in 41% (9 cases) of moves into nursing care.

Vallely et al. (2006) also found that impeding the ability of extra care to provide a 'home for life' were complexities relating to how long term care is funded. The report gives the example of a tenant whose place in the extra care scheme is funded by a local authority. When she developed a serious illness the authority wanted her to be transferred to a nursing setting which would mean that funding would no longer come from social care budgets. The authors point out that,

"Continuing care funding should be available in any living environment and is not limited to care homes or hospices so there has been some confusion about the application of this policy".

Garwood (2008) compared the number of tenants who had moved elsewhere to the number who died as tenants at Duddon Mews which aspires to provide a home for life to all tenants. Since April 2005 nine tenancies had come to an end: four people had died whilst tenants at the scheme, and five had moved elsewhere.

The five who had moved elsewhere:

- One moved to live with relatives;
- The mental illness of another deteriorated and she was assessed and moved to an EMI nursing unit;
- The remaining three moved in to residential care, following a stay in hospital, due to significant increases in risks and care needs both physically and mentally. It was also identified that these people required 24 hour observation which could not be offered within this setting.

Similar findings were identified in a survey of Hanover extra care schemes carried out in 2002 (Baker, 2003). Most residents with dementia who moved out of schemes had severe dementia (around 62%), although some had moderate dementia. Residents moved on to residential or nursing care (sometimes after a hospital admission) or "Elderly Mentally Infirm" (EMI) units.

In the survey, the most common reasons given by scheme managers for people with dementia moving on were carers' time (57% of schemes), and residents with dementia being unable to cope, or being seen as presenting a risk to themselves (43% of schemes). In a number of schemes, other residents' concerns over the welfare of a resident with dementia had been a contributory factor. Hostility from other residents was a contributory factor for 24% of schemes relating to diagnosed dementia. Few estate managers saw demands on their time as being a contributory factor in any residents with dementia moving on (Baker, 2003).

Croucher et al.'s (2007) comparative study of seven extra care schemes reported that supporting people with dementia and/or chronic and life limiting illnesses in extra care could be difficult. In common with other studies, the most commonly agreed challenge for schemes was the capacity to care for tenants who develop dementia,

"agreed points of strain for all service sectors within schemes were around behaviour which became challenging in some manner. Wandering behaviours were a particular concern, as were what staff

perceived as the misuse of alarm cords, particularly during the night when there was sleeping night cover”.

Although most of the schemes could support people who were becoming confused or forgetful, only one of the seven extra care schemes in the study could, “provide care for people with more challenging and difficult behaviours and this was within the care home element of the scheme”. The care services all seemed to be geared much more towards supporting people with physical disabilities and illnesses than towards the needs of people with mental health conditions including dementia (Croucher et al., 2007).

The authors found that all seven schemes, “were reluctant to initially select residents who suffered with dementia, although there was a general will to provide for those residents who developed dementia-type illnesses while they lived in the scheme”. One of the schemes had invested considerable resources in dementia services, including providing training for staff and awareness raising among residents. This was found to have had a positive impact on both staff and residents.

These findings from UK studies are analogous to those from American studies of people with dementia living in assisted living facilities. Hawes et al. (1999) found that more than 50% of assisted living facilities would not retain residents with moderate to severe cognitive impairment, with 76% of the facilities citing behaviours that challenge as the most common reason for discharge. Kopetz et al. (2000) reported that significant predictors of move-ons were depression, falling, and walking about. Transfer triggers identified in a survey conducted among ten South Carolina ALFs (Kelsey et al., 2008) included tenants leaving a facility without anyone’s knowledge, disturbing behaviours, and increased care needs.

A longitudinal study (Ball et al., 2004) found that more than one third of move-ons were the result of confused, disruptive, or risky behaviours related to dementia or mental illness and that, “wanderers typically were dealt with speedily”. A review of assisted living research (Mead et al.’s, 2005) concluded,

“needing more care than the facility could provide, specifically related to behavioural, medical, and functional problems, was the most frequently cited reason for discharge.”

A key factor influencing whether ALFs in the USA can offer a home for life are the regulatory requirements for admission and retention which vary considerably for each state. These specify the characteristics of residents who can live in assisted living, and the types of services that can be provided for them (Mollica and Jenkins, 2001). Ball et al. (2004) write, “Although many states include a general statement that facilities must have the capacity to meet the needs of their residents, only a few allow residents who need continuous skilled nursing care, are bed bound, or require a two-person transfer.”

The Concept of Independence

Promoting independence is a core concept of extra care housing. Some staff in Croucher et al.’s (2007) comparative study raised the issue of whether ‘independence’ was a realistic objective for people with dementia. This viewpoint was also found among some respondents to the survey carried out among housing

and care professionals (Hanson et al., 2006), that self-contained flats might not necessarily be an appropriate living solution for a person with dementia.

In the '*Housing choices and aspirations of older people*' report, Croucher (2008) points out that there is an,

“inherent tension between the promotion of independence and the needs of some very frail older people, and the need for appropriate support (as opposed to care) services to sustain the concept of independence.”

This was also raised in the *Opening Doors to Independence report* (Vallely et al., 2006) which observed that it is not always easy to determine how much independence a potential resident desires, given the complexities of health, cognitive and frailty issues. Previous experiences can have an influence on what people expect or can cope with. For example, some people who moved into an extra care scheme from residential care found it difficult to adapt to living independently, and some felt isolated in their flats. The provision of appropriate support from staff in helping people to regain independence is crucial. Evans and Means (2006) recommend using person-centred risk assessment strategies in order to maximise independence for people with dementia in extra care housing.

Accommodating Couples

Findings from a recent evaluation of Stanton Lodge (Jevons, 2008), a new extra care scheme for couples where one has dementia, suggest that,

- “Couples have tended to move to Stanton Lodge at times of poor health resulting in a relatively short period of residence before the death of one partner. The earlier a couple can move before a health crisis forces a change in previous residence, the greater the benefit of living as a couple in the supported environment which Stanton lodge can provide.
- Although tested out in very few circumstances, experience to date shows that individuals with dementia do not need to move to other forms of care if they outlive their caring partner. Remaining at Stanton Lodge with additional care is a realistic choice for them.
- Similarly, remaining at Stanton lodge is a realistic choice for care partners who outlive their partner with dementia. “

The author concludes that Stanton Lodge is proving of particular value for couples where both partners have high care needs, and that it is paramount that extra care schemes such as Stanton Lodge are able to accommodate a variety of high care needs as well as dementia (Jevons, 2008).

Tenant Expectations and Concerns

Initial findings from the *Evaluation of the Extra Care Housing Funding Initiative* (Darton et al., 2008) (not dementia-specific) found that over 90% of residents expected to live in their extra care accommodation for as long as they wanted to. 30% of residents with current care needs reported that they did not intend to move

on. Of those currently without care needs, 88% thought that the need to move into a care home was a very unlikely future possibility but did not rule it out.

At Berryhill retirement village, one in five residents had concerns about what would happen to them if their future physical and mental health needs could not be met on-site (Bernard et al., 2007). At Hartigg Oaks, some residents were concerned that they might have to leave if they became cognitively impaired. Couples particularly worried about potential separation (Croucher et al., 2003). The same uncertainties are also faced by residents in AL schemes in the USA (Croucher, 2006).

Hartigg Oaks tenants had mixed opinions about the appropriateness of people with dementia having to move away from the scheme. Some felt it better to be moved to a specialist care setting, whilst others felt that the required specialist care and support should be available within the scheme (Croucher et al., 2003).

What Works in Extending Lengths of Tenancy and Maximising the Probability of a Home for Life?

Care services provided from within and outwith the extra care schemes are very important

Overall findings from the evaluation of Duddon Mews extra care scheme (Garwood, 2008) were that it looked to be providing a home for life for at least some tenants with dementia,

“the scheme clearly caters for people with a wide range of needs, some with high levels even at the point of entry. It provides them with a quality, individually tailored, specialist service. Some may be able to reside there for the rest of their lives, so not having to move away”.

One specific enabler at Duddon Mews was found to be the involvement of the Older People’s Community Mental Health Team who sit on the allocation panel, actively support both tenants and staff, and were involved initially in the development of the scheme.

The ‘*Raising the Stakes*’ literature review (IPC, 2007) reported evidence that the success of schemes is dependent on the ability of care and support to be adapted around the individual, and that the ability of a scheme to provide a home for life is dependent on, “the package of care that is set around the scheme.” A home for life cannot be guaranteed as, “social services, and health services may not be able to support a person with high care needs indefinitely.”

Assisted living care staff in Ball et al.’s (2004) longitudinal study were not allowed (by regulation) to provide skilled nursing or medical care, but each ALF had a significant role in tenants’ health care and health promotion, both of which are essential for managing resident decline,

“These roles entailed direct provision of services and facilitation of access to other health care providers and included medication management, consulting with physicians and pharmacies, monitoring conditions and treatment regimens, responding to

health crises, transportation to medical appointments, and arranging for home health care” (Ball et al., 2004).

Transparent entry criteria

Criteria or guidelines for entry to a scheme for people with dementia and/or other health issues need to be as transparent as possible but there also needs to be an emphasis on the importance of individual assessment and flexibility (Garwood, 2008).

CSIP (2006) recommends that schemes make a distinction between permitting people who already exhibit dementia symptoms to move into a scheme, and encouraging occupants who develop dementia to remain in a scheme.

Move in before it is too late

The ability to support an individual with dementia is greatly increased by an early move into a scheme, whilst they still have the understanding and capacity to develop relationships and adapt to new surroundings, albeit with support (CSIP, 2006). If a person who is already living in extra care housing develops dementia then it is more often possible for them to remain living in the accommodation (Poole, 2006).

Availability of specialist facilities

Croucher (2006) considers that retirement villages have an advantage in that it becomes more viable to have specialist care staff and specialist on-site facilities to care for people with dementia. In the author’s experience,

“larger communities also appear to have more capacity to absorb the problematic behaviour of a few individuals, whereas the problematic behaviour of one or two individuals within a smaller setting can be very dominating. Nevertheless, dementia sufferers can cause considerable anxiety and distress to their fellow residents, whatever the setting.”

Treatment of dementia, activity participation and improved mobility

The findings from the Maryland Assisted Living Study (MD-AL) indicate that having dementia is a major determinant of outcomes in residents of ALFs,

- dementia shortens the predicted time to moving out from the ALF (by an average of 209 days)
- treatment of dementia, activity participation and improved mobility may lessen this effect.

“These findings are cause for optimism by suggesting that the detection and treatment of dementia with currently available pharmacological and non-pharmacological means may make a real difference for AL residents.” (Lyketsos et al., 2007)

Accessibility

Accessible features including level entrances, a single-story construction or otherwise lifts, handrails, wide doorways, walk-in showers, and grab bars enable

tenants with gait, balance, grasp, and mobility difficulties to function more independently and safely (Mollica and Jenkins, 2001).

Facilitating family support

Families can play a key role in filling care provision gaps, and tailor their involvement in accordance with the needs of the resident and the setting (Port et al., 2005).

Managing Decline: Findings from a Large Scale Assisted Living Ageing in Place Study

Ball et al.'s study¹² *Managing Decline in Assisted Living: The Key to Aging in Place*, (Ball et al., 2004) was the first longitudinal study to examine in depth the process of ageing in place in ALFs. This included ALFs where residents have their own apartments. The study concluded that the ability of ALFs to support residents' was largely determined by the ability of both residents and facilities to manage decline. The capacity to manage decline, both preventing decline and responding to it, was influenced by many factors associated with the community, facility, residents, and the 'person–environment'¹³ fit'.

A key component was found to be family support, which came mostly from daughters. Family support, "often tipped the balance between retention and discharge". Examples included: one lady helping her mother to get ready for bed every night; another helped with washing and dressing every morning and took her mother to dialysis three times weekly when her kidneys began to fail. Other family members,

"paid bills, managed medications, monitored conditions and care, encouraged compliance, and provided assistive devices. Many offered critical emotional sustenance. Such support extended residents' AL tenure and maybe their lives". (Ball et al., 2004).

Some tenants with dementia were also given regular support from other residents, such as wake-up visits every morning, and being taken down to meals.

Some negative aspects resulted from keeping tenants in place as they declined, both for other tenants and for the facilities themselves, to the extent that, "when care needs were especially high, some residents experienced physical and social neglect" (Ball et al., 2004).

In one apartment style ALF, high ADL needs, particularly incontinence care, invariably led to discharge. The availability of other community options facilitated discharge of 'unwanted residents'. For example, all residents who left one of the apartment style ALFs went either to the adjacent nursing home owned by the same company, or to another nearby ALF.

¹² Tenants were tracked in five ALFs over a one year period. The researchers carried out participant observation, interviews with providers, residents, and residents' families, and reviewed records.

¹³ 'environment' encompassing both physical and social dimensions as well as facility and community factors

Overall the study highlighted,

- the complexity of ageing in place in ALFs
- the importance of a coordination of efforts between the facilities, residents, and families in managing decline of the resident
- the need for residents and families to be well informed about both their own needs and the capacity of a facility to meet them.

Challenges for the Future

Mitty and Flores (2007) write in their paper *Understanding Defining Characteristics of Assisted Living*,

“ALFs must continue to find innovative ways to meet the increasingly challenging needs of their residents. Some areas of particular need include medication management, end of life and hospice care, and care for the cognitively impaired ... Addressing cognitive decline is perhaps the most significant challenge assisted living faces in terms of comprehensiveness of care.”

This applies equally to extra care housing in the UK.

EVIDENCE GAPS IDENTIFIED – HOME FOR LIFE

- ▶ 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.
-

6.5.8 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.

There is much debate as to whether people with dementia are better off living within a general extra care scheme, or separately in a specialist area or wing, or in a building solely for people with dementia, and which approach is preferable for other tenants, and for the management of support and care.

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 can 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.
-

The Integration Model

Advantages of Integration

Identified advantages of an integration extra care model include:

- People with dementia have additional opportunities for stimulation, social integration and support from other residents.

The ‘*Opening Doors to Independence*’ study, where the majority of extra care schemes had an integrated design, found close friendships had developed between some tenants and their neighbours who had dementia. Other tenants, “felt they were aware of problems associated with memory loss and went out of their way to be kind and supportive” (Vallelly et al., 2006).

The *Living at Hartrigg Oaks* study found,

”Some residents did report more positive attitudes towards other residents who had early stage dementia. This seemed to be particularly the case when someone was in a seemingly benevolent state” (Croucher et al., 2003).

- Other residents without dementia can enjoy ‘looking after’ and ‘looking out for’ cognitively impaired friends and acquaintances and benefit from feeling they have a useful role.

Shortcomings of Integration

Current evidence indicates that, overall:

- Integration has more disadvantages for tenants without dementia.

Ball et al.’s (2004) longitudinal study in the USA found that very frail or confused residents altered the physical and social environment and that sometimes upset or created barriers for residents without dementia. One person living in an apartment-style ALF said of one tenant who had dementia, “I just feel this isn’t the place for him ... It’s maybe not quite the atmosphere I expected.” Other studies of ALFs in the USA have found residents without dementia preferred to be separated from residents with dementia .e.g. Dobbs, 2004. O’Malley and Croucher (2005) concluded in their literature review of

housing and dementia care that, “integration is unpopular and problematic for non-demented residents.”

There have been similar findings in retirement village settings in the UK. At Berryhill, Bernard et al. (2007) established that, “the habit of ‘wandering’ of some people with a dementia was not acceptable in the Village, because other residents and staff found it difficult to cope with”. The authors stressed that mixing ‘fit’ and mentally ‘frail’ older people in one community raised issues. Likewise, Henwood (2007) warns, “the implications of mixing people with physical, sensory or cognitive impairments with others need to be addressed.”

- The advantages it offers those with dementia diminish over time as their cognitive impairment increases.

Molineaux and Appleton (2005) argue that those with severe cognitive impairment need high levels of care and have a very limited capacity to take advantage of the facilities offered by extra care schemes.

There is an argument that people with dementia should be accommodated in integrated extra care models because separating them reinforces discrimination (Molineaux and Appleton, 2005). It is possible that this is the case but some studies have shown that discrimination can also occur within integrated schemes, e.g.

“Difficulties for some residents in living alongside people with dementia were reported by both staff and residents. Staff reported that one resident with early stage dementia sat alone in the coffee shop as no one would sit with her” (Croucher et al., 2003).

The Dementia-Specialist Models

Prevalence and Characteristics of Specialist Cluster/Units or Schemes

In the USA many ALFs set aside floors, wings, and sometimes entire buildings specifically for tenants who have dementia. The literature review carried out by Hyde et al. (2007) identified:

- There are signs that the size of facilities are reducing. An overview by the Assisted Living Federation in America (ALFA) in 2006 reported that dementia-specific facilities had an average size of 39 units, 17% fewer than they had reported in a similar study six years earlier. Also, in 2006, non-specialist assisted living facilities had an average of 52 units and buildings housing both general and dementia-specialist sections had an average of 92 units, 22 of which were in dementia-specific wings.
- Keane et al.’s (2003) study of assisted living facilities found that 12% were stand-alone buildings specifically for people with dementia, and 34% were general ALFs with a specialist dementia unit. Of the other general ALFs
 - 9% had a specialised program but with no separate unit,
 - 20% offered some type of dementia services,
 - 6% had other dementia arrangements, and
 - 27% had no specific programs or services for people with dementia.

Advantages of Dementia-Specialist Cluster/Units or Schemes

Dementia-specialist models are liked by residents and their families, and they provide a useful option for some commissioners in the context of local dementia services (Cox, 2007).

Some researchers have advocated that care provided in settings dedicated to people with cognitive impairment is the best option, if resources allow, although this model is usually more costly and does not necessarily provide better care than integrated settings (e.g. Reimer et al., 2004).

There are some indications that specialist approaches may be able to sustain people longer in an independent setting (CSIP, 2005) and that non-specialist extra care schemes may lack the capacity, expertise and resources to accommodate people with dementia over the full course of illness (IPC, 2007).

One of the extra care schemes included in the *'Opening Doors to Independence'* longitudinal study had a specialist cluster of eight flats for people with dementia (two designed for couples, with two-bedrooms) accessed through security doors (and not open to residents from the rest of the scheme). The cluster also had communal seating areas, a dining facility, and a residents' lounge. The evaluators identified benefits of such a specialist cluster compared to an integrated design to be that,

- specialist care and support can be directed towards those people most in need
- fewer tenants with dementia moved on to other care settings, although having limited alternatives due to a rural location may have influenced this
- tenants' walking about can be supported and orientation difficulties are less problematic.

The case study of Duddon Mews (Garwood, 2008), a specialist extra care scheme for people with mental health conditions and physical frailty, reported similar benefits and that a specialist scheme enables a focus on dementia training and enhancement of skills.

Shortcomings of the Dementia-Specialist Models

Limitations of the dementia-specialist models were identified by Vallely et al. (2006) as,

- partners without dementia living in flats for couples can find the cluster to be a constraining environment
- because tenants in the extra care scheme outside of the cluster also have memory difficulties it can make it difficult to target intensive care and support to tenants in the specialist cluster.

Anyone in early stages of dementia may be unwilling to move into a specialist unit (Molineaux and Appleton, 2005).

Effectiveness and Cost Effectiveness

No studies were found specific to extra care which compared integration with dementia-specialist models. However, a great deal of research has been carried out on the characteristics and effectiveness of Special Care Units (SCU) (specialist

dementia units) in USA nursing homes since they became a popular feature in the 1980s, and much of it of has direct relevance to dementia services in extra care settings. Hyde et al. (2007) conclude,

“Overall, although providers and experts generally believe that SCUs offer benefits to residents, most of the research on SCUs in nursing homes has found that living in an SCU does not, in itself, appear to lead to better outcomes (Chappell and Reid, 2000; Phillips et al., 1997). For example, a study of the advantages of mainstreaming versus living in a special unit in assisted living (Kuhn, Kasayka, & Lechner, 2002) suggested that mainstreamed residents might be more engaged in social activities.”

Hernandez (2007) carried out a study of assisted living and residential care in Oregon where he interviewed state officials, operators, developers, lenders, and consumer advocates. He reported that specialist unit operators preferred to be licensed as a residential care facility because the assisted living facilities which required single occupancy, private bathrooms and kitchenettes were,

“neither cost-effective nor desirable for residents with dementia.”

EVIDENCE GAPS IDENTIFIED - INTEGRATION VERSUS DEMENTIA-SPECIALIST MODELS

- ▶ 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 models¹⁴.

¹⁴ 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).

6.5.9 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.
 - ▶ 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 hair dressers, 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.
-

There are positive messages from recent evaluation studies of extra care schemes regarding the impact of, and satisfaction with, the core concepts of extra care.

Example 1: Moor Allerton

Overall findings from the evaluation of the MHA Moor Allerton extra care sites in Leeds (Cantley and Cook, 2006) which has a specialist dementia scheme included,

- “the philosophy and culture of the Centre with its emphasis on community, individualised care, choice, and empowerment of service users is highly valued”
- “the Centre is widely regarded as providing high quality care that is flexible, responsive and promotes independence”
- “the approach to dementia care emphasises individuality, personhood and ‘normalising’ the lives of people with dementia”
- “Service users and their families gain a welcome sense of security from the services, particularly from the staff cover and assistive technology provided in the extra care housing.”

Staff at the dementia-specialist scheme at Moor Allerton found that having a café on site can make it difficult for them to encourage tenants to prepare meals for themselves and were concerned that this could accelerate the loss of tenants’ skills and abilities. The scheme was considering installing cookers in lounge kitchen areas so that staff would be able to cook and bake together with tenants.

GPs who had regular contact with tenants in the Moor Allerton extra care schemes were generally very positive about them. GPs felt it very helpful being able to have staff accompany them when visiting tenants with dementia (Cantley and Cook, 2006). GPs, community nurse and social workers were all very positive about the services provided and about their working relationships with staff.

De Montfort University’s (2007) more recent study of Moor Allerton found:

- Staff value the person centred approach as they feel able to help people achieve what they wanted in their lives.
- Staff have good relationships with residents and like to do extra things for them in their own time. They feel that building relationships supports people better, and also increases their confidence and reduces stress.
- Families can be risk-averse and block certain activities.

Example 2: Stanton Lodge

Findings from the evaluation of Stanton Lodge, an extra care scheme for people with dementia and their partners (Jevons, 2008), indicated that:

- The support and care services provided from the well-being package, the meals service, and the additional personal care and domestic care services are all of high quality, appropriate and responsive to people’s needs.
- The additional personal care and domestic care services offered are well regarded. For tenants with high care needs they offer a cost effective supplement to the well-being package.
- The precise nature of the well-being package should be clarified as some residents did not recognise themselves as being recipients and consequently felt it to be a compulsory charge for a service not required or used.

- The respite care available for partners within Stanton Lodge, which includes an intensive activities programme, provides a good model of respite care for future schemes.

Outcomes of Care Approaches

Zimmerman et al. (2005) evaluated the dementia care and quality of life of residents with dementia in 35 RC/ALFs and 10 nursing homes in four American states. They collected cross-sectional information at baseline and at a 6 month follow-up. They found:

- Changes in quality of life were better in facilities which,
 - had better resident–staff communication including increased levels of communication, positive person work (positive interactions between staff and resident) and physical contact, and fewer personal detractors (staff behaviours that demean or depersonalise)
 - used a specialised worker approach
 - trained more staff in more domains central to dementia care (depression, pain, behavioural symptoms, ambulation, nutrition, and hydration)
 - encouraged activity participation.
- Residents perceived their quality of life as better when,
 - staff were more involved in care planning
 - staff dementia-sensitive attitudes were more favourable.
- More stable resident–staff assignment was related to lower quality-of-life ratings from care providers.

Implications of their findings for practice are that,

- improved training and deployment of staff can lead to improvement in resident quality of life
- schemes should involve staff in care planning, encourage care providers to feel more hope, and avoid antipsychotic and sedative hypnotic medications where possible
- staff should increase levels of communication, and communicate more positively, with residents.

Tilly and Reed (2008a) carried out a literature review on *intervention research on caring for people with dementia* in assisted living and nursing homes. The studies they reviewed provide evidence of interventions that can be used effectively in dementia care settings, including extra care type housing, and have beneficial effects, including:

- *Physiological interventions*
 - Verbal prompting helps maintain independence in eating and drinking leading to increased food and fluid intake.
- *Hygiene and Personal Care*

- A pleasant environment facilitates bathing and minimises residents' aggression and agitation
 - Tailored interventions focusing on an individual's capabilities can promote independence in dressing
 - Skill training can improve residents' Activities of Daily Living functioning.
- *Psychosocial and behavioural symptoms*

A diverse range of methods for reducing agitation and aggression have been shown to be effective, such as

- Minimising disruptive stimulation, (e.g. excessive noise) and providing bright, entertaining areas for residents
- Well supervised and trained staff (including training in managing behaviours associated with dementia) who know their residents and interact well with them.

Another large study by Zimmerman et al. (2008), *The Dementia Care project*, studied the care and quality of life of 421 residents with dementia in the USA from 35 residential care/assisted living communities (many of these were apartment-style ALFs) and 10 nursing homes in Florida, Maryland, New Jersey, and North Carolina. Data collected during the study related to care, training, practices, and resident quality of life. They found for all facility types that,

- treatment for food and fluid intake is the least common, and treatment for behavioural symptoms is the most common
- staff reports indicated that around 22% of residents were experiencing pain whereas resident reports indicated 33% were in pain.
- Among residents where the staff recognised pain, approximately 25% had no professional assessment, and 40% were not receiving pain medication
- staff who have more training and better attitudes have more job satisfaction
- "residents who consider their care to be better (eg, report that staff smile at them, listen to what they say, and understand them) also report a better quality of life".

Positive effects were found where,

- more supervisors are trained to assess and manage behavioural symptoms
- there is more accurate assessment of depression
- there is more family involvement regarding activities
- staff are aware when treatment for pain is successful
- the environment aids mobility
- a more homelike environment encourages food and fluid intake.

The study demonstrated the importance of,

- a focus on behavioural symptoms, food and fluid intake, and social engagement,
- staff training in dementia care (including behavioural and depressive symptoms and pain)
- person-centered care attitudes and practices
- positive interactions between staff and residents

- the involvement of family in matters related to activities, resident grooming, and involving staff in care planning
- assessment and treatment for pain.

The authors point out that,

“No single component or set of components define “good” care, and that recommendations should not focus narrowly on any one area to the exclusion of others.” (Zimmerman et al., 2008).

Levels of Care

In a review of dementia care in ALFs in America Hyde et al. (2007) reported that residents with dementia require on average two hours per day more care than those without dementia. The authors raised concerns about whether current staffing levels in ALFs were adequate to provide appropriate dementia care.

Similar concerns are being raised in the UK. The Wanless review of housing options for older people Poole (2006) recognised that increasing amounts of care are needed as dementia worsens and this leads to complexities in terms of affordability and feasibility of providing this in an extra care setting,

“A higher level of care is necessary in order to enable someone with moderate to severe dementia to remain in an extra care setting. Local authorities are sometimes unenthusiastic about providing this extra care. The higher level of care also potentially creates a grey area over the question of whether the extra care facility is providing a level of care more normally associated with a care home. According to the Department of Health guidance, having a valid tenancy is fundamental to the distinction between housing and residential care. But someone with advanced dementia may not themselves be able to enter into a valid tenancy if they can no longer understand it.”

Involvement of Family Members

The survey of Hanover extra care schemes (Baker, 2003) recommended that relatives should be supported and encouraged to be involved with supporting their relatives with dementia in extra care schemes. To achieve this, advice or training should be given to scheme managers, and the needs of relatives should be considered when designing new schemes.

Vallely et al. (2006) recognised that the potential for relatives and friends to be involved in the care and support of tenants is a major benefit of extra care housing. Their longitudinal study found that,

“People with dementia and their families were particularly happy with this aspect and felt it made extra care housing a more ‘homely’ environment than other housing options that may have been available to them.”

Preventing Falls and Minimising Injuries

Tilly and Reed (2008c) reviewed interventions for individuals with dementia in assisted living facilities and in nursing homes. They concluded that,

“Individually tailored programs combining both fall prevention and injury reduction appear to have the most success in reducing falls and fractures. Such programs rely on individual assessment of a resident’s abilities and needs to develop care plans that address the particular causes of that resident’s falls.”

An Australian literature review and other studies have shown that it can be difficult to engage residents with dementia with falls interventions, particularly as dementia advances to moderate or severe levels. As with any therapeutic intervention for people with dementia, the focus needs to be on staff and environmental change, rather than resident change. Interventions designed to reduce falls and impacts of falls therefore need to take into account staff compliance issues (Tilly and Reed, 2008c).

Communication

A recent study of communication between residents and staff in an ALF (39 residents) in the suburbs of a large Midwestern city in the USA (Williams and Warren, 2008) found that communication was problematic and similar to typical traditional nursing home communication, including ‘infantilisation’ and a lack of interaction opportunities. Cognitive impairment was found to pose special challenges,

“Dementia, over time, loosens the association between actions, communications, and consequences for those afflicted. The victims of this disease are no longer able to try to respond to directives, manipulations, or threats — compliance moves gradually away from their grasp ... For staff members, problems with dementia residents revolve around not only the lack of compliance but the lack of reason that underlies the possibility of compliance.”

It seemed common for residents without dementia to fear and dislike those with dementia, and having to witness the effects of dementia made many afraid,

“One staff member comments on the reaction of other residents to the impaired: they want them out of here. Because they don’t want to look at their future....This is what they are seeing and they are offended by it. “

Those with dementia who were still aware of their condition experienced emotional distress including anger, unhappiness, loneliness. Appearing to be rude was one of the consequences of this distress. Staff were coping well with this negative communication style through not seeing it as the residents wanting to be rude to them, but as a manifestation of their unhappiness (Williams and Warren, 2008).

Recognising Dementia

Baker’s study of Hanover extra care schemes (Baker, 2003) recognised the need for staff to correctly identify dementia symptoms (and distinguish from other disorders),

and to arrange for effective assessment and diagnosis. In guidance for managers they recommended including a clear statement of the process staff should follow if they believe a resident may have dementia.

Brooker et al. (2008) in their study of ten ExtraCare Charitable Trust schemes and villages found that a significant number of residents had a high degree of psychiatric morbidity and vulnerability, and that the prevalence and incidence of dementia is still being under-estimated,

“Housing staff do not generally focus on diagnosis of mental health problems as a key issue in the way as health care staff or nursing home staff. Our experience in carrying out this research is that housing staff have a limited awareness of psychiatric diagnosis or diagnostic criteria and the benefits of obtaining a diagnosis and treatment”

“Staff teams in extra care housing are able to recognise that people are at risk but they do not readily express this in diagnostic category terms or recognise the need to gain diagnosis and treatment for mental health issues” (Brooker et al., 2008).

Dementia Knowledge and Understanding of Staff

Smith et al. (2008) studied dementia-specific ALFs in two different urban communities located in the Midwest of the United States over a nine month period. One of the ALFs provided apartment living. The authors found that staff were caring and compassionate but they appeared to often misinterpret behaviours and did not have a good understanding of residents' distress. For example,

“behaviors that are consistent with agitation (e.g., pushing, grabbing, abrupt withdrawal, yelling, being argumentative or resistive to care) were commonly offered as examples of anxiety. Participants who stayed up until 11pm were described as having sleep disturbance, and not finishing meals was considered evidence of appetite disturbance, even in the absence of weight loss. In one case, intense paranoid delusional ideas relating to the participants' children being unsafe were considered “usual worries” and “just the way she is” by staff.”
Smith et al. (2008)

Training

Respondents to Garwood's (2007) *Housing and Dementia Survey* felt there are important information gaps for care practices and training relating to:

- Promoting tolerance and an ethos of inclusion
- Dealing with challenging behaviour and difficult situations
- Understanding dementia including what to look for regarding the onset of dementia and advice on whom to approach
- Person-centred dementia care
- Maintaining the skills of a person with dementia
- Communicating with people who have dementia
- Positive risk taking
- Responsibilities arising from the Mental Capacity Act.

On-site Facilities

Vallely et al. (2006) reported that on-site facilities such as restaurants, cafés, shops and hair dressers can provide good opportunities for community engagement and social interaction.

At Moor Allerton (Cantely and Cook, 2006) the café was used regularly, particularly by tenants from the dementia-specialist scheme and they and their relatives were generally happy with having the café facility and with the quality of the food. Tenants with dementia benefited from the social aspect of eating in a communal facility, and families felt reassured to know that their relatives were having regular meals.

Despite obvious benefits of having a restaurant, and demonstrated satisfaction with meals provided, authors of some evaluation studies,

“feel the provision of meals moves a scheme towards being an institution and stops people from preparing their own food, thus constraining their independence, and that communal eating areas can have a negative impact by making the environment feel more institutional.” (IPC, 2007).

Equality and Diversity

No literature was identified relating to extra care and people with dementia that specifically addresses issues of equality and diversity such as Black and Minority Ethnic (BME) or lesbian, gay, bisexual, and transgender/transsexual groups. Kerr et al. (2005) point out that symptoms of confusion can be intensified for BME people with dementia if the services and surroundings provided for residents are not culturally aware. A set of guidelines have been published by the Housing Learning and Improvement Network regarding the specific needs of BME older people in extra care housing (Patel and Traynor, 2006).

No research studies of extra care environments were found that shed light on issues for people who have both dementia and sensory loss. Existing evidence regarding the design and impact of the built environment has been generated from settings other than extra care, and is predominantly focused on sensory loss issues that are caused by dementia (as opposed to those experienced by many in tandem with it).

EVIDENCE GAPS IDENTIFIED – CARE, SERVICES AND FACILITIES

- ▶ 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).
-

6.5.10 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.
-

Prevalence and Types of Psychosocial and Behavioural Symptoms

Psychosocial and behavioural symptoms require careful clinical oversight and management because of their high impact on quality of life (Hyde et al., 2007).

Recent American research literature describes a high prevalence of neuropsychiatric symptoms among residents with dementia in ALFs. The situation is no different in the UK. The 'Opening Doors to Independence' longitudinal study of Housing 21 extra care schemes (Vallelly et al., 2006) recorded the incidence of a variety of behaviours associated with dementia. The authors questioned whether some challenging behaviours could be addressed through changing staff perceptions and improving their skills in communicating with people with dementia. For example,

“frequently pulling the emergency alarm cord for no apparent reason was often cited as a trigger for moves to other care settings. However, the emergency alarm is a key factor in giving residents and their families peace of mind and residents are encouraged to use the alarm when they need to. Just because a reason is not apparent to staff does not mean that there isn't one.”

The study found that many tenants with dementia had orientation difficulties, however there were very few examples where their walking around was problematic (Vallelly et al., 2006). Regarding aggression,

“Staff felt that aggressive behaviour may lead to moves to other care settings, but even then, appropriate training could enable staff to identify triggers for aggression and hopefully avoid its recurrence.”

The Hanover 2002 survey of extra care schemes (Baker, 2003) found that:

- 71% of Hanover extra care schemes had at least one resident with dementia who exhibited behaviour they had to “manage”.
- Some of the effects of dementia could be managed reasonably well in the extra care setting by working with residents with dementia as well as the staff and other residents. These included behaviours such as,
 - walking about (experienced in at least 52% of schemes)
 - disorientation, confusion, forgetfulness, repeated talk or actions (in at least 33% of schemes)
 - entering other residents' flats (in at least 24% of schemes)
 - ringing door bells and knocking on doors (in at least 19% of schemes)
 - anxiety (5% - one scheme).

Although these behaviours were able to be effectively managed, they could however be the cause of concern, worry, sleep disturbance, frustration, annoyance and sometimes fear among other residents.

- A second set of effects appeared to be more difficult to manage. These included,
 - suspicion (experienced in at least 29% of schemes)
 - aggression (in at least 19% of schemes)
 - inappropriate (in at least 19% of schemes)
 - “magpie” stealing (experienced by one scheme).

These types of behaviours could cause distress, fear and even hostility among other residents.

Managing Psychosocial and Behavioural Symptoms

Baker's evaluation of Hanover extra care schemes (Baker, 2003) recommended a multi-stakeholder approach to the management of the effects of disruptive behaviours through working with the people with dementia themselves, other residents, care staff, relatives, and other professionals

A systematic review of psychological approaches to the management of dementia-associated neuropsychiatric symptoms by Livingston et al. (2005) concluded that the only approaches where there is evidence¹⁵ of lasting effectiveness are:

- behaviour management therapies,
- specific types of caregiver and residential care staff education,
- (possibly) cognitive stimulation.

Interventions to prevent walking about were studied in a *systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia* carried out by Robinson et al (2007). They concluded,

“There was no adequate, good-quality evidence from controlled trials to recommend the use of any specific non-pharmacological intervention to reduce wandering in people with dementia.”

A further literature review incorporating interventions for walking about in ALFs and Nursing Homes was conducted by Tilly and Reed (2008). The authors reached these conclusions from the evidence identified:

- Person-centered care incorporating careful assessments, care planning, and individualised interventions are likely to be successful in managing unsafe walking about.
- Approaches should be tailored to meet individuals' needs, preferences and abilities.
- The use of physical restraints is not an effective method of managing falls or walking about among people with dementia.
- The use of physical restraints is harmful to residents' physical and emotional health and the removal of restraints causes them no increased harm.

In a meta-analysis, Heyn et al. (2004) concluded that exercise training increases fitness, physical function, cognitive function, and positive behaviour in elderly people who have cognitive impairments and dementia.

¹⁵ “lack of evidence regarding other therapies is not evidence of lack of efficacy”

EVIDENCE GAPS IDENTIFIED – MANAGING PSYCHOSOCIAL AND BEHAVIOURAL SYMPTOMS

- ▶ 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.
-

6.5.11 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.
-

Overview of Enabling and Disabling Factors

Mitty and Flores (2007) writing about *Defining Characteristics of Assisted Living* point out that ALFs need to provide the following in order to be able to effectively address the needs of residents with dementia:

- Staff training
- Assessment and reassessment procedures
- Supervision
- Specialised activities
- Procedures to address behavioural symptoms
- Move-in and move-out criteria.

The evidence from international and UK literature supports these claims.

Regarding service delivery models, whether the management of the housing scheme is separate, or integrated with the management of the care and support, there is evidence that both approaches can be successful and sustainable as long as there is flexibility in the way in which services are delivered.

Evidence from Recent UK Surveys

Hanson et al. (2006) carried out a survey among professionals working in the extra care field and asked what, in their view, contributed to successful extra care schemes. Responses included:

- Provision of person-centred care and personal care plans;
- An operational policy that emphasises an individualised approach to assessment and care;
- Joint support and joint care plans, enabling a ‘seamless service’;
- A focus on provision for older people’s mental health, including dementia, with sensitively designed buildings and environments to support orientation and way finding;
- The ‘home for life’ concept is not to be confused with a ‘Lifetime Home’;
- 24/7 care does not necessarily need to be provided on site because social services packages can be provided 24/7 in a person’s own home irrespective of location.

The Raising the Stakes, Promoting Extra Care Housing Survey (IPC, 2007) asked extra care scheme managers what aspects they felt contributed to the ability of an extra care scheme to successfully support people with dementia. The most common response was having a balance of needs in the scheme, followed by specialist training for staff and people moving in before their dementia is too advanced (see table below).

<i>Successful Aspects</i>	<i>Proportion of Respondents</i>
Balance of needs within the scheme	60%
Specialist training of staff	54%
Early entry of residents with dementia	51%
Enabling design	40%
Assistive technology	26%

Purpose built	14%
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The survey also identified the factors that scheme managers felt prevented extra care schemes from being able to successfully support people with dementia. The most common response was having no specialist support available (see table below).

<i>Aspects Preventing Successful Support</i>	<i>Proportion of Respondents</i>
No specialist support available for people with dementia	49%
Environment not appropriate for people with dementia	31%
LA not willing to fund	20%
Scheme aims to provide for one client group only	20%
Other (behaviour)	14%
Difficulty recruiting/retaining levels of staff required	11%
Too expensive for self funders	6%
Accessibility of flats	6%
Accessibility of communal areas	3%
External access into the scheme	3%
Lack of facilities at scheme	3%

Co-ordination and Partnership Working

The Opening Doors to Independence study identified difficulties arising from a lack of shared information across organisations,

“the lack of detailed information from health and social care services about potential residents at the time of referral meant it was sometimes difficult to assess their suitability for housing in extra care”

(Vallelly et al., 2006).

Regarding policies and strategies the authors concluded that,

“Joint working is vital to the success of extra care housing for people with dementia and all residents.”

Findings from that study indicated that schemes were able to provide a better quality of care and quality of life for tenants with dementia where,

- there were integrated local strategies for housing, health, and social care services
- there is Interdisciplinary working in referral, assessment, care planning, and the provision of services
- there are agreed arrangements for tenants to receive timely and appropriate community health services (physical and mental health services)
- links with the wider community are promoted.

The comparative evaluation of models of housing with care study (Croucher et al., 2007) recommended,

“Resources for housing with care must include appropriate support from community health and specialist health care services. There needs to be greater clarity on the part of health providers about exactly what housing with care can provide and similarly the types of services, particularly community health services, that will be required. We are thinking here particularly of community nursing services and general practitioner services – including out-of-hours cover.”

The case study of Duddon Mews (Garwood, 2008) found that effective partnership working between key partners (Cumbria County Council, Croftlands Trust, Home Group, Age Concern, Millom Community Mental Health Team) has, “resulted in the development of a much valued, innovative resource for older people with dementia and other mental health problems”.

Learning points highlighted by the study included,

- Where there are different organisations involved in carrying out assessments it is important to clarify who is to be the key case co-ordinator.
- There should be regular formal meetings between the scheme manager and care manager.
- Provision of good quality multi-agency information and education on extra care for both public and professionals is needed at the development stage.
- It is helpful to continue inter-agency liaison at a senior level in order to resolve teething problems and provide leadership.
- It would be advantageous to have more communication between the steering group and the Mental Health Trust senior managers.
- If Adult Social Care does not have a housing function, and housing benefit is needed to support extra care tenants, it is useful for the district council to be involved in project development, have nomination rights, and to sit on the allocation panel.
- Service provision could be even better if care and support were more integrated and defined more flexibly. This could be achieved either through a single provider managing and delivering the care and support services, or by high levels of co-ordination, joint activity and shared responsibility between the different agencies.
- A written record of agreements between partners is strongly recommended.

A similar finding to this last point was also found in the evaluation of the Fred Tibble extra care scheme for people with dementia which recommended that partnership working needs to be built upon a structured approach (IPC, 2005).

Resources and Capacity

An evaluation of Hanover extra care schemes (Baker, 2003) recognised the importance of ensuring appropriate support is in place for tenants with dementia. Croucher et al. (2006) recommended that,

“Greater clarity is required regarding the capacity of housing with care to accommodate people with cognitive impairment, particularly severe impairment. There are issues here regarding the skills and training of staff, the communal dimension to housing with care and the well-being of all residents, the design of buildings and spaces, as well as the

appropriate use of technologies (for example, security systems to prevent exit or access, surveillance measures and so forth).”

Regarding the promotion of independent living by extra care schemes Croucher et al. (2007) write,

“there needs to be a realistic assessment of the type of support services that need to be in place (and provision of appropriate resources) to sustain these concepts.”

Vallelly et al. (2006) found there were considerable differences between extra care housing schemes in the quantity and type of activities provided, partly due to differing staffing and funding arrangements.

Recommendations from UK extra care scheme evaluations:

- *Escorting hours*

“where possible, ‘escorting hours’ should be built into the support element of block care contracts so that people with dementia and mobility difficulties can be enabled to use and make the most of the wider facilities in the court.”

(Housing 21 extra care schemes - Vallelly et al., 2006).

- *Minor maintenance service*

The provision of a minor maintenance service plus a more comprehensive ‘settling in’ service within the Well-being package.

(Stanton Lodge - Jevons, 2008).

- *Floating care hours*

Floating care hours are crucial in a communal setting (30 hours had been introduced at Duddon Mews) and not all care staff activity should be assigned to named tenants.

(Duddon Mews evaluation - Garwood, 2008).

- *A responsive service*

A responsive service is needed and it is essential this is reflected in the care and staff employment contracts (tenants who have dementia and memory difficulties frequently require unplanned care and a flexible service).

(Duddon Mews evaluation - Garwood, 2008).

- *Amount of staff time varies in proportion to number of tenants with dementia*

The availability of staff time is the major factor in determining the ability of any scheme to be able to support tenants with dementia. The amount of staff time available to provide necessary support should be increased as and when the proportion of tenants with dementia increases.

(Hanover extra care schemes - Baker, 2003).

Social activities can be much appreciated by, and can increase well-being for, people with dementia. However, “resource constraints and pressures on staff

time meant that opportunities for staff to maximise provision of social activities were compromised.”

(Housing 21 extra care schemes - Vallely et al., 2006).

- *Clear remits for staff roles*

Organisations need to determine if limits are needed in staff's roles in managing dementia i.e. to what extent a scheme manager should be involved.

Hanover extra care schemes (Baker, 2003).

Staff

It is important to ensure the well-being and empowerment of staff, including support available to them (e.g. Cantley and Cook, 2006). Baker's (2003) study of Hanover extra care schemes noted that that working with people with dementia can be stressful for staff and recommended that ways to help staff cope with stress should be found. Also, more training on dementia should be provided for scheme managers on specific challenges such as dealing with hostility from other residents. This would preferably be practical rather than theoretical.

The general view of staff at Moor Allerton extra care scheme was that they 'loved their job' and that the support they received, along with team working, contributed greatly to the work being enjoyable (Cantley and Cook, 2006). Staff who had worked in other care environments reported feeling less stress in comparison. The staff found that work in the non-specialist extra care scheme tended to be more physically tiring whereas working in the dementia-specialist scheme was more psychologically tiring. A benefit of having two types of scheme on one site was that staff could have a change by working in the other scheme.

Knowledge Transfer and Training

Baker (2003) recommended that structured meetings should be organised for scheme managers to share experiences, ideas and good practice on dementia. Also, scheme managers need to have a source of useful information to pass on to tenants and relatives.

A study of ALFs found,

“Most providers lacked skills in assessing residents' abilities and developing care plans. Only three homes were designated as having the capacity to care for residents with Alzheimer's disease, indicating their staff had received specialized dementia-care training, despite the fact that all homes had residents with dementia.”
(Ball, 2004).

Although most care staff interviewed by Vallely et al. (2006) had some awareness of the nature of dementia and its implications for the support and care needs of tenants, few had received dementia specific training relevant to their current roles and, “this clearly had a negative impact on how effective some care staff were when working with people with dementia.”

Culture / Philosophy

The evaluation of the dementia-specialist Fred Tibble Court showed that the creation of a culture or philosophy of the scheme was a useful contribution to seeing the tenant as an individual first rather than a bundle of dementia symptoms (IPC, 2005).

Dependency Mix

In the *'Evaluation of the Extra Care Housing Funding Initiative'* (Darton et al., 2008) all the eight extra care schemes (for which data had been collected to date) had been designed to support tenants with a range of dependency needs, and to provide an alternative to residential care for at least some people. Most schemes were aiming to have a balance of residents with high, medium and low care needs, and findings so far indicate that this is being achieved. One of the schemes is aiming to specifically support residents with dementia, but most prefer to admit tenants with less cognitive impairment so that they can become familiar with their new environment before dementia becomes more severe.

There were indications that the dependency mix had a number of benefits, such as the sustainability of a scheme's social life, but also that it presented challenges, not least by impacting on the schemes' social climate,

“The only problem among us is [resident with dementia], because she upsets everybody. But nobody seems to think anything should be done about it, everybody just takes it as everyday. But people worry about it.”

“I think a lot more people are quite ill or frail here than they are fit.”

“I don't think they looked closely enough at the ability of the person. From my personal view, there's only about two or three people here that I would want to have a conversation with.”

Baker's study of Hanover extra care schemes (Baker, 2003) recommended that the appropriate proportion of residents with dementia in each extra care scheme needs to be determined (and maintained). This should be a proportion that is viable and does not change the nature of the scheme by, for example, impinging on the quality of life of other tenants. As a guide, Baker estimated that a maximum of 30% of tenants with dementia could be supported in a typical extra care scheme (with typical levels of care staff) without changing the nature of the scheme.

The evaluation of Berryhill retirement village (Bernard et al., 2007) found,

“the habit of 'wandering' of some people with a dementia was not acceptable in the Village, because other residents and staff found it difficult to cope with. This clearly raises issues about the mixing of 'fit' and (mentally) 'frail' older people in the one community.”

A study evaluating the social consequences of remodelling ten sheltered housing and residential care units to extra care schemes in England (Wright et al., 2009) audited the buildings and sought to identify social and design problems. Regarding dependency, some schemes aimed for a balance whilst others set a dependency threshold at admission. None would accept people with severe dementia. Several of

the schemes would accept people with mild dementia only, so that they would be able to familiarise themselves with the scheme, and that other tenants would be tolerant of them.

Location of Schemes

Some studies have highlighted advantages of an extra care housing schemes being situated within a large complex, such as a retirement village, and/or next to a nursing home, notably with regard to tenants not having to move far if they are required to leave the scheme due to increasing high care needs. The evaluation of Stanton Lodge (an extra care scheme for people with dementia and their partners) concluded that there is not a strong case for locating schemes next to residential or nursing homes, unless there are other unrelated advantages presented by the site,

“While there are perceived advantages to the location of Stanton Lodge adjacent to Fitzwarren House dementia and nursing home (including priority access on death of the care partner), in practice the only real benefit is access to a hot meals service, shared garden and shared chaplaincy.” (Jevons, 2008)

Effect of the Size of Scheme on Care

Benefits and drawbacks of smaller sized schemes include,

- staff have constant contact with fewer residents, there is greater continuity, and care providers tend to know residents’ routines more intimately (Ball et al., 2004).

Benefits and drawbacks of larger sized schemes include,

- they can provide more opportunities to accommodate both fit and frail older people and more easily enable the development of a ‘vibrant community’ (Croucher et al., 2006).
- problems can sometimes be overlooked where residents do not require regular care and therefore have minimal daily contact with staff. E.g. “Several days went by before caregivers at Oak Manor (apartments) noticed significant swelling of a resident’s ankles because of her failure to take a prescribed diuretic” (Ball et al., 2004).

Streib and Metsch (2002) determined that people with dementia and mental health conditions living in large retirement communities are, “more likely to be socially isolated and possibly subject to resentment and hostility.”

Transitions / Moving On

Mead et al. (2005) studied sociocultural aspects of people with dementia moving on from ALFs. They found that scheme managers and administrators were pivotal figures in decisions relating to transition timing and care. Factors influencing retention or transfer were the scheme culture and family member involvement in decision making and/or care.

Kelsey et al.'s (2008) survey of ten ALFs in South Carolina, USA found that most of the facilities used a preadmission screening process to assess cognitive status. At admission about half of the ALFs discussed with the families at admission the possibility of future transfer to another level of care but, although most of them had transfer policies in place, only two-thirds discussed these with families. ALFs that were situated within a continuing care retirement community used more multidisciplinary transfer decision-making than free-standing ALFs.

'Exit' Criteria

Croucher et al.'s (2006) *housing with care for later life* literature review discussed the desirability of having explicit 'exit' criteria which define the circumstances and conditions under which a tenant would be required to move out of extra care. They reported that the evidence shows that explicit criteria is perhaps not an achievable objective due to the ad-hoc nature of how decisions are taken regarding move-on placements. Contributing to variations and inconsistencies were the absence of explicit 'home for life' policies and a lack of clarity as to who had the responsibility for determining whether a person needed to move on (e.g. housing provider, GP, or resident's family).

Legalities, Regulations and Contracts

Garwood (2004) recommends, "Both tenant and prospective attorney should sign the tenancy agreement".

In the case study of Duddon Mews, Garwood (2008) suggested it would be advantageous, in terms of communal living and complications over definitions of care and support, for the service contract to resemble a supported living contract so that care and support are brought together.

Dow (2006) points out,

"There are particular issues that need to be considered when developing extra care housing for people with dementia. Any doubts about a person's capacity to enter into a tenancy agreement could affect both the registration of the scheme and the enforceability of the tenancy. The Disability Discrimination Act should also be considered both in relation to refusal to accept a person on to the scheme and if it is proposed to end the tenancy."

Ownership

The evaluation of Stanton Lodge found that residents did not have strong views regarding 'ownership' of the apartments and that the form of the tenure was relatively unimportant to them (Jevons, 2008).

Health and Safety Regulations

Evans and Vallely (2007) reported that having a rigorous implementation policy of health and safety regulations may have a negative effect on the well-being and

independence of tenants, for example the fear of injury can discourage staff from allowing free access to outdoor spaces.

Monitoring and Evaluating Extra Care

“Monitoring whether local extra care developments are successful requires clarity from the outset around objectives, as well as appropriate measurement tools and analysis of outcomes” (Henwood, 2007).

.....

EVIDENCE GAPS IDENTIFIED - SERVICE DELIVERY / MANAGEMENT / ORGANISATION

- ▶ 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.
-

6.5.12 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.
-

Quality of Life

Current research and evaluation evidence supports the claim that extra care improves quality of life for residents in general and improves or maintains feelings of well being (IPC, 2007).

“There are very positive messages about extra care housing offering a good quality of life. It appears to offer for some people with dementia, an alternative, more independent lifestyle than is possible in a care home.” (Cox, 2007).

The three year longitudinal study of people with dementia living in Housing 21 extra care schemes concluded that, “extra care housing is providing a good quality of life to the majority of residents who have dementia, many of whom are very old and additionally have complex health needs.” (Vallely et al., 2006). The study found that nearly all of the residents with dementia were frequently visited by family who provided a good deal of informal support. Families appreciated the benefits that extra care housing gave to their relatives with dementia. Both parties were reassured that there was someone on-site to ‘keep an eye’ on things.

The ‘*Opening Doors to Independence*’ study (people with dementia living in Housing 21 extra care schemes) observes that the balance between independence and social isolation is a key challenge in maintaining quality of life.

Tenants of Fred Tibble Court (a dementia specialist extra care scheme) were found to be experiencing a reasonable quality of life (IPC, 2005), although almost one third of them expressed feelings of loneliness and felt that staff did not spend enough time talking to them.

Extra Care Scheme for Couples

The recent evaluation of Stanton Lodge (an extra care scheme for couples where at least one partner has dementia) found that the quality of life for all 13 tenants with dementia for whom it was possible to make a judgement was described as,

- ‘good’ or ‘excellent’
- better than previous circumstances, and
- better than other care options considered.

For care partners, where judgements were possible, their quality of life was described as ‘good’ or ‘excellent’ for 65% (9 cases), and ‘medium’ or ‘poor’ for 35% (5 cases). (Jevons, 2008).

The evaluation determined that there was a trade-off for active well care partners who described their own quality of life as no better than ‘medium’, feeling that their life had become more restricted. They were however content that Stanton Lodge was providing a better environment for their partner. When asked to make a

judgement on that trade-off, only one felt that the decision to move to Stanton Lodge had been a mistake, the other three clearly felt the decision had been the right one.

“For all individuals interviewed the ability of the couple to remain living together appeared to dominate all other considerations of both care partner and younger family members” (Jevons, 2008).

Retirement Villages

The three year study of Berryhill retirement village found that health-care professionals believed that residents who had complex conditions, typically involving both mental health (including dementia) and physical, ‘did not do so well’ (Bernard et al., 2007).

Assisted Living

Zimmerman et al. (2008) conducted *Dementia Care* research project in collaboration with the Alzheimer’s Association. This was a study¹⁶ of the quality of life and care of 421 residents with dementia from 35 residential care/assisted living communities (many with apartment living) and 10 nursing homes in Florida, Maryland, New Jersey, and North Carolina.

With help from liaison panel members, key quality care domains were identified as foci for the study. These were: resident pain, depression, behaviour, activity involvement, food and fluid intake, mobility, and overall (aggregate) quality of life. In addition, there was a specific attention paid to staff training, care and family involvement related to the identified domains.

Key findings included,

- the existence of significant relationships between resident quality of life and the structure and process of care
- person-centered care has an important influence on overall quality of life
- there is a need for improvements in both assessment and care
- “no single component or set of components define “good” care, and that recommendations should not focus narrowly on any one area to the exclusion of others”.
- “quality is a multifaceted concept, and that what is considered good by one definition may not be as good by another. “
- “care in one area is not necessarily complemented by good care in another”
- different stakeholders have different perspectives.

Enhancing Quality of Life

Findings from the enriched opportunities programme (ODPM, 2004) demonstrated that the following elements are needed in order to enhance the quality of life of tenants with dementia in extra care:

¹⁶ They collected data using interviews with residents, staff, and residents’ families, and using observation of residents during one meal and during the course of one day. Information collected related to care, training, practices, and resident quality of life.

- specialist expertise;
- individualised assessment and case work;
- activities and occupations;
- staff training; and
- management and leadership.

Stanton Lodge provides a package of flexible care and support services which includes personal care, domestic help, shopping and meals services. In addition, all tenants receive a 'well being package' which includes daily drop-in visits, activities, and ten days of respite to allow partners to have breaks from caring.

Vallelly et al. (2006) found that social activities had a major role in contributing to the well-being of people with dementia. Their evaluation of extra care schemes indicated that activities which provided mental stimulation and which involved other people from the wider community were particularly beneficial. At the same time, having choice and opportunities to spend time alone in a safe and private environment is also important to many people with dementia and this was found to have a large contribution to quality of life, as did living in a safe and secure environment generally.

Good nutrition is essential for health and well-being. In the *Opening Doors to Independence* study some people with dementia were reported as having increased wellbeing and less 'challenging behaviour' as a result of using on-site restaurants. Overall, "people with dementia value the feeling of being cared for, and the peace of mind they get from living in extra care housing" (Vallelly et al., 2006).

Other factors which have been shown to have a positive effective on quality of life are partnership working, continuity of care (and a solid staff base) (IPC, 2007), flexibility of care and support, staff attitudes, and the culture of the scheme.

Social Isolation

Despite extra care offering community living along with opportunities for social interaction, Croucher et al. (2006) found there were consistent reports of people with dementia being 'socially inactive' across all types of housing with care settings. There is a weight of evidence suggesting that people with dementia (and their carers) suffer social isolation and even resentment and hostility,

"The integration of the fit and frail does not appear – on the basis of these studies – to always work well from the perspective of residents. On the basis of this evidence it seems that providers need to take a proactive approach to promoting the social well-being of frail older residents in housing with care schemes."

Baker's evaluation of Hanover extra care schemes recommended that ways should be found to effectively integrate tenants with dementia into the extra care community (Baker, 2003). Recent studies however are still finding evidence that people with dementia (as well as people with physical frailties and/or impaired mobility) are at higher risk of being less socially integrated (Evans and Vallelly, 2007b). (Brooker et al. (2008) also found, "people living in extra care housing experience significant problems associated with dementia and depression that places them at risk of being excluded from the community in which they have chosen to live".

The MHA have a site in Leeds comprising both a specialist dementia scheme (20 one bed flats) and non-specialist scheme (45 flats). The tenants in the specialist dementia housing all have a diagnosis of dementia and have high care needs (some receiving up to 30 hours per week). An evaluation of the site conducted by Cantley and Cook (2006) described the experiences and views of staff organising activities for tenants. Firstly, they found that a, “more proactive approach” was needed to encourage dementia-specialist scheme tenants to participate. Secondly they found it better to hold activity sessions for the two tenant groups separately.

The staff had initially run activities for tenants from both the schemes to join in together but found that the non-specialist tenants were “rather intolerant” which had an adverse affect on the dementia-specialist scheme tenants. Activity sessions were then run separately for each group of tenants. Staff believe this is preferable for tenants from both schemes, with the dementia-specialist scheme tenants appearing to enjoy the sessions more and to be more relaxed. The authors concluded overall that, “the community is generally socially inclusive although not everyone fully accepts the involvement of people with dementia.”

Discrimination / Stigmatisation

The longitudinal study of people with dementia living in Housing 21 schemes found that there were some instances of tenants feeling isolated and lonely and having difficulties in making friends. (Vallelly et al. 2006) The study found that a few people with dementia were being discriminated against by other extra care tenants, including attempts to exclude them from social activities. The authors concluded that information and awareness raising about dementia with other tenants and families is an effective strategy.

In Croucher et al.’s (2007) longitudinal study of several extra care schemes people with dementia were, “often dismissed as potential friends or companions – ‘you can’t have a conversation with half of them’ – or were a source of anxiety and disruption.”

A study in the USA which included apartment style ALFs found that if residents did not “fit in” socially this increased the likelihood of them being transferred to the dementia unit on site. During the study, several residents were moved from ALFs to the dementia unit when other residents began to ostracize them because their behaviour began to differ from what was considered to be the ‘norm’ (Ball et al., 2004).

Dobbs et al. (2008) carried out a qualitative study of stigmatisation among older adults living in six RC–AL settings in Maryland, USA. The study included 309 participants, residents, family and staff. They found that,

- it was common for residents to display strong intolerance of those with dementia
- the most widespread stigmatising attitudes and behaviours were towards people with dementia
- there was frequent concern from residents about ageing and forgetfulness in others but denial of these traits in themselves
- some residents and relatives thought dementia to be a contagious disease
- family members often believed their relative was not as cognitively impaired as the other residents in the facility, even though that was not the case.

Their findings suggest that the incidence of stigma could be reduced/minimised through:

- Changes to the process of care delivery including staff recognition of resident preferences and strengths, rather than limitations.
- Changes to the structure of care such as examining how best to accommodate and organise care for persons with dementia given the resident case mix (e.g., separate units or integrated care – see section 6.5.8).
- “Learning about a person’s preferences at the time of admission, and structuring opportunities around such preferences ...can combat stigma ... devoting effort into the provision of activities that are desired by a resident population is perhaps more important for RC–AL, as it is consistent with the values of autonomy, dignity, and respect that are the core of its mission.”

EVIDENCE GAPS IDENTIFIED – WELL-BEING AND QUALITY OF LIFE

- ▶ Studies of satisfaction and quality of life for people with dementia in extra care.
- ▶ More studies addressing issues regarding resident empowerment, consultation and participation.
- ▶ Studies responding to diversity, for example black, minority and ethnic communities.
- ▶ Further investigation of resident and environmental factors that influence quality of life in extra care, the predictive power of these factors over time, and the effects of interventions that target these factors.
- ▶ Tools for assessing outcomes where residents have communication difficulties.
- ▶ 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.

6.6 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)

Study period: 2006 – 2010.

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. 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)

Second phase: January 2008 – June 2009.

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.

6.7 Determining Research Priorities

There is strong consensus among research authors that there is a pressing need for data on outcomes for people with dementia living in extra care, with the ultimate goal to find out what works for what kinds of people in what circumstances. Different stakeholders will have differing views on which of the numerous gaps are most important and urgent but perhaps one of the most notable gaps is the lack of views from people with dementia themselves.

This literature search identified three key exercises that have been carried out to determine themes as priorities for research action, one in the USA and two in the UK.

1. In the USA Kane et al. (2007b) generated a research agenda for assisted living (for older people in general) using a process built around a working conference largely for, and composed of, researchers active in the field of assisted living. The process involved reviewing existing literature, preparing commissioned papers, identifying stakeholders, and getting feedback on a long list of potential research topics (prior to the conference itself).

The research priorities identified at the conference were:

- AL residents' characteristics, preferences, and decision-making process
 - service capacity in AL
 - staffing strategies
 - specialised services for residents with dementia
 - cost and financing
 - resident outcomes
 - family involvement in resident care
 - transitions to and from AL
 - regulatory oversight.
2. A Consultation and Planning Forum held in the UK in January 2008 brought together some of the largest older people's housing providers in the UK, and a range of other key stakeholders including practitioners, managers, researchers, and chief executives from a wide range of organisations (Housing 21, 2008). Delegates identified evidence gaps, priority areas for research, challenges, and opportunities to help achieve timely, appropriate, high quality 'what works' focused research. The forum was organised and hosted by Housing 21 – Dementia Voice, with support from the Joseph Rowntree Foundation.

The research priorities identified were:

- Building and environment - What works?
 - What sort of homes should be built for the future?
 - What is most effective in terms of design, the built and social environments?
- Matching services to need - What works?
 - Do the typical transition points in the housing, support and care pathway meet the needs of individual people with dementia?
- Early intervention - What works?

- What 'early interventions' can help to prevent:
 - a) emergency admissions to hospital
 - b) transfer to a different housing setting
 - c) deterioration in quality of life?
 - Psycho-social interventions - What works?
 - Which psycho-social interventions are effective – psychotherapy, Cognitive Behavioural Therapy, activities, engagement opportunities, communication techniques, community cohesion?
 - How can we best balance independence and isolation, and assess need against opportunity?
 - Existing evidence
 - What do we already know about what works?
 - Up to date literature reviews and meta-analyses are needed.
 - Change management
 - What are the most effective change management strategies?
 - How can we most effectively transfer knowledge into practice?
3. A Housing LIN survey¹⁷ (Garwood, 2007) provided feedback from 44 respondents and highlighted the following areas as high priorities for research and evidence based information:
- A comparison of the suitability, costs and benefits of different services/ service combinations in meeting the needs of people with dementia at various stages of the condition: housing with care compared to residential care, nursing home care and care and support at home: pros and cons of "centralising" services in a specific built environment vs supporting people where they live currently.
 - Costs and benefits of different models of housing with care for older people with dementia at different stages of the condition, in particular, comparing an integrated model, a separate dementia unit within extra care and separate specialist housing with care for people with dementia.
 - The impact of different design features on the outcomes for people with dementia.
 - Length of stay in housing with care schemes for people with dementia and the pathways they follow from housing with care.
 - Whether different management and staffing models in housing with care produce different outcomes for service users with dementia.
 - The effectiveness of different care interventions with individuals who have dementia.

¹⁷ Carried out among commissioners and providers of: housing, health and social care services; care and repair agencies; housing related support; and assistive technology.

7 Discussion and Conclusions

7.1 The Evidence Base for Extra Care for People with Dementia

The evidence base regarding people with dementia living in extra care settings is in its infancy, particularly in the UK. Very few studies of extra care housing exist at the moment that focus on characteristics, experiences, and outcomes for tenants who have dementia. In the UK there is just one longitudinal study, and a small but growing number of case studies and evaluations of single schemes. These use mainly qualitative approaches and are producing rich and detailed information giving insights as to what works and what does not work for specific schemes although they vary in terms of objectivity. There are a number of emerging themes and consistent findings arising from these studies that also reflect evidence from the USA and other countries. These are contributing to growing pockets of evidence enabling some fairly robust general messages from research to be formulated and/or act as a guide for further research work.

Until recently there were no large-scale research studies looking at the costs and benefits extra care schemes in the UK; the current Department of Health funded evaluation of the *'Extra Care Housing Funding Initiative'* is the first major study of its kind (Darton et al., 2008).

Elsewhere, and in the USA particularly, the number of research studies has expanded rapidly over the last decade, including many longitudinal studies and several major multi-site, multi-state studies. However a lot of these include residents from non-apartment 'assisted living' and residential care settings and do not present results broken down by accommodation type.

Many more robust and larger scale studies are needed in order to fill important gaps in knowledge and to be able to generate more comprehensive and clear recommendations for policy and practice.

7.2 Overarching Findings

It is widely agreed that "one size does not fit all" for older people generally when it comes to housing and care and that a range of options should be available to accommodate a wide range of needs and preferences.

Important Outcomes for People with Dementia Living in Extra Care

There is strong evidence that important aspects contributing 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 the 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.

Is Extra Care an appropriate environment for people with dementia?

There is mounting evidence that people with dementia living in extra care housing generally have a good quality of life. Stakeholders, including tenants, tend to have positive views about the housing, facilities and care aspects of extra care schemes. Studies also consistently show that some people with dementia however can be at risk of loneliness, social isolation and discrimination and proactive interventions are needed to overcome this.

Extra care is able to offer some people with dementia an alternative, more independent lifestyle than is possible in a care home and can delay or prevent moves to nursing care. Indeed, a UK longitudinal study has found that tenants with dementia are able to live independently for nearly as long as those without dementia. The promotion of independence is a key feature of extra care housing and this appears to be an achievable goal for those with early to moderate stages of dementia. However, independence will inevitably decrease over time as dementia and/or other conditions worsen. .

Some researchers question whether self-contained flats are the most appropriate and/or cost-effective 'living solution' for people with dementia. Some studies, for example, find that people with dementia make little use of their kitchens.

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

- intensive in terms of staff time
- manageable in terms of accommodating common effects and behaviours such as incontinence, anger and distress

- difficult in terms of managing other types of behaviours which can be disruptive, annoying or disconcerting for other tenants

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 also strong evidence and general agreement that it is not appropriate for people to enter extra care when they already have advanced dementia.

Can Extra Care Be a Home for Life?

Many people with dementia are also able to be supported in extra through to the end of their lives. However, enabling *all* tenants, with and without dementia, to remain in place through to the end of their lives in extra care housing is not usually possible. Common factors influencing whether people with dementia need to move on 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 for increasing care needs
- availability of resources (including increasing demand for carers' time)
- targets for dependency mixes, and maximum numbers of high-dependency tenants that can be cared for in schemes
- the availability of placements in other facilities
- the willingness of funders to pay for increasing levels of care for individuals
- choices and preferences of tenants themselves and their families.

There is some evidence that managing decline (in terms of both prevention and response) is key to supporting tenants to remain in place. Capacity to manage decline is influenced by multiple interacting factors including the individual, the extra care scheme and the wider community.

7.3 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.

7.4 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.

7.5 Complexities and Challenges Researching Populations with Dementia in Extra Care Settings

Carrying out research in extra care housing for people with dementia is fraught with difficulties and complexities. Not only are there the same challenges as in other long term care settings, and of course the ethical and communication challenges of researching people with dementia, but also many additional challenges due to the non-standardisation of extra care schemes such as,

- the wide variety of providers, policies, clients, partners and other stakeholders

- a lack of standardised assessment tools
- a lack of sharing of health data including medical diagnoses
- a lack of constancy in assessment and service-planning records e.g. to be able to compare resident characteristics in order to be able rate the effectiveness of different interventions on different populations.

There are wide variations in terminology and meanings. Many aspects studied within extra care settings such as 'ageing in place' are labelled differently, or are interpreted differently depending on researcher, provider, local policies, etc

Also, attempts to characterise the variety of different types of extra care housing for the purposes of research have been fraught with difficulty. There is a large variety of innovative extra care schemes and, even within the UK, there are wide variations in,

- building and interior design, facilities, and provision of services in extra care housing
- policies, management and care practices
- partnership working arrangements including: entry and exit criteria; capacity of schemes to be able to support people with dementia; and the levels of expertise of staff in managing behaviours that impact on other residents
- the proportion of residents with dementia living in extra care schemes, which also can vary enormously across schemes managed by the same organisation.

7.6 Recommendations for Approaches to Extra Care Research

For research to be useful in informing policy and practice, where possible:

- ▶ research studies should be devised so that they make meaningful recommendations about evidence-based practices
- ▶ there should be more standardisation in the way variables are measured
- ▶ there should be more rigour and consensus in the reporting of characteristics relating to residents, extra care and services, and in the reporting of sampling techniques, time frames and measures used
- ▶ research on extra care housing should analyse the population with dementia as a distinct group
- ▶ to enable synthesis of multiple studies, common assessment tools need to be used, e.g. across studies even cognitive impairment is measured using a wide variety of different methods
- ▶ there should be greater standardisation in describing the elements of extra care buildings, services, and outcomes
- ▶ comparisons across schemes must take account of dependency-mix differences
- ▶ when looking at issues relating to suitability of extra care for people with dementia, researchers should distinguish between types and levels of need at point of entry, and what can be managed if symptoms develop or accelerate once there.

Version 1.7

It is also essential that relevant knowledge from other settings, spheres and disciplines is transferred, to avoid unnecessary duplication and delay.

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9 Glossary

ADL	– Activities of Daily Living
AL	– Assisted Living
ALF	– Assisted Living Facility
ALR	– Assisted Living Resident
AT	– Assistive Technology
BME	– Black and Minority Ethnic
DH	– Department of Health
EAC	– Elderly Accommodation Council
EC	– Extra Care
ECH	– Extra Care Housing
HDRC	– Housing and Dementia Research Consortium
HLIN	– Housing Learning and Improvement Network, part of the DH.
MHA	– Methodist Homes Association
NH	– Nursing Home
RC/AL	– Residential Care/Assisted Living
PSSRU	– Personal Social Services Research Unit
SCU	– Special Care Unit
UK	–United Kingdom
US	– United States