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COMMISSIONING EXTRA CARE HOUSING FOR PEOPLE WITH DEMENTIA: KEY CONSIDERATIONS

INTRODUCTION

I received the following e-mail a couple of months ago :

"My name is Samantha Smith, and in February of this year my Mother moved into a brand new extracare scheme. I believed it would be the answer to our problems---however it has actually thrown up a whole load of new ones. These problems have not been brought about by any serious deterioration in my Mothers condition (although there is no doubt that she is in decline) but by the very fact that the provider seems not to understand their role or advise any ethos. None of the staff have received any training in dementia care. The design of the building causes great confusion - simple things like signs being put up on walls have not been actioned. I could go on and on. I hope you don't mind my contacting you but I am so very desperate. Can you please advise me?"

It highlights the importance of the inter-agency preparation needed to develop a scheme in terms of shared vision, ethos, agreements, services, policies, processes and training. If you are aiming to cater for people with dementia there are lots of extra facets to think about.

Appended is a sheet entitled "Extra Care Housing for People with Dementia – Key Points to Consider When Developing a Scheme". Although many of the points also apply to scheme commissioning generally, I have for the most part only listed those which have a dementia-specific angle. It may not be comprehensive, but these are some of the aspects that organisations developing Extra Care schemes for people with dementia should think about.

What is meant by dementia-specific? Take for example the second bullet point under physical aspects. Of course you have to think about the layout and number of units for any scheme, so why list it specifically for one which caters for people with dementia? Because, the fact that it aims to cater for people with dementia may well affect your decision. A smaller scheme may be better for this group, but may also make it very expensive. Thus there may need to be a trade off between number of units and the range of facilities. Ideally your decisions should be driven as much by what is best for the target group as by the economics. What we could all do with is a cost-benefit analysis of different models.

This paper explores a number of issues and elaborates on some of the key points that commissioners and developers need to consider.

- 1) Should Extra Care housing replace care homes, or does the model have limitations for people with dementia?
- 2) What are the pros and cons of different models of Extra Care for meeting the needs of people with dementia?
- 3) Achieving a match between the needs of the people being targeted, and the features of the Extra Care development.

1) REPLACEMENT FOR RESIDENTIAL CARE

This is a very complex area, and I can only skim the surface, though a more thorough exploration of the issues can be seen in an article recently published in the Journal for Dementia Care and published as Viewpoint 4 by the Housing LIN.

<http://www.changeagentteam.org.uk/library/docs/Housing/Viewpoint04.pdf>

It is very much a matter for debate and research, and my view is not necessarily correct.

Which should be paramount – promoting independence or promoting well-being which in some cases means functioning independently?

People often interpret the government mantra of “promoting independence” in a very narrow way; essentially, helping people to do things for themselves. That’s great for those who choose, and are able to benefit, from this approach but not everybody does or can. In my book, promoting independence means allowing older people to make their own life choices in so far as they are able, and some may choose to have things “done for” them.

Christine Bryden, in her inspiring book “Dancing with Dementia” talks about living with dementia and “tiredness of the brain”. She says: “Find out what our real priority is, and then manage our life by helping with all sorts of other things so that we can focus on that one thing we want to do”.....”being with the family”...”caring for the garden” or whatever. “Paul has freed me to focus my limited energy on what really matters to me.”

That is why I sincerely believe that promoting an individual’s sense of well-being however that is achieved, is a more important fundamental principle than promoting independent functioning. No two people with dementia are the same and whilst some may be more fulfilled in the independence promoting environment of an Extra Care housing scheme, others may feel a greater sense of fulfilment in a residential care setting which offers closer care and supervision, and hands out cups of tea, so long as it also enables meaningful activities to maintain interests or unlock latent skills.

“Choice” reason for not eliminating specialist residential care

So there is a “choice reason” why I believe that Extra Care should not be a total replacement for residential care. My view is that we should be developing a variety of provision which recognises diversity, and the “universal panacea” approach to Extra Care is in danger of inhibiting diverse development.

Suitability of a housing model

But there is also the question of the suitability of a housing model for some people with dementia.

Moving in early

I have reached the conclusion that many of those people who need a very high level of care and supervision, and whose capacity for self-reliance and independent functioning has become very limited, may actually be better off and more fulfilled moving to a good specialist residential home than to an Extra Care scheme. Even at the specialist schemes I’ve visited or heard about, there seems to be general consensus that Extra Care has its limitations, and timing of entry to the scheme is very important. People need to move in early, when they still have the capacity to be involved in the decision and process, to understand that they are moving home, to build new relationships and learn their surroundings – albeit with help and support. Once part of the resident community, they are likely to be supported by other residents¹ as their dementia advances, something which tends not to happen if they move in much later. And, assuming they settle in, there is a good chance of remaining in the scheme for the rest of their days.

Advanced dementia

¹ The term “resident” is used to cover people occupying under a range of tenures.

It is not as simple as saying that a move to Extra Care is not suitable for people in the advanced stages of dementia or with particular challenging behaviours. It is very much about an individual - what he or she is like as a result of personality, life experience, physical and mental health including dementia - as well as whether he or she is the sort of person who craves maximum independence or prefers to be looked after. The key is a really good assessment and preparation.

Features of a housing model which make it unsuitable for those with severe cognitive impairment

So, on what grounds have I concluded that Extra Care is not the ideal solution for everyone with dementia, in particular those with severe cognitive impairment? (Let me just emphasise that what I am talking about here is not those people already living in an Extra Care scheme. I am talking about those people with dementia living in their home in the wider community, for whom a move has become necessary because the services available are inadequate to support them where they are.)

- By definition, the people we are talking about have very limited cognitive capacity to exercise the rights and choices afforded by possession of a tenancy or lease, such as refusing care.
- The intensity of care and supervision needed is likely to result in an institutional feel
- Dementia-trained domiciliary care staff, purchased by the hour at the level needed, is likely to be prohibitively expensive
- If the tenancy is taken on at a point where the individual lacks capacity to sign it, and doesn't have Enduring/Lasting Power of Attorney in place, even if legally it counts as a tenancy, there may be a risk that CSCI would question its validity. The argument may then go: not a valid tenancy, therefore not living in own home and therefore accommodation and care is being provided together within the meaning of the Care Standards Act.
- Some of the features of Extra Care which facilitate freedom of movement and independent living for those with capacity are likely to be impediments, or the subject of misidentification, to those who are unable to learn their use - for example door entry systems, and alarm pull cords.
- Physical design for those needing continuous human contact and reassurance is likely to be different from those seeking to live independently - in terms of scale, line of vision etc.

The case for specifically designed provision

I feel that there comes a point where the very essence of the housing model, its distinctive features and benefits, become compromised, meaningless or counterproductive in the context of people with advanced cognitive impairment. Some people argue that a residue of benefit remains. My own view is that if we didn't polarise between "Extra Care - good" and "Residential care - bad", we could - within existing frameworks - develop provisions in terms of physical design, assistive technology and staffing, specifically tailored to people with higher levels of need. These would combine the best relevant facets of housing and residential care, to provide accommodation and care which optimally promoted the well-being of this group, whilst delivering value for money to all funders.

A plea for honesty

Of course, you may disagree with my conclusion. All I would say is this. IF you choose to go down the Extra Care route for people in the more advanced stages of dementia or with particularly challenging behaviours, please do not skimp on staffing levels and training, and then pretend you are doing the residents a favour. Contrary to popular belief, Extra Care may not always be a better or cheaper option than residential care. Good quality dementia care does not come cheap. All too often providers have told me that local authorities want the scheme to cater for people with dementia, but are not prepared to commission appropriate levels of care.

So, then, for reasons of choice and optimum suitability, I do not believe that Extra Care should completely replace residential care for people with dementia, Extra Care should become increasingly capable of meeting their needs.

2) MODELS OF EXTRA CARE

If you are intending to develop a scheme which caters for people with dementia, which approach should you adopt?

- Should you develop an integrated “dementia-friendly scheme” which targets people from a wide range of need domains, but in terms of design, assistive technology and staffing is suited to people with dementia?
- Should you develop specialist or dedicated schemes, targeted primarily or exclusively at people with dementia?
- Or should you have a geographically distinct housing unit for people with dementia, within a general Extra Care scheme?

Common characteristics of schemes with separate housing dementia wings

I have visited a number of schemes with separate dementia units and contrary to expectation did not find them to be ghetto-like points of no return. I preferred those with a “daisy” design of central core for communal and office facilities, and several “petals” off it with a cluster of flats, one “petal” comprising the dementia wing, to those where the dementia unit was a separate limb at the end of a corridor. The former design made the dementia wing feel less singled out. They all had a high calibre Scheme Manager to provide leadership and stamp a clear ethos of inclusiveness onto the scheme, as well as an integrated housing and care management model.

Of the applicants accepted for the scheme, all those with dementia tended to be directed towards the dementia unit. In other words there wasn't some arbitrary distinction between those who went into the unit and those who were offered flats elsewhere in the scheme. But of course, people in the other parts of the scheme are not immune to dementia, and, quite rightly in my view, when they developed dementia, they were not asked to move, so the distinction between the dementia wing and the rest of the scheme started becoming blurred anyway. Even with a separate wing, some people with dementia were not offered places because it was considered that their needs could not be properly catered for.

Advocates of separate wings made the point that clustering those with dementia together meant more tolerance, not less on the part of residents in the rest of the scheme, as they were less likely to be disturbed by someone entering their room uninvited. It was also argued that when staff were not delivering care and support plans, the dementia unit provided a focal point for the staff to gather.

Despite a discrete physical area, little attempt seemed to have been made to tailor the design, décor, assistive technology and staffing levels in the unit specifically to the needs of people with dementia. That strikes me as a missed opportunity, and if you are not planning to do that, my view is that the potential disadvantages of a separate wing outweigh the advantages.

Preference for other approaches

To my mind, a separate parallel unit is potentially divisive, and becomes undermined over the life of a scheme anyway. I think there is only justification for - what feels to me like - “segregation”, if something significantly different is being provided; something which meets the needs of those residents in a much better way and which needs to be geographically discrete to deliver these advantages. But these differences could in themselves trigger resentment from other residents. So I personally prefer any of the other approaches to having a separate unit. But I totally uphold your right to disagree if you can make the case.

I have seen integrated dementia-friendly schemes work well. In any case whether they specifically target people with dementia or not, all Extra Care schemes should be as dementia friendly as possible because some people will develop dementia once they're there. I also think there is a lot to be said for specialist schemes because all aspects of the provision can be specifically tailored to meet the needs of people with dementia. I know of large and small ones which work well, although with these, you may have to work harder to ensure the scheme does not become isolated from the wider community.

One particular scheme which really impressed as providing fulfilment and well-being to its residents was a small dedicated scheme with 8 flatlets and two shared kitchens, and a high staffing ratio funded by Supporting People and Adult Social Care. But even at this scheme, where much attention is paid to proper assessment and preparation, with applicants spending time at the scheme in the guest room as part of a mutual assessment process, commissioners and providers agree that it is not suitable for everybody with dementia. And they don't always get it right. One woman who moved in subsequently moved away because it was felt her needs could not be met in that setting.

Scope for meeting higher need levels in specialist schemes?

Do dedicated and specialist schemes, offering as they do the opportunity for a more tailored provision, have the capacity to meet higher level or more complex needs including challenging behaviours? I think this does apply to a degree. In part this is because of the physical design aspects. But also, commissioners are more likely to be willing to fund specialist care staff who have had proper training in dementia care rather than a one or two day "what is dementia" course. The advantage therefore is in the quality of the care which in turn is likely to result in happier, more fulfilled residents with fewer signs of ill-being.

Combination Developments

There are a number of organisations which are developing specialist dementia resources which combine a range of provision – including Extra Care, residential-cum-nursing home care, day care, and outreach services, some even with plans to incorporate a children's day nursery to have an inter-generational mix. Such developments seem very positive.

3) ALIGNING SCHEME FEATURES WITH TARGET GROUP NEEDS

Mr Clark moved into a new dementia-friendly Extra Care scheme, much to the relief of his daughter who felt he wasn't managing any more in his own flat. As someone in the relatively early stages of dementia, he seemed an ideal candidate for Extra Care. The ethos of the scheme was very much about promoting independence. Early one morning he went out, and was seen by a member of staff in the local supermarket. The member of staff went about his own business and returned to the scheme. When Mr Clark didn't arrive back for lunch, panic ensued and he was reported missing. He was found late in the afternoon shivering in his daughter's garden some distance away. Two days later he died. There's no proof of cause and effect, of course, but his behaviour back at the scheme demonstrated that he was deeply traumatised by his ordeal.

What lessons can be learnt from this story?

So what does this tell us? It's about listening to what the family has to say, and working with the family. Getting to know your residents. It's about communication – ensuring all staff know that it is fine for Lottie Shaw to go out unaccompanied and she will be able to find her own way back, whereas it is not safe for Mr Clark. It's about staff training. Crucially, it's about the quality of the assessment, including assessment of risk. For each individual there needs to be a balance between promoting self-determination and autonomy on the one hand, and safeguarding on the other. Be too cautious and protective and you unnecessarily curtail an individual's freedom, and with assistive technology to assist, there is less justification for undue restrictions. Get it wrong on the other hand, and the individual could be seriously endangered.

Implications for scheme development

Approach to "wandering"

So what do you do about those people for whom walking out of the scheme unaccompanied is deemed too risky? You have a range of options. Do you exclude them from moving to the scheme and reflect this in your eligibility criteria? Do you use tracking devices or door sensors and agree protocols for using them? Do you provide a high enough staffing level to enable someone to

accompany Mr Clark if he chooses to go out? Do you make exits secure so that he cannot get out unaccompanied, and if you do, are you at risk of making the scheme too institutional, undermining the very advantages of a housing approach? Do the residents' families understand and accept your general approach and the balance you intend to apply to their loved one? Much better to think about these things in advance and agree general approaches and frameworks, than leave it to staff to feel their way. That way applicants and families know what to expect and can turn down an offer if it is not to their liking.

The features of the scheme such as design, services and policies should be shaped by the eligibility criteria, including need levels you are targeting – or vice versa. The assessment in turn has to look at the individual's needs in the context of those criteria. If there is a mismatch between scheme characteristics, eligibility criteria and allocations you are unlikely to have a quality scheme. And of course, review mechanisms and flexibilities need to be built into agreements and contracts so that adjustments can be made down the line. This is just as important for a dementia-friendly scheme as a specialist one.

Eligibility Criteria – dementia related

What might dementia-related eligibility criteria look like? This will depend on the nature of the particular scheme in terms of staffing, design, assistive technology, policies etc. The following are likely to be relevant:

- Degree of cognitive impairment – ability to understand and get involved in discussions about a move, express agreement, form new relationships and learn new surroundings with help
- Level of insecurity, distress and anxiety and likelihood of this being reduced by Extra Care environment
- Personality – Independently minded sort of person who is likely to feel fulfilled by being as self-reliant and self-caring as possible, with support
- Presence and extent of certain behaviours:
 - Anti-social behaviours such as aggression, disinhibition and extent to which it is felt that these are likely to be reduced by the Extra Care service configuration, or at least containable
 - Likelihood of being able to abide by quiet enjoyment clause in tenancy
 - Walking about and extent to which that can be safely accommodated
- Capacity to sign a tenancy agreement or lease or authority in place for someone else to do so on resident's behalf – e.g. Enduring/Lasting Power of Attorney

Many schemes aim to accommodate people with a range of need levels and a mix of need domains to retain a balanced community.

Assessment

Guidance on eligibility is important but can only be applied if a proper needs and risk assessment is undertaken – and the results properly communicated. SAP principles apply. Ideally the assessment should be undertaken by a dementia specialist. It could be a joint assessment between care manager/CPN and the scheme manager - often the scheme manager has specialist knowledge. Ideally the same member(s) of staff should undertake all assessments so that they build up expertise based on an in-depth understanding of dementia, the characteristics, strengths and limitations of the particular Extra Care scheme, and the other options available. Much attention should be paid to:

- engaging the individual in the process as far as possible
- taking into account her views and wishes
- gathering information on personality, likes and dislikes, history, physical and mental health
- preparing her for the move over a suitable period of time
- exploring legal aspects such as Enduring/Lasting Power or Attorney

One specialist scheme won't accept anyone to the scheme who hasn't at least visited it.

Moving On

Despite all the rhetoric, the most common reason for people moving from Extra Care schemes, apart from death, still seems to be dementia. And all too often this is because commissioners are unable or

unwilling to increase the level of care provision, and/or staff have not been adequately trained to understand and handle challenging behaviour.

All of that said, it is very unlikely to achieve a situation where no-one ever has to move from Extra Care, and therefore it is probably dishonest to promise a home for life. However all partners should be working together at all levels to make that aspiration as close a reality as possible. The factors which play a part in deciding whether a resident needs to move will 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

These variable are things that commissioners and providers have significant influence over, and therefore some EC schemes will cater much better for people with dementia than others. In my experience, it is very unusual to use eviction as a tool for getting older people to move out of their flats. In fact, you would fall foul of the Disability Discrimination act if you tried to evict someone whose flouting of the tenancy agreement resulted from their disability. Where a scheme can no longer meet the needs of a person with dementia properly, with all the services that can be mustered – and in an ideal world with a peripatetic specialist dementia team – the individual, family, advocate and professionals need to work together to find an acceptable solution... sometimes easier said than done. Each case should be dealt with on its merits, but preferably on the basis of a jointly agreed framework of criteria drawn up during the scheme commissioning phase. Whilst you cannot anticipate every scenario that could apply, you can anticipate many.

If care cannot be increased to meet the changing needs of individuals or the tenant population as a whole, it is better to be open and honest about that at the outset than raise false expectations amongst staff, residents and their families.

CONCLUSION

There are two key themes I feel it is really important to convey about developing Extra Care in general and Extra Care for people with dementia in particular.

Firstly, when planning and developing Extra Care schemes it is essential to engage all partners in thinking about these and the other points outlined on the attached list, researching the different options as necessary, and developing a shared vision.

Secondly, it is essential to ensure that all its features – physical design; ethos and eligibility; policies, procedures, operations and internal communications; assistive technology devices; staffing levels and training – are properly suited to the group of people for whom the scheme is aiming to cater, and that the assessment and allocation process does not form a weak link in the chain.

This preparation forms the foundation of a robust, effective, quality operation. Do it, and we are less likely to get situations like those of Samantha Smith's mother and Mr Clark.

Sue Garwood

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EXTRA CARE HOUSING FOR PEOPLE WITH DEMENTIA

KEY POINTS TO CONSIDER WHEN DEVELOPING A SCHEME

PARTNERSHIPS

- Identifying key stakeholders

FINANCE

- Sources of capital funding
- Sources of revenue funding

PHYSICAL DEVELOPMENT ASPECTS

- Range of provision – Housing only or resource centre, nursing home and other services as well?
- Implication of intended usage for building design – facilities for staff, outreach service, day care, respite and intermediate care, base for other staff/organisations, parking facilities
- Building Design – number, size and specification of individual units; lighting; aids to orientation; use of the familiar; scale; security features; field of vision; use of colour; walkways etc
- Assistive technology and telecare – infrastructure and choice of devices

OPERATIONAL DEVELOPMENT ASPECTS

- Dementia-dedicated, dementia-specialist or dementia-friendly?
- Integrated or separate dementia wing?
- Tenure – rented, for sale, shared ownership or mixed tenure?
- Legal aspects – validity of tenancies or leases, registration requirements (domiciliary or residential)
- Eligibility criteria – point of entry and criteria for directing elsewhere
- Assessment process and individual preparation – including diagnosis, E/LPA and personal history
- Policies and procedures – e.g. risk assessment and management; guidelines and protocols for use of assistive technologies
- Service Design – person-centred provision, management structure, staffing levels, group work
- Staff training – joint, where housing and care separate
- Ownership and support from peripatetic services – community mental health services, Alzheimer's Society, PCTs, GPs
- Moving-on criteria and processes
- Potential user consultation and involvement
- Communication strategy – ensuring potential applicants and families understand what's on offer