

Housing Learning & Improvement Network

The Health and Social Care Change Agent Team (CAT) was created by the DoH to improve discharge from hospital and associated arrangements. The Housing LIN, a section of the CAT, is devoted to housing-based models of care.



The Challenges of Providing Extra Care Housing to People with Dementia

Adapted with kind permission from a presentation given by Sue Garwood of Hanover HA to a Worcestershire County Council Extra Care conference on 20th July 2004.

Introduction

In January 2004, I attended a conference on Housing for people with dementia arranged by the Department of Health. I went hoping to learn how other people had addressed some of the fundamental issues we at Hanover Housing Association had been grappling with over the past five years. I felt that the presentations, interesting though they were, barely acknowledged the issues let alone suggested solutions.

The sorts of questions I was asking included:

- 1) On what grounds can one justify having a separate housing wing for people with dementia in an extra care scheme, and what are the challenges and implications of such an approach
- 2) Are there boundaries to the suitability of a housing model for people with dementia?
 - a) If so what are they?
 - b) Which apply at the point of people moving in?
 - c) Which apply to existing tenants?
- 3) What are the issues when a person is not capable of understanding and complying with a tenancy agreement?
- 4) Does there come a point where the requirements for security and supervision so outweigh the need for and ability to be independent that a model based on housing and domiciliary care becomes phoney?

About Hanover Housing Association

Hanover is a specialist housing provider for older people. We have around 11,000 sheltered units, 5,000 leasehold properties and 1,000 Extra Care units in 34 schemes. Of course many of the people living in our properties develop dementia. Research undertaken in 2002 revealed that 10% of Extra Care tenants were **diagnosed** as having

dementia and a further 16% were believed to have dementia – around quarter of the Extra care population. We have also been very aware that Extra Care housing with its 24 hour care cover offers the potential to meet the needs of people with dementia which less supported forms of housing cannot.

In 2001, a group of us got together to develop a Dementia Policy for the Hanover Group which was subsequently ratified by dementia experts. With our specialist trainer, we then developed further guidance and training to back it up. However, our thinking did not stop there, and we have continued to grapple with the issues and widen our knowledge and understanding.

Aim of this paper

This paper seeks to

- Raise and explore fundamental issues
- Stimulate thought and debate
- Suggest acceptable approaches
- And make a plea for an honest appraisal of the issues, putting the needs of people with dementia ahead of dogma, fashion or saving money. I realise this is the plea of an idealist.

However the following issues are not covered here, except tangentially:

- **Designing for dementia** - Mary Marshall of the Stirling Dementia Centre has written widely on this subject. A few years ago, we produced a list for Hanover which is attached as an Annex.
- **Assistive technology and telecare** – there is a wide range of useful technology on the market, including door sensors or wandering bracelets which, with appropriate protocols and proper staffing can replace closed and locked doors. Hanover's Smart Choice service can assist.
- **Person-centred service delivery and staff training** - I would say that everyone working on an Extra Care scheme needs basic training on understanding dementia and communicating with people who have dementia. It is important that this is the person centred approach espoused by the likes of Tom Kitwood, and not the organic medical model. The more dementia orientated the service the more extensive the training should be. The goal should be for staff to recognise signs of distress and work to enhance a sense of well-being and "personhood". Dementia mapping, developed I believe by the Bradford dementia centre is a very helpful skill in this regard
- **Legal instruments for a person lacking capacity** – For more detail in this area, I would recommend Belinda Schwehr who has a useful website: www.careandhealthlaw.com

The following areas are addressed below:

1. Point at which people with dementia move in to a scheme
2. Moving on from Extra Care
3. Registration issues
4. Models - including an integrated approach vs separate wings
5. The issue of housing models and advanced dementia

1. Point of Entry

At Hanover we firmly believe that people with dementia should move into Extra Care as early as possible, whilst they still have some understanding of what they are entering into, and still have the capacity to develop relationships and learn new surroundings, albeit with support.

It is helpful for people to have early specialist assessments and diagnosis so that they can plan and prepare for the future. It is preferable to get as much of their life story, likes and dislikes etc from individuals themselves rather than only from family and friends. It is also advisable to recommend people arrange Enduring Power of Attorney which has to be done while they still have capacity.

People who move in to schemes past this “window of opportunity”, when they have difficulty building new relationships and learning their surroundings are likely to have great difficulty settling in and feeling part of the community.

However, of those who have moved in and settled early on, many will continue to live in the scheme for the rest of their lives very successfully. This applies too to those who develop dementia once there. So what are the limits to this happening.

2. Moving On from Extra Care

I am very careful not to promote Extra Care as a “home for life”. I tend to say we **aspire** to offer people a home for life. We cannot guarantee to do so. It is not within our power to make this possible for everyone.

There will be situations where it is in the interests of an individual and/or the community to move to a more protected environment. Each case needs to be assessed on its merits. Key factors to take into account include:

- Safety of/risk to the individual
- Safety of/risk to others
- Level of disruption to other residents
- Quality of life of the individual

There are a number of variables which play a significant part in influencing these factors. These include:

- Physical factors – design of the building and availability of assistive technology
- Availability of appropriate and SUFFICIENT care and support
- The culture and attitudes of other residents
- The availability of additional specialist services such as group work, CPN support
- The ability of staff to work effectively with all parties in the situation

Extra Care housing really is about working in partnership. Meeting the needs of people with dementia is a good example of this. It applies operationally with scheme managers, care staff, peripatetic specialist practitioners and voluntary organisations all working

together to support the tenant and family. Without this the situation can break down very quickly.

It **also** applies at a service commissioning level. I occasionally find that Health and Social Services want to have it both ways. They want people with dementia to be managed in Extra Care schemes but they are unable or unwilling to pay for the higher levels of care or specialist input needed to make this viable. Our research has shown that the single most prevalent reason for people with dementia moving on from Extra Care is the additional demands on carers' time.

Basically, the better the range of services in place and the closer the co-operation between agencies, the greater the chances of being able to meet the needs of a person with dementia in an Extra Care scheme for life.

3. Registration Issues: Care Standards Act and Risk of Registration as a Care Home

An establishment must be registered as a care home if it provides "accommodation together with nursing or personal care". You must all be familiar with that. But what does "**together**" mean? My understanding of it is basically that living there is conditional upon accepting the care service.

The Department of Health Guidance on this issue says: "Where it is clearly the case that personal care is being provided in a person's **own home**, then registration as a domiciliary care agency is likely to be required. There will be no registration as a care home, irrespective of the level of personal care available". The guidance also says, "In the case of Extra Care Housing or supported housing, possession of an assured tenancy will generally mean that a person has a right to deny entry to other people, including care workers, without this having an effect on their right to occupy the dwelling". Since receipt of care is not a condition of tenancy, arguably the accommodation and care are not being provided "together" in the way that the Act means.

Essentially then, having a valid tenancy is fundamental to the distinction between housing and residential care. But what if the tenancy lacks validity? A diligent CSCI (Commission for Social Care Inspection) inspector might be forgiven for considering a scheme registrable if its primary target is people who have passed the point of having capacity to sign a Tenancy Agreement **when they move in**.

Arguably, for this reason if for no other, people should move into Extra Care Housing while they can still legitimately sign a Tenancy Agreement and understand, if not the letter of the agreement, at least the essence of it.

Would the attorney of an Enduring Power of Attorney (EPA) be an acceptable substitute? At the moment the powers of an EPA are limited to financial areas, not decisions about the person, so whilst it might satisfy the financial aspects of a tenancy, it may not be sufficient legally. Under the new "Mental Capacity Bill" I believe a "Lasting Power of Attorney" is being introduced which will widen the scope of the powers, allowing decisions to be made about where people live. Whether that will also include taking on legal responsibility for a tenancy, I don't know. In either case the attorney can exercise no control over whether the occupant complies with the agreement or not, and if the tenant

doesn't have the capacity to understand what is expected of them, they cannot be held responsible.

I think a sensible approach is for the tenant AND the attorney to sign the Tenancy Agreement. This should ideally take place whilst the individual still has capacity. [Perhaps, in exceptional circumstances, this could be waived if the person clearly expressed a wish whilst they still had capacity to move in to Extra care, and this has been recorded, for example in a living will.]

My personal, admittedly pragmatic view, is that Extra Care housing is such a superior model for delivering independence and quality of life to most people, that if - as almost certainly will happen - somebody loses capacity during the course of the tenancy, the fact that when it was signed they **had** capacity should be sufficient to continue regarding it as valid. I think it would be a mean inspector who chose to interpret this differently. As to compliance: If, de facto, people's behaviour conforms to quiet enjoyment, that too should be sufficient.

But I personally draw the line at letting someone move into an Extra Care scheme when they clearly have little understanding of what they are doing. Getting someone who lacks capacity to put their signature on the dotted line is, in my view totally unacceptable however worthy the motives.

Another issue which is sometimes put to us is: "Can we give people short-hold tenancies as it will be easier to get them out?" (So much for putting the interests of the person uppermost). I am not going to dwell on this except to say that the process for moving people on would probably not be any different whether the tenancy was assured or short-hold, and in the eyes of CSCI you would arguably be reinforcing the case for registration as a care home by reducing the status of the tenancy.

4. Models of housing for people with dementia

Hanover has identified a range of possible Extra Care models for meeting the needs of people with dementia in Extra Care housing. These are:

Integrated Dementia Friendly schemes – These are essentially schemes where the design and décor as well as service delivery caters to the needs of people with dementia, but is essentially an integrated model which targets people from a wide range of need domains and levels of need. All Hanover's new schemes aim, at a minimum, to fall into this category.

Dementia Specialist schemes – These are schemes which are designed for and targeted primarily at people with dementia, but with a recognition that, unless on a fairly small scale, it may be difficult to fill such a scheme. Therefore, people from other need domains can also move to the scheme. We are currently developing such a scheme with a London Borough and it is seen very much as a pilot because it throws up fundamental questions like "will anyone without dementia want to move into it?"

Dementia Dedicated schemes – These are designed exclusively for people with dementia, probably on quite a small scale, a bit like supported housing for people with

learning disabilities. Dementia dedicated schemes are more likely to incorporate more extreme design and décor features such as the use of bolder colours to aid orientation and more personal touches such as photographs of the tenant on his/her front door.

Dementia Wings in Extra Care schemes.

I shall explore in a bit more depth the issue of wings vs an integrated model.

The following are some of the questions that I believe need addressing:

If these are also “housing” rather than “residential care”

- a) How should they differ from the rest of the scheme? Staffing levels? Security? Design features?
- b) At what point is it deemed that a person with dementia should be housed there rather than in one of the other flats?
- c) Does there come a point when even in a dementia wing, a housing solution is no longer suitable?
- d) What is the impact on community life and relationships between the wing and the rest of the scheme?
- e) Do the benefits of this approach outweigh the issues and problems?

Hanover gave considerable thought to these issues, and we reached the conclusion that we would not support the idea of separate housing wings for people with dementia. Our thinking went as follows:

We felt there was a danger of creating the perception of a ghetto and point of no return which could have a very divisive effect on the community. We are all aware of the cliqueishness and prejudice that can occur in housing communities, and we felt that separating out people with dementia would foster rather than discourage such discrimination.

We wondered how you decided whether a given applicant should move into the dementia wing rather than one of the flats elsewhere in the scheme. Also, we wondered what we would do when someone elsewhere in the scheme developed dementia. Would they be expected to move?

We took the view that those whose dementia was not very advanced could be catered for in ordinary dementia-friendly Extra Care schemes and would probably be too aware to want to be hived off in a special unit. They would therefore probably be unwilling to apply for the separate unit even if we wanted them to.

This would leave those whose cognitive impairment or behaviour was such that they would be unsuitable for ordinary Extra Care. The separate wing would therefore be catering for this group of people. They would need a high level of care and supervision by definition, and would have very limited capacity for taking advantage of the independent living aspect that a self-contained flat, own front door and tenancy/or lease would enable. Therefore it is hard to see how this could be anything other than residential care by another name.

We concluded therefore that we favoured an integrated, inclusive model of Extra Care housing which was dementia-friendly. We would discourage development of schemes which had a separate housing wing for people with dementia.

We **could** however see the arguments in favour of having a separate specialist residential provision on the same site, since this represented a true progression rather than a parallel service. For example, Fold Housing in Northern Ireland combines Extra Care housing for people with mild dementia and residential units for those with moderate to severe dementia. We could also see the value of having specialist services for people with dementia delivered in and from Extra Care schemes, for example group work for people with dementia which could benefit both residents and people from the wider community.

Some counter arguments:

I visited a scheme run by another housing association which has a dementia pod, and I found what I saw reassuring:

The whole scheme was “pod” based. Each pod’s communal lounge was situated at the beginning rather than the end of the pod, if that makes sense. Doors were kept open. Assistive technology and intensive staffing levels were used to manage any “wandering”. Relatives understood and accepted the risks. Staff collected in that lounge when not delivering care, and residents from the whole scheme were encouraged to pop in to that lounge. The manager argued that the fact that people with dementia were not scattered amongst the other tenants **aided** integration, because any disruptive behaviour was contained in the pod.

Their policy was that everyone with signs or a diagnosis of dementia would be allocated a place in the pod. However people who developed dementia elsewhere in the scheme would not be expected to move. Also, they were clear that the pod was not targeting people in the advanced stages of dementia and indeed someone who had moved in past the “window of opportunity” had to move on to residential care. Their eligibility criteria precluded people who manifested extreme behaviours.

The reason that scheme worked included:

- A very dynamic highly paid scheme manager who had excellent group work and leadership skills
- Highly trained staff
- The fact that the pod design applied to the whole scheme, and the open plan approach
- Additional services including “enhanced day care” for people with dementia
- Many tenants knew each other before they moved in

Of course many of these can and should apply equally to an integrated model, and I would still argue that on balance it is much more difficult to enable the integration of a community which is physically separated, than one which is physically integrated. And the pod is not catering for people with advanced dementia or extreme anti-social behaviours, which brings me to my last topic:

5. Is a housing model suitable for people to move to if they are in the advanced stages of dementia?

First, a couple of questions:

What is the essence of a housing model?

What is it that makes it distinctive?

Is it that people have tenancies, leases or are owner occupiers? If they are unable to hold a tenancy agreement or equivalent, needing somebody to act on their behalf, does this undermine the validity or point of using a “housing model”? I think the answer to this is, yes, to a significant degree, because virtually every other characteristic of a housing model could be replicated in a residential care model.

Is it that they have their own self-contained flat? Perhaps. This may not necessarily be an advantage to someone who moves in with severe dementia. If it is, you could provide it without a tenancy or lease.

Is it being able to exercise control and choice over who steps across your threshold? Probably. Without the capacity to make informed choices, how valid or relevant is this?

Is it about quality of life – privacy, quiet enjoyment etc? This feature need not be exclusive to housing models.

Is it “intensive housing support”? The sort of understanding, encouragement and gentle guidance that people with dementia need goes beyond an artificial distinction between care on the one hand or support on the other, and is certainly not intrinsic or exclusive to a housing setting.

People in the advanced stages of dementia or with extreme challenging behaviours need a high level of care and supervision by definition and are unlikely to be able to sign a Tenancy Agreement in their own right, so why not admit that we are entering the realms of residential care?

Arguably once people have reached this stage, holding a tenancy is relatively meaningless, quiet enjoyment is a hit-and-miss affair, and making an informed choice to refuse care or entry to their flat may be somewhat dubious. In other words they would have very limited capacity for taking advantage of the independent living aspects so fundamental to a housing model.

So why not aspire to incorporate the best relevant aspects of the housing model into specialist residential care provision, in terms of design, opportunity for fulfilment and an independence promoting ethos, rather than trying to shoe horn people into a model which either has to mimic what it purports not to be, or is inadequate to meet its residents’ needs? I am aware of some excellent residential care models which are designed specifically for people with dementia and which work to promote quality of life and well-being.

Very well-meaning people have said to me, “Sue, to exclude people with advanced dementia from Extra Care housing is to discriminate against them.” I may be proved

wrong, but I feel that to push people without capacity into housing models may be to discriminate against them...or alternatively to be living a lie.

I am a passionate advocate of Extra Care housing, but I don't see it as a universal panacea, and I believe one of its limitations is in the area of advanced dementia.*

In summary:

- Extra Care housing can be very suitable for people with dementia
- They should move in early and with appropriate support, many may well be able to remain for life
- Both tenant and prospective attorney should sign the tenancy agreement
- People in the more advanced stages of dementia should be housed in specialist residential care rather than Extra Care housing
- Think and plan very carefully before going down the route of a dementia housing wing

We don't know all the answers. I have just given my viewpoint on the issues. I am eager to learn how others have addressed them. What I am not keen on is overlooking or dismissing them because they are not simple, clear-cut and easy to resolve.

If you would like to **comment on this paper** or wish to share your experiences, visit the Housing LIN discussion forum on www.changeagentteam.org.uk/housing.

*The writer is aware that to lump together incapacity, disruptive behaviour and other distressing manifestations of dementia as "advanced dementia" and capacity, non-disruptive behaviour and fewer distressing manifestations as early dementia is an over-simplification. However, this liberty was considered necessary to make some clear points of principle in a paper of limited length.

Annex

CHECKLIST OF FEATURES FOR DEMENTIA-FRIENDLY DESIGN

Outside

- Secure boundaries so that it is safe to wander, but perimeter to be as unobtrusive as possible e.g. hedging rather than fence.
- Circular paths with interesting features along them to stimulate interest and aid orientation
- Wide field of vision without major visual obstacles to allow staff observation
- Planting should include sensory & tactile planting & avoid poisonous/dangerous plants
- Design should preferably include a working area including potting shed/greenhouse & raised planters & traditional washing lines (not whirligigs)

Indoors

- Use of wall colouring to aid orientation should be neutral and not patterned. Subtle changes in colour aren't helpful to the person with dementia they should therefore be obvious albeit not aesthetically unpleasing.
- Conspicuous colours on doors needing to be identified by person with dementia – e.g. all toilet doors to be yellow N.B. signage see below.
- All doors **not** needing to provide access to residents e.g. sluice room to be same colour as walls to merge into background.
- Flat doors to be denoted through pictures, colours and signs as personal to the occupant as possible e.g. pictures of the occupants/tools used in former trades etc.
- Use of symbols (obvious not stylised) in addition to words to aid orientation. Signs to be at eye level.
- Use of distinctive pictures, artefacts, bay windows, activity alcoves etc to provide unique landmarks to aid orientation and to provide points of interest.
- Several small meeting and activity areas aid interaction as well as assisting with orientation.
- To prevent the wanderer from exhausting themselves common rooms should be as open plan (or easily viewed through maximising windows both internally and externally) as possible. This assists sense of security and means that the individual can be easily diverted to an activity that interests them in addition to staff being enabled to monitor individuals unobtrusively.
- Minimal use of corridors as these increase disorientation; where necessary should be wide to avoid feeling restricted.
- Preferably there should be no corridor ends e.g. there should be a continuous circular path (both internal & external) at ground level with activities/rooms etc to prevent the individual with wandering characteristics from exhausting themselves. Where a corridor end cannot be avoided then a mirror is sometimes useful to divert the individual back the way they came.
- Increased lighting in activity areas, aiding interpretation. Effort to maximise lux levels to mimic natural daylight as far as possible by using borrowed light etc. Maximising natural light in communal areas assists the individual to differentiate between night & day.

- Reduce as far as possible echoes and features introducing sound distortion
- Floor finishes should be plain coloured; heavy patterns can be confusing. Carpet is preferable to vinyl. Texture & colour should be as consistent as possible throughout common areas of the scheme. Flat floor coverings should be distinguishable from common areas but should be consistent throughout the flat.
- Fittings and equipment to be as standard and domestic as possible, aiding familiarity
- Heavily sprung doors should be avoided
- Windows should allow good view from a seated position
- PIR sensors (Infra-red sensors) may be useful tool in monitoring wandering.
- Bathrooms should include tile bandings particularly where there is no natural light to aid the individual to calculate depth/height. Tiles should be of an obvious different colour to basin, toilet etc to enable the individual to locate them.
- Consideration should be given to include a backlit light switch between bedroom & bathroom, to enable location during the night.
- Consideration should be given to incorporating manual cut off switches external to the flats to enable staff to isolate supplies if a resident becomes a danger to themselves (e.g. gas).
- It may be necessary to 'hide' some control switches e.g. for fridges to remove the temptation to the individual to switch everything off.
- As far as possible design should incorporate the principles outlined by Mary Marshall in Designing for Dementia.

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(This list is based mainly on work by Mary Marshall of the Stirling Dementia Centre; it was compiled in July 2001 and may not include all current thinking on the subject.)

Other Housing LIN publications available in this format:

Case study no.1: **Extra Care Strategic Developments in North Yorkshire** *A snapshot view of partnership-based strategic planning for extra care in North Yorkshire, highlighting the variety of issues that need consideration in a large and mostly rural area. One recent scheme and one in progress are described.(01.09.03)*

Case study no.2: **Extra Care Strategic Developments in East Sussex** *Some of the key issues involved in partnership-based strategic planning for extra care in East Sussex. A small conversion from sheltered housing and a larger new scheme catering for a range of use. Different management models are briefly discussed.(01.09.03)*

Case study no.3: **'Least-use' Assistive Technology in Dementia Extra Care** *Rowan Court, Eastleigh, Hampshire - An example of provision of extra care facility for older people with dementia, based on a philosophy of promoting and maximising independence.(02.02.04)*

Case study no.4: **Tenancy Issues - Surviving Partners in Extra Care Housing** *The development of tenancy agreements for couples in Extra Care Housing, based on the experience of an Extra Care project in Southampton (01.06.04)*

The Housing LIN also publishes a range of Factsheets examining different aspects of Extra Care. These are all available from our website;

www.changeagentteam.org.uk/housing

Factsheet no.1: **Extra Care Housing - What is it?**

Factsheet no.2: **Commissioning and Funding Extra Care Housing**

Factsheet no.3: **New Provisions for Older People with Learning Disabilities**

Factsheet no.4: **Models of Extra Care and Retirement Communities**

Factsheet no.5: **Assistive Technology in Extra Care Housing**

Factsheet no.6: **Design Principles for Extra Care**

Factsheet no.7: **Private Sector Provision of Extra Care Housing**

Factsheet no.8: **User Involvement in Extra Care Housing**

The Housing LIN welcomes contributions on a range of issues pertinent to Extra Care housing. If there is a subject that you feel should be addressed, please contact us.

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