

“Is it that time already?”

Extra Care Housing at the End of Life:

A policy-into-practice evaluation

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Summary

Background

Changes in the funding and provision of housing and social care for older people have, over the past 15 years, resulted in older people increasingly not receiving support until a point where disabilities and illnesses have become a significant factor in their daily lives (CSCI, 2008). This is as true for more recent provision such as extra care housing as it is for long-established services such as residential care homes, and home care.

More recent policies have become focused on ensuring that older people have more choice and control over their lives, including choice over the place where they die. For example, at the end of the project, in July 2008, the government published its 10-year National End of Life Care Strategy. This has significant implications for extra care schemes such as those run by Housing 21, whose older tenants' support needs are increasing and many of whom want to be remain living there until their death.

Aims and objectives

In early 2008, Housing 21 and the National End of Life Care Programme began a 6-month service improvement pilot project designed to enhance dignity and choice in end of life care (EoLC). The project was designed to be delivered locally with national support. It aimed to:

- Enable (terminally ill) extra care tenants to die at home if this met their choice
- Put in place processes to ascertain and meet tenants' wishes and preferences
- Develop an integrated approach to work within the community in accessing supportive care for tenants, their families / carers, and staff
- Explore the challenges represented by providing EoLC in extra care housing settings
- Improve the skills and knowledge base of staff
- Develop high quality data monitoring tools and ensure the ongoing provision of good baseline data.

Pilot sites

Three extra care schemes, identified by Housing 21, took part. Two were in the north east of England, and one in East Anglia. The schemes reflected a number of differences, including:

- Rural versus urban areas
- Different care staff configurations
 - Housing 21 directly employed and managed the care staff at Court B;

- the local authority employed and managed the care staff at Court C;
- the local authority employed – but Housing 21 managed – the care staff at Court A.

Methods

This service improvement project took place between January and July 2008. Initial meetings were held in each area, with Housing 21 and the National EoL Care Programme bringing together the key stakeholders from both organisations, to explore the main challenges and outline roles and responsibilities for the project.

In both areas the work was locally driven, with national support from both organisations. As the project progressed, it was guided by ongoing discussions between the relevant NHS Facilitators and Court managers as to what would be most helpful in terms of training and other support to the participating schemes.

The project was evaluated over the same timescale, using qualitative and quantitative approaches. It was supported by the project group. Two visits were made to each site, in February/March 2008, and again in June 2008. Face to face interviews and discussions were held with a wide range of staff, managers, tenants, and local health and social care professionals. Some telephone interviews were also carried out. A survey designed to collect data on the deaths of tenants across all Housing 21's extra care schemes was completed during the course of the fieldwork.

The evaluation was based on the Realistic Evaluation approach. This considers what works, for whom, and in what circumstances; and builds in from the beginning an understanding that circumstances will vary across sites, and over time.

Key outcomes

Aside from external developments, over the course of the evaluation several significant changes became clear:

- It had become more 'normal' for extra care staff to talk and think about end of life care;
- Staff knew more about what signs to look for, and how to respond: for example, when during the course of the project a tenant deteriorated suddenly and died over a weekend, they were able to improvise whilst waiting for the district nurse to attend with supplies;
- Health, housing and social care professionals wanted to talk about and plan how extra care schemes could support end of life care;

- Health professionals began voluntarily to offer additional support to scheme staff;
- Extra care staff knew more about what the local specialist services offered, and how to access these.

Main issues

Four key issues emerged during the project and its evaluation. These concerned issues to do with:

- Promoting dignity and choice for older people and family carers
- Staff support and skills development
- Extra care and its links to wider health and specialist resources
- Commissioning and funding.

Conclusions

Despite some initial lack of understanding of extra care housing amongst service commissioners, health and social care providers and tenants and their families alike, this project demonstrated a very real desire to learn more about what was possible in terms of supporting people at the end of their lives in extra care housing, and to put examples of best practice into place.

What appeared to have been holding professionals and organisations back was essentially an uncertainty about what to do for the best, and a fear of doing something wrong. This is a particularly pertinent aspect, given our current overall tendency as a society to avoid talking about death and dying. It is not surprising, then, to find these personal reluctances carried into professional situations.

The increase in the numbers of extra care schemes is taking place at a time when the profile of tenants is of their growing older and having greater levels of disability before moving in. This includes rising numbers of extra care tenants with dementia.

This is particularly important given the current policy priority to what is being called the personalisation agenda: in other words, and in this context, older people having far greater choice and control over how any support needs are decided and met. Coupled with the recently published NHS End of Life Strategy, this will increasingly include choice and control over where tenants die.

This relies heavily on knowing what tenants would like to happen; which in turn relies on asking them about and recording their wishes, and then

ensuring these are known, respected and adhered to by all involved, whether family or paid professional.

At the heart of effective personalisation and partnership working, everyone involved needs to have a shared understanding of their individual role(s) in helping the tenant achieve what the tenant wants at the end of his or her life. Actual roles for commissioners, care staff and managers, landlords, families, health professionals, and organisations, will differ – but it needs to be clearly understood how these roles, and critically the way they are delivered, work together.

In terms of improving end of life care in extra care housing settings, what is important is to start with what is easy and possible locally, and build from there. There are potential challenges in situations where whoever operates the housing element of extra care housing does not also manage the care service. The importance of ensuring that both the housing and care providers are at the same stage in terms of their approaches to personalising support is already evident; this is likely to become essential over the next 2-3 years.

Overall, the respectful listening and learning that all parties in the two pilot areas have demonstrated has in many ways formed the heart of this service improvement project. It is an approach that has added to the whole, and has helped many people better understand what is happening now, and what needs to happen next.

Recommendations

Personalisation for end of life care involves working together, across any professional or organisational boundaries, to achieve the tenant's wishes. This in turn requires prior knowledge and understanding of what the tenant wants, as well as what the extra care scheme in which he or she lives can support and accommodate:

- Clear and concise information about extra care housing is needed for and by tenants, families and health / housing / social care professionals and organisations.
- Policy makers and service commissioners should ensure that extra care housing is seen as part of the continuum of living at home, as part of the community rather than in the context of care homes.

- Opportunities to raise public awareness about death and dying should be developed and taken; this is a critical, ongoing role for the NHS End of Life Care programme.
- At a local, operational level, opportunities need to be found to bring professionals together to talk about who does what and how things might need to change to improve outcomes for tenants. This includes ensuring that extra care colleagues are involved in relevant local Forums and working groups, and that extra care schemes offer to host external colleagues' meetings at the schemes, combining this with an opportunity to raise broader awareness of extra care by offering an organised visit around the scheme.
- Extra care housing providers should incorporate a basic introduction to end of life issues as part of staff induction so that the issue is embedded in professional practice.
- Specific training for extra care managers and staff should include new arrangements under the Mental Capacity Act 2005; symptoms of terminal stages of life and technical knowledge of what to look for, report and record; information about local services and how to access these; support for bereavement and grief.
- It is important for tenants and their families to have opportunities to discuss and record their wishes. A 'one size fits all' model is not appropriate and any questions or forms should be optional. Extra care providers should consider how to incorporate the issue of end of life care into existing policies and practices. For example, a simple question could be linked to an existing care or support plan.
- Tenants need to feel sure that their wishes will be respected as far as possible. This includes respect from families, even if they are opposed to what the tenant has chosen for him or herself.
- Extra care housing providers should ensure that specialist support can be accessed for people with dementia or other mental capacity issues, so that the choices of people with dementia can be communicated and recognised. With the support of the King's Fund, Housing 21 has recently appointed an End of Life Dementia Nurse. Initially working in London, the nurse will help ensure family carers and care staff access the specialist support they need.