housing21

NHS

End of Life Care

"Is it that time already?"

Extra Care Housing at the End of Life:

A policy-into-practice evaluation

By Lorna Easterbrook with Sarah Vallelly

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Foreword by Jeremy Porteus

It is hard to think of a more "personalised" issue than how we die.

End of life care is therefore likely to figure strongly as personalisation policy continues to evolve.

With their emphasis on personalised services geared towards meeting individual needs, extra care schemes can provide the opportunity for people to die at home with dignity surrounded by loved ones and cared for by people with whom they have built up a relationship.

Some tenants who took part in the project certainly made plain that they had strong feelings on where they should die. The project also underlined that - with a little effort - staff from across health, housing and social care could appreciate what each could offer in the care and support of a dying extra care tenant.

In many cases, paid carers in extra care schemes build up a real relationship with the tenants they support. The study shows that armed with appropriate training, they can turn the instinctive warmth, concern and empathy uncovered in this study into an effective plan for each tenant's end of life care – and help deliver it.

It is both illuminating and disappointing that hospital staff arranging the discharge and care planning of a person near the end of her life did not initially consider extra care housing to be someone's home. That woman was finally able to return to an extra care scheme to die in her own flat in the presence of a male tenant of whom she had become fond.

That is the most eloquent evidence of the worth of this project – and the worth of listening closely to tenants of extra care schemes as they approach death.

Jeremy Porteus is the National Programme Lead for CSIP Networks

About the Author

Lorna Easterbrook has been an independent consultant specialising in health, housing and social care for older people, since 2000. Before this, she worked with a Home Improvement Agency, Age Concern England, and the King's Fund. Lorna's recent publications include *Your Rights to Health Care* (Age Concern Books, 2007), and *Living on the Edge: enabling older owner occupiers with moderate learning disabilities to live independently* (Care & Repair England, 2008).

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.

Acknowledgements

We would like to thank everyone who took part in this project, and its evaluation, for so readily sharing their time, experiences, and ideas – especially the tenants and families, staff and managers at the three Courts involved.

This End of Life Service Improvement Project was led for the NHS and Housing 21 by Annette Villis in East Anglia, and Isabel Quinn in North East England. The project was supported by a group co-chaired by Claire Henry (National Programme Director, NHS End of Life Care programme) and Sarah Vallelly (Research Manager, Housing 21), which also comprised:

- Pam Fenner, Lead Nurse End of Life Care (EoLC), East of England
- Mary Bryce, Head of Extra Care, Housing 21
- Isabel Quinn, NHS Facilitator (seconded to the National EoL Care Programme from North Tyneside Primary Care Trust)
- Annette Villis, NHS Facilitator (seconded to the National EoL Care Programme from St Elizabeth's Hospice, Ipswich)
- Valerie Anderson, Housing 21 Court Manager
- Carole Bertram, Housing 21 Court Manager
- Debbie Wilcox, Housing 21 Court Manager

Mary Casey, who was also a project member and supported the group from the perspective of her regulatory role at the Commission for Social Care Inspection/Healthcare Commission, sadly and unexpectedly died in July 2008.

We are also grateful to Mandy Bowler, Senior Nurse Business Manager Planned Care at NHS South of Tyne and Wear, for permission to quote from her 2008 study of deaths of patients reported by Community Matrons.

The project was evaluated by Lorna Easterbrook, independent consultant. The quantitative survey was analysed for inclusion in this report by Sarah Vallelly.

Aims and objectives of the study

In early 2008, Housing 21 and the NHS End of Life care team began a 6-month service improvement pilot project designed to enhance dignity and choice in end of life care (EoLC) in three extra care housing settings in the north east of England, and East Anglia. The project was designed to be delivered locally with national support. It aimed to:

- Enable (terminally ill) residents of extra care housing to die at home if this meets their choice
- Put in place processes to ascertain residents' wishes, preferences and to maximise the ability of Housing 21 (as an extra care provider) to support those choices
- 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.

This report sets out the evaluation of that project. It explores what changed over the course of the 6 months; and assesses the extent to which the approaches used in this service improvement project might be translated to other extra care settings nationally.

About the National End of Life Care Programme

The National End of Life Care Programme is working to support teams across England to implement the National End of Life Care Strategy. The aim of the End of Life Care Strategy is to bring about a step change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person maybe: at home, in a care home, in a hospital, a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money

The Programme aims to share good practice emanating from different parts of the country on all aspects of the strategy including:

- Local profile raising regarding end of life care issues
- strategic commissioning by PCTs and local authorities
- each step in the end of life care pathway
- workforce development
- environments of care.

About Housing 21

Housing 21 is a national specialist housing association which promotes choice and independence for older people through quality housing, care and support. Our vision is a life of choice for older people. With over 40 years of experience working with older people we provide a whole service to meet the needs of older people through our sheltered housing, extra care housing, care and dementia services.

We have a set of values that underpin our work. Our values are caring, individuality, empowering, integrity, improving, investing and ambition. Our aim is to support older people to have a good later life. We have recently appointed a specialist end of life care dementia nurse who will initially work in London helping family carers and care staff access the specialist support that they need

Why End of Life care in Extra Care Housing?

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.

Even over the last 5 years, the prevalence of disability amongst Housing 21's extra care tenants has been increasing steadily. A survey of tenants carried out in 2007 found that nearly half (46%) of those living in extra care schemes used mobility aids to get around, including 21.3% who did so using a wheelchair (Housing 21, 2008). One in ten had a visual impairment, and a quarter used a hearing aid.

Extra care tenants have mental, as well as physical, ill health. In 2007, 8% had been diagnosed with depression, and a further 7.7% presented with similar symptoms but had not received a diagnosis. With one in twelve diagnosed with some form of dementia, and an equal number believed to have dementia, it appears that as many as one in six of Housing 21's extra care tenants has some form of dementia. Overall, at least 40% of extra care tenants have some kind of mental health difficulty.

These levels of disability and illness are higher amongst extra care tenants than amongst those living in ordinary sheltered schemes (see below), and are reflected in a greater use of community and hospital services. In its 2007 survey, Housing 21 found that 4.7% of extra care tenants were reported to have experienced a hospital stay (at least overnight) during the previous month; at the time of reporting, 3.4% were actually in hospital.

At the same time, the number of extra care schemes is increasing as the government makes funds available for further developments – schemes that intend to offer a 'home for life'. Increasing numbers of older people, often with high levels of disability and illness, will therefore be expecting to remain in their extra care scheme for the rest of their lives.

This established, long-term, and cross-government, policy of supporting older people to remain living in their own homes (including living in extra care schemes) has been augmented in recent years by policies that are focused on ensuring that older people have more choice and control over their lives, including choice over the place where they die.

There is therefore a critical role for providers such as Housing 21 in ensuring that what is provided at the end of life meets older people's wishes. For those with dementia or other cognitive difficulty, this includes being supported to express – and record – those wishes. Delivering good quality end of life care involves knowing what older people want; what services are available and how to access these effectively; and how best to support everyone concerned – the older person, their family and friends, extra care scheme staff, health and social care personnel, and other tenants.

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Background

What is Extra Care Housing?

Many people are familiar with sheltered housing, which has existed in various forms for more than 40 years. Sheltered housing schemes consist of perhaps 30-40 flats or bungalows, with an emergency alarm system and some communal facilities – such as a large shared lounge, or laundry. Any care services needed by tenants would be met through social services' usual community assessment and provision arrangements.

Sheltered schemes tend to be available to anyone over the age of 55. In the past, people have moved into these flats simply on the basis of age, without having any care needs. Increasingly, and in line with the focus of services on those with higher levels of need, the average age at which people move into sheltered housing has become older – and they are more likely already to have a disability.

Extra care schemes are a much more recent development. In general, they differ from the older, sheltered schemes, in two important ways. Firstly, as they are newer, they have been built to be wheelchair accessible, and to offer flexible accommodation to suit both a range of disabilities and family circumstances. Secondly, they offer access to 24 hour on-site care – providing support to individuals according to their specific care plans, and able to respond flexibly if an unforeseen situation arises. The aim of this care is to enable and support independent living within the scheme.

Extra care housing is often seen as the service most likely to replace residential care homes over the long-term. Unfortunately this expectation can cause confusion in terms of current provision, since it may lead professionals to regard extra care schemes as simply 'upmarket' residential homes. In such cases, the major difference between a care home and an extra care scheme is seen simply that the latter offers people their own front door. One reason for this confusion may lie in the fact that, as with those requiring state funding for residential care places, people must be assessed by their social services department as 'qualifying' for the extra care scheme on the basis of their care needs.

Once people have moved in, however, any similarities fade. Those living in rented extra care are tenants – and have just the same legal rights as tenants renting any ordinary flat or house. Those living in schemes where extra care facilities are for sale (whether in whole, or as a part buy/part rent arrangement) have exactly the same rights of owner occupation as if they owned any house, flat or bungalow. Given that those living in extra care schemes are either tenants or owner occupiers, any care needed is assessed, regulated and charged for as domiciliary care because extra care inhabitants are living in their own homes.

Those living in care homes, in contrast, are neither tenants nor owner occupiers – and so do not have any of those rights. Instead, they hold a particular type of licence and have a contract with the home for their care and accommodation, which the home provides as a package. Their care is assessed, regulated and charged for as a residential service, not as domiciliary care.

This distinction is important because it can affect how health and social care professionals support tenants, their understanding of what extra care is, and what it can offer. It is also important in terms of whether and how health and social care professionals expect extra care schemes to support end of life care.

Individual extra care flats (called Courts in Housing 21) typically comprise a bedroom (or two), a fully accessible bathroom, and a lounge with either a fully-equipped kitchen area or separate kitchen. Courts may provide shared lounges (often with tea and coffee- making facilities), where tenants can choose to meet up for a chat or a coffee, to watch television, or otherwise spend time together.

There are other benefits from living in extra care schemes that are generally not found in ordinary streets of housing or blocks of flats. It is these additional facilities that help to provide the ‘extra housing’ element of Housing 21’s extra care Courts. For example, extra care schemes may also offer facilities such as a restaurant or cafe, shop, or a hairdressing salon on the schemes’ site – all of which are also open to anyone else living locally. They may offer meeting rooms for local interest groups, or voluntary sector organisations such as Citizen’s Advice Bureau. Some Courts also offer a small number of flats that can be used for short-term purposes, such as intermediate care following a hospital stay, or for respite care.

What is End of Life care?

At its simplest, end of life care is the support that people receive as they approach death. This support might continue for weeks or months, or perhaps longer, for someone whose illness has been diagnosed as having reached a terminal stage. For others, the end of life may come much more suddenly.

End of life care can involve specialist palliative services – such as hospices, or Marie Curie and Macmillan nursing services. It can include equipment, NHS community teams such as district nurses and GPs, social care staff, hospital admissions, and support from families, friends and others. Those needing end of life care could potentially receive this from all these sources.

Around half a million people die in the UK each year – 2/3 of whom are over the age of 75. Although most people currently die in hospital, many would prefer to die in their own home. Traditionally, hospices and other specialist services have tended to concentrate on people with a diagnosis of cancer; more recently, these services have expanded to provide support for terminally ill people with a much wider range of conditions, but this development is not necessarily widely understood within health and social care services, or by the general public.

In July 2008, in answer to these and other challenges, the Government published its 10-year End of Life Care strategy.

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Policy context

Aside from the overarching agenda of supporting people to remain in their own homes for as long as possible, there are five specific policy areas that will influence the provision of end of life care in extra care housing.

The first of these is the **End of Life Care Strategy**. This 10-year strategy provides a framework to promote high quality care across the country for adults approaching the end of their lives, with a vision to ‘enable more people to die with dignity in a place of their choosing’. It addresses issues such as raising the profile of end of life care; improving strategic commissioning; identifying people who are reaching the end of their lives; care planning and coordination; rapid access to services; training and professional development; information and research; and new funding, and improving the use of existing funding, to support people at the end of life.

It also makes a number of recommendations including:

- *Improved community services* - expecting Primary Care Trusts (PCTs), working with local councils, to develop rapid response community nursing services available 24 hours, 7 days a week (24/7) so that people are cared for and can die in their own homes if this is their wish.

- *Workforce training and development* - in assessing people's needs and in providing the best quality care.

- *Development of specialist palliative care outreach services* – regardless of the person's health condition or diagnosis.

- *End of life care research initiative* - to further understand how to care for people at the end of their lives. (This includes an interest in the different 'environments of care' and the 'effectiveness of different models of care'). However, the main focus of the research appears to be clinical issues, and enhancing the skills of health professionals.

- *Develop quality standards* - with the Strategic Health Authority next stage review so that PCTS and providers can be assessed by regulators against various quality criteria.

To support these recommendations, the government is to invest £580m in order to meet the outcomes set out in the National Strategy.

The End of Life Care strategy recognises the value of specialist housing and draws attention to the needs of extra care housing tenants at the end of their lives, but does so within the context of residential and nursing home provision. This may add to the confusion the already exists about the definition of extra care housing and where it lies in the health and care continuum.

The second policy issue lies in the **National Housing Strategy for an Ageing Society.** Published in February 2008, *Lifetime Homes, Lifetime Neighbourhoods* sets out the future role for extra care and sheltered housing. It highlights the need for more such specialised housing (including housing for older people with mental health needs), and reiterates the government's support for the further development of extra care housing, noting the Department of Health's latest investment of £80m for this purpose. While the report focuses on the link between housing, health and care for older people (and although the strategy is issued jointly across the Departments of Health, Work and Pensions, and Communities and Local Government), the role of housing in health and care remains one that needs to be promoted at national and local levels.

A third, broad, agenda covers **well being, choice and dignity**. These aspects relating to older people's lives are apparent in many policy documents and initiatives, from the National Service Framework for older people, through the Partnerships for

Older People Projects (POPPs), and successive health and social care Green and White Papers.

The government's Dignity in Care campaign, launched in 2006, aims to create a climate of 'zero tolerance' to abuse and disrespect of older people in care services, and to inspire and support people to take action. It is concerned to ensure that people are treated with dignity regardless of whether they are in hospital, at home, in a care home, or living in specialist housing. The campaign has established and supports a network of dignity champions, to further ensure that issues about dignity and respect are addressed in all health and care policies.

The well being agenda goes beyond health and social care to cover all older people, and is arguably best expressed in *Opportunity Age*, the government's 2006-published strategy for the UK's ageing population, and which is being reconsidered during 2008.

The fourth aspect concerns **personalisation**. This has its roots in person-centred care approaches, but is now expected by government to transform local authority's social care services arrangements. It is also expected increasingly to influence at least some aspect of NHS provision, and potentially some housing services.

It involves the shifting of power away from service providers and funders, to individuals – giving people much greater control over the ways in which their needs for care and support are met. Personal Budgets are seen as a major way in which personalised services will be accessed (whether people have and spend the actual money, or instead control how it is spent). People will be able to choose whether to receive their usual service, or whether to have their needs met in an entirely new way. Key aspects of this will include information and advice, advocacy and what are being called 'brokerage' services – where someone else assists in making arrangements. Personalisation is also a key part of the Independent Living strategy published in March 2008, and which sets out its aims to promote more choice and control over their lives for disabled people, including older disabled people.

The fifth, and final, policy area concerns **dementia**. In August 2007, the government announced that dementia would be a national priority, and a national strategy would be developed. A consultation was launched in June 2008, with a strategy due in October. This is expected to cover proposals under three key themes:

- Improving dementia awareness amongst the public and professionals
- Ensuring early diagnosis and intervention
- Developing high quality care and support for people with dementia and their carers.

Key issues that have been identified include gaps in terms of quality research evidence relating to housing, care and support solutions for people with dementia; and the need for a combined approach to commissioning services for people with dementia across housing, health and social care agencies. This suggests a higher profile in this strategy for housing solutions such as extra care schemes, if the demand for high quality services is to be supported.

Other significant policy documents expected in 2008 that may affect the provision of end of life care in extra care housing include a 10-year plan for (informal, unpaid or family) carers; and a Green Paper on the future of long-term care for older people.

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Methodology

About the Service Improvement Project

The Service Improvement Project formally began in January 2008 and ended in July 2008. Housing 21 selected three extra care schemes for the pilot project and evaluation. Two schemes were in the North East of England, and the third in East Anglia. The table below gives a summary of the key features of each scheme:

	Court A **East Anglia**	**Court B** **NE England**	**Court C** **NE England**
Opening dates & background to developing the scheme	2004 – partnership between Housing 21 and local authority. Part of the county's 'very sheltered housing' strategy	2003 – part of partnership between Housing 21 and local authority to deliver 5 extra care schemes	2005 – partnership between Housing 21 and local authority to deliver 5 extra care schemes
Details of scheme	New build on edge of village to replace old residential care scheme. This scheme has 38 apartments and includes an enhanced care cluster of 8 flats for people with dementia	New build. 40 apartments – one and two bed for rent	Court C is unique – a refurbished 11 storey tower block which has had a new ground floor complex of community amenities added on
Number of tenants/ allocation details	45 tenants. Some tenants and staff transferred from the old residential care home that this scheme replaced. Community Psychiatric nurse is on the allocations panel.	42 tenants. All tenants have a care package of at least four hours per week and / or a partner / carer who needs more structured support or respite services.	47 tenants – some single person households and some couples.
Staffing arrangements	Court Manager is responsible for managing housing and care. Care team seconded from local authority	Court Manager manages housing and care. Care team is employed and managed by Housing 21	Court manager is responsible for housing and domestic support. On-site care team employed and managed by local authority

Care contract	382 hours per week personal care block contract	400 hours per week of personal care	Care contact is run by the local authority
How care is delivered	Key working arrangement	Team approach – flexible and personalised	Task oriented, process driven

There were a lot of variations across the three schemes, in particular:

- Rural versus urban
- 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.

Project management and the role of the NHS Programme Facilitators

Prior to the start of the project, Housing 21 and the NHS EoL Care Programme held initial meetings in each case study area. The purpose of these meetings was to bring together the key stakeholders from both organisations, to explore the main challenges from the two perspectives, and outline the roles and responsibilities of the project group.

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.

Training sessions were held, and more planned, at all three Courts. In East Anglia, initial training with staff at Court A was carried out by a trainer from the nearby hospice, from which the relevant NHS Facilitator had been seconded. This session gave an overview of palliative care. The manager and one senior staff member at this Court also attended a free, local training event on bereavement, and were arranging for more staff to attend in turn. The Facilitator drew together a resource pack, setting out local contact details for relevant specialist services, and information leaflets. Towards the end of the evaluation, some of Court A's care staff had also begun to try out some of the Advance Care Planning documents with tenants.

In the North East of England, an initial training session was run at Court C by the local NHS Facilitator together with a colleague, for the Housing 21 and local authority care staff based there. There were plans for further 'bite-sized' training at Court B (using case studies of now-deceased tenants); these were to take place after the evaluation had been concluded, to fit in with a timetable for recruiting new staff. The Community Matrons involved at Court B were also keen to play an ongoing role in supporting and debriefing care staff in the event of subsequent deaths amongst tenants. In addition, a local palliative care college educator had been introduced by the Facilitator to the scheme and had offered the possibility of further training. As in East Anglia, the Facilitator also put together a resource pack for the Courts – this also contained local contact details, information about relevant elements of the Mental Capacity Act 2005 (reflecting the Facilitator's other, at the time, part-time role within the NHS) and other materials including a leaflet for the public about planning for future health and care needs. Court B had also been used by the Facilitator for a Marie Curie event and subsequent meeting with health and social care practitioners involved in end of life issues.

Essentially the Facilitators covered the same aspects – training and education, information and practice – but using different approaches, tailored to and influenced by factors such as local resources, what was possible for staff at a particular time, existing professional contacts, and the shape of health, housing and social care services within their respective areas.

At both sites, staff wanted to be able to discuss examples of real cases so they could better understand what was involved in different aspects of end of life care. They wanted to know what to look for and what to record for their respective primary care colleagues (particularly the District Nurses and Community Matrons), with whom all three schemes reported good working relationships.

About the evaluation

The evaluation used qualitative and quantitative approaches. It was supported by an initial workshop (February 2008) and subsequent meetings (April, July and September 2008) with key people involved in this Service Improvement pilot project, alongside a quantitative piece of work designed to collect data on the deaths of tenants across all Housing 21's extra care schemes over the course of the fieldwork.

Two visits were made to the sites – consisting of 2 days for each visit to Court A in East Anglia (February and June 2008), and three days for each to the North East of England (March and June 2008). At each visit, face-to-face interviews were carried out with a wide range of staff from and managers of the schemes; tenants and relatives; local community and hospital personnel; Primary Care Trust and Strategic Health Authority; the charitable health sector; local government. Some telephone interviews were also carried out, at the time of the visits and subsequently. Some small group discussions were held with tenants.

Everyone involved was informed that the evaluation to which they were contributing would be published. It was agreed to keep details anonymous, so that no one could be identified from the report.

The approach used in the evaluation is based on a research method often referred to as realistic evaluation (Pawson & Tilley, 1997). In broad terms, this approach considers three factors – what works, for whom, and in what circumstances? – by looking at the context, the mechanisms used, and the outcomes achieved. One of the reasons for using this approach is that it is helpful in finding transferable and cumulative lessons that can be usefully applied by others working in different organisations, areas and settings. This is in part because it builds in from the beginning an understanding that circumstances will vary across sites, and over time. This also makes it a good approach to use when an evaluation is running alongside the project itself, as in this case.

In the visits, similar, open, questions were asked of as many of the range of people involved in each site as possible, with the aim of identifying key issues across the schemes. From this analysis, critical elements can be identified that are likely also to affect other schemes, with different set ups, elsewhere in the country.

Both Facilitators played a significant role in setting up interviews and visits for the purposes of the evaluation. The evaluation in turn had some small impact on aspects of the project; for example, an interview in East Anglia with one of the Marie Curie nurse team took place at Court A – creating in turn an ideal opportunity to introduce her to some of the scheme's team and facilities.

The second visits, and the meetings of the project support group, also had an impact since this involved further swapping of information and ideas across the schemes, and Facilitators. This ongoing development is important since the 'landscape' of end of life care continues rapidly to change across the UK. For example, in April 2008 Marie Curie nurses were commissioned in both areas to support those with illnesses other than cancer, whilst social care commissioners and local government housing bodies were also actively focused on how the notion of a Home for Life might include end of life support. Also, nationally, the End of Life Care Strategy was published as the fieldwork phase of the study came to a close.

Quantitative element of the evaluation

During the course of the project and evaluation, Housing 21 asked its 35 extra care schemes to complete a questionnaire about recent deaths of any tenants – the analysis of those findings also forms part of this evaluation report. Data was collected on 65 cases where a person living in an extra care scheme had died over the course of the study. Whilst this data set is not sufficiently extensive to give findings the offer statistical validity, it is nonetheless useful, giving some clear indicators. Where possible, cases from the three pilot schemes were identified as a subset and compared to the wider findings from the control group of schemes that had not taken part in the service improvement project. A copy of the questionnaire and summary results can be found in Appendix 2.

Further information
Pawson R & Tilley N (1997). *Realistic evaluation*. London: Sage

Findings

Key outcomes – what changed?

Aside from external changes, 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.

Key results from the quantitative component of the study

Responses from the 35 extra care schemes run by Housing 21 found 65 reported recent deaths amongst tenants. Of these, 16 people (24.5%) had died at home in their flat; 46 (70.1%) died in hospital; two in a nursing home, and one in a hospice.

Analysis confirmed that those who had lived longest in the schemes (and so tended to be amongst the oldest), and whose deaths were expected, were far more likely to die in their flat. Doing so had met the known wishes of 75% of this group.

In contrast, hospital deaths were much more likely to be unexpected, and amongst more recent tenants. Just over half (58.7%) of those who died in hospital had been there for more than a week. These hospital deaths were reported to have met the wishes of only 20% of that group. In addition, and of the 46 tenants who died in hospital, the families of just 18 tenants (39.1%) were believed to have known about the person's wishes regarding where they would prefer to die.

The average age of the tenants who died was 83 years old; the average amount of care they had been receiving was around 11.5 hours per week. Care for more than 10 hours per week means the person has been assessed as having high dependency needs.

In analysing the results, where possible, data on resident deaths from the three pilot schemes was compared with data from the remaining 32 Housing 21 extra care schemes that had not taken part in the project. The data set was small, which means it cannot be given full statistical confidence; however, there were some indications that the service improvement project may have had a positive impact on the ability of the three extra care schemes to meet the choices of people. Other factors may also have influenced these findings.

People who died in the case study schemes were likely to be older than those who had lived in other schemes, and to have lived there for longer. Of the 7 people who had died having lived in the case study schemes 3 died at home in their own flat, the remaining 4 were admitted to hospital.

Nonetheless, the survey suggests that people who lived in the pilot schemes, and who died during the course of the project, were more likely to have been consulted over their preferences for care at the end of their life (including where they would like to be cared for), and to have these choices met (71%). In contrast, amongst the other Courts, there remained a minority of cases where what happened had only partially met the person's choice or had not met their choices at all.

Four key issues

Four key issues were identified across the evaluation of the fieldwork and the findings of the survey questionnaire. These issues also reflected the findings of the Peer Education research previously carried out by the University of Nottingham for Housing 21, and which looked in two of Housing 21's extra care schemes at ways in which education for end of life care could be supported based on older people's views.

The four key issues are:

- Promoting dignity and choice for older people and family carers
- Support and training for staff

- Extra care and its links to wider health and specialist resources
- Commissioning and funding.

1. Promoting dignity and choice for older people and family carers

It was particularly important, given the policy focus on personalisation, to gain as much input into the project from tenants as possible. Tenants' views, gleaned from small group discussions and some private interviews about planning ahead for serious ill health, ranged significantly. As with the findings of the Peer Education project, some tenants said:

> *"We think about this* [end of life] *much more than people realise."*
> (Crosbie et al, 2008)

The role of family members and carers in terms of talking about end of life issues is critical to the whole process. Families can be the key to ensuring that their relative's wishes are met; but they can also hinder the process, making it difficult for the older person to discuss the issue or even overriding the person's choice. This can be particularly difficult if the person has dementia or other communication/ comprehension difficulties.

Some tenants reported that, whilst they wanted to discuss with their families what their wishes would be if they were terminally ill (and what to do in the event of their death), their families refused to engage in the conversation. In other cases, relatives reported the opposite:

> *"My mum didn't want to talk about death, so I had to go at it sideways, she would sing a hymn and I would say, that's nice, would you like it at your funeral, and she would say yes. So by the time she died I had it all planned out, hymns, prayers and readings.*
>
> *I knew she wanted to be buried with Dad because she bought a double plot when he died in 1979 and that was the only time she ever mentioned it. I didn't want to do anything she didn't want but I had to read between the lines the whole time."*

Other views ranged from the positive –

> *"We want to be able to make our own decisions and not make demands on our family but make our own arrangements if we were terminally ill. We have always planned ahead and this would be no different."*

– to the negative:

> *"If you can't reason or decide for yourself* [at the time] *then it doesn't matter what happens* [at the end of life]."

For some tenants, poor experiences of being admitted to hospital in the recent past had seriously coloured their views:

> *"Give me a form and I'll sign it to say I'm not going to hospital."*
>
> *"My family say it's my life so it's up to me. They all know better than to try to get me to hospital."*
>
> *"I've told the* [Court] *Manager. I'm not going."*

This range of views seemed typical. As one Community Matron put it:

> *"Some people will never discuss their own end of life – that's fine;*
> *Some people will stagger from health crisis to health crisis – that's fine;*
> *Some people will have everything planned – that's fine.*
> *It just means being skilled enough to take what you know and apply to each person differently."*

Information about living at the Courts

Especially when tenants first move in, they and their families need information about living in their flat through ordinary illness, severe ill health and any other changes in their situations. Without this information, families and tenants may make assumptions about what is possible within the scheme that fundamentally undermine what the tenant would prefer to happen. Such information needs to be repeated at critical moments, including when someone is taken ill. For example:

> *"The family wanted their mother to die in her own home. The tenant had a great fear of 'having to go into a nursing home.' The family needed lots of reassurance that we would carry out her wishes. The funeral left from the Court as this was her home, and the staff and some of the tenants stood at the front of the Court, as a mark of respect, until the coffin car left. The family held the funeral tea here at the Court, in one of the meeting rooms."*
> [Quote from quantitative survey]

Some tenants of course actively choose to be in hospital, a hospice or a nursing home at the end of their life:

> *"Roy felt that he needed the* [hospice] *nurses' care due to pain relief and injections he needed which were frequent. He always said he wanted to be*

> *there when he died. Roy already went to the day centre at the hospice weekly, so felt comfortable in their hands. He died there."*
> [Quote from quantitative survey]

Choice, control and capacity: information about planning ahead

Being able to express a choice depends on a number of elements, including ability and opportunity to do so, as well as having information about what support is available. The questionnaire highlighted a number of examples where either dementia, or loss of consciousness, reduced or removed people's abilities to decide or to communicate those choices.

"Due to the dementia, exacerbated by COPD and variability of mood it is hard to assess how the outcome correlated to desires and expectations" (Quote from quantitative survey)

"Betty could have come home to (court name) but for some reason the family preferred to keep her in hospital" (Quote from quantitative survey)

"Due to Alma's dementia and sudden illness, [her choices around end of life care] were never really discussed." (Quote from quantitative study: tenant died in hospital)

Tenants and staff – both scheme staff and health staff – reported a lack of knowledge or understanding about the arrangements introduced in 2007 under the Mental Capacity Act 2005. Health staff commented that they had 'not yet' received training on the Act, but that this was planned.

This lack of knowledge related particularly to the new Welfare Lasting Power of Attorney (LPA), and the recording of advance decisions regarding health care. Both are especially pertinent to end of life care. The Welfare LPA allows someone to appoint another person to make health decisions on their behalf, should they lack the mental capacity to do so for themselves at the time. Advance decisions give people the opportunity to record, in advance, their refusal to receive specific health interventions under certain conditions. Again, this is an advance record to be used in the event of the person not being able to express their views at the salient time.

Some tenants knew about the previous Enduring Powers of Attorney, but did not know that the new arrangements extended beyond handling financial matters to include deciding about health care. One tenant had previously made – but forgotten about – a Living Will, which set out the circumstances under which she did not wish to be resuscitated. Our conversation prompted her to ask her daughter to find out where it was stored, with a view to updating it.

A few tenants were asked by the evaluator to look at some information about the new arrangements (booklet from the Department for Constitutional Affairs; factsheet from Age Concern England). These tenants felt it would be helpful for others to know that information about these possibilities was available.

Advance Care Planning

The outcomes described above might also be expected as a result of someone carrying out advance care planning. This is increasingly used in end of life care, and involves people recording a range of possible wishes regarding care at the end of their lives.

One particular Advance Care Planning format was tried with a few tenants in one scheme towards the end of the project, but did not prove universally popular. One reason given was that it was not clear why the particular information was being requested, and, more importantly, it was not clear to tenants what would be possible – so they felt unable to 'choose'. There were also problems with the form itself, as it seemed to repeat certain questions. Staff felt it would be helpful to see an example completed for a particular tenant, so they had a better idea how to communicate its value and use.

Some tenants who were asked about Advance Care Planning did say it helped them to think through some issues for the future more clearly. They were pleased to have a chance to record details such as who they wanted contacting, and what their wishes were. This small group all recorded that they wanted to remain living in the scheme and avoid any unnecessary hospital admissions:

> *"Give me a form and I'll sign it to say I'm not going to hospital."*

This highlights the importance of having informed conversations about options and issues, as well as recording decisions. It also strongly suggests that a 'one size fits all' approach will not work for everyone. Any Advance Care Planning tool used in extra care settings would need to be person-centred, driven by outcomes rather than processes, and optional.

Staff and tenants felt there would be merit in discussing Advance Care Planning as part of a broader conversation about tenants' plans and wishes for their future. This could be started a few weeks after first moving in, following the initial settling-in period, and form part of an ongoing discussion. Starting this conversation at an early stage, soon after someone has moved in, could also help support these newer tenants by creating opportunities for them to discuss and record their choices.

Housing 21's survey questionnaire revealed that those tenants least likely to have their wishes about end of life care either known about or met are those who have not lived very long in the schemes. One likely reason is that longer-established tenants are simply far better known to staff.

This aspect – that people are not necessarily known by staff for long before their deaths – was reflected in a recent audit of patient deaths taken from Community Matrons working in part of one of the case study areas, in NHS South Tyne & Wear:

Experiences of Community Matrons

Data from 36 Community Matrons recording deaths of patients for the year ending 31 March 2008 was collected and analysed. This revealed that most (59%) died in hospital – those most likely to do so had respiratory failure. Twenty five per cent had died at home – those most likely to do so were aged between 15 and 44. People aged 75-84 were more likely than other adult age groups to die in hospital.

Sixty five per cent of patient who died had been known to the Community Matrons for less than a year; the Matrons had been involved with 34% for fewer than 6 months prior to their deaths.

Source: Bowler, M (2008). *NHS South of Tyne and Wear Community Matron developments in Palliative Care.* Gateshead: NHS South of Tyne & Wear

This not only underlines the importance of having conversations with tenants at early opportunities, but that staff need to feel sufficiently skilled to be able to identify and take those opportunities when they arise.

Having 'difficult' conversations

As with relatives, some staff reported feeling awkward if tenants expressed views about death and dying; at the beginning of the project they were tending to try to change the subject, or to reassure the person that death was *'a long way off yet.'* Opportunities to ask tenants what was on their minds, and for the tenant to discuss things further, were generally not being taken.

In part, this was because staff felt ill-equipped to have those conversations. They were uncertain whether to treat the subject with such delicacy that even the words 'death' and 'dying' were avoided for fear of upsetting people; or whether to confront the issues head-on. This awkwardness was apparent on one occasion, when the evaluator was introduced to a group of tenants by a member of staff as having *'come to talk to them about death,'* – not, as one tenant remarked, the most tactful start to a difficult subject.

During the course of the evaluation, staff reported they were feeling more comfortable and confident talking about death and dying with each other and with tenants, particularly after having attended training sessions. By discussing it regularly, the topics had become more 'normal'.

In addition to talking to new tenants shortly after having moved in, about what they want to happen if they become very ill shortly, staff and tenants felt that another good time for this conversation would be after the tenant has come back from hospital, or otherwise been very ill.

Some staff also reported a concern in discussing this matter with tenants they felt might not be sufficiently able to understand. In such cases they felt they would need to rely on information from relatives. Staff and managers felt it would be helpful to have a leaflet describing the range of support that can be given, including supporting someone at the Courts at the end of their life, that could be shared with relatives and tenants on first moving in, to help answer and questions and promote a better understanding of what is possible at the Court.

Such a leaflet would, they felt, also prove helpful in explaining to health and social care professionals what could be achieved at the Courts.

Acting on someone's wishes – contexts and complications

As well as knowing about the person's wishes (including whether, and how, these have been recorded), there were also concerns about how staff, relatives and tenants might best work together to act on the wishes.

There were three elements to this. Aside from the difficulties reported by staff in talking with tenants about the subject, there were sometimes clashes between what the tenant wanted, and what their family wanted. In such cases it seemed relatively common for the family's wishes to take priority over those of the tenant. A third aspect related to the medical and/or nursing opinion, which often appeared to take precedence over all other views. Three cases outlined below highlight different aspects of these complex situations.

For example, one tenant (who died during the course of the project) had previously said that she wanted to die in her flat at the Court. The Manager reported feeling under pressure from her daughter, an ex-health professional, who wanted her mother in hospital because she believed that this was a better medical option. As the tenant had not recorded her wishes and could no longer articulate these, the Manager felt unable to intervene beyond sharing her opinion regarding the tenant's views and offering to help provide, at the Court, whatever support was required.

In a second example, a relative of a tenant who had died at home, reported:

> *"The GP was brilliant. Earlier last year she had breathing problems one weekend, the doctor who came out then* [locum] *said she should go to hospital; she went in at 9am and came out at 6pm. I only said yes because that* [locum] *doctor said it was needed. But her GP said at the end that sending her to hospital would disorientate her, and that they couldn't do anything in hospital they couldn't do here* [at the Court]*. Also they* [extra care staff] *wanted her to stay here. But if he* [GP] *had said go to hospital then I would have said yes."*

A third case highlights the tensions created when families' wishes take priority. During the first evaluation visit, the Court Manager reported how one woman's current stay in hospital had been lengthened because she had had a hospital-acquired infection. She had by then been infection-free for 3 weeks – but the Manager had only just been told, by hospital staff, that she could leave hospital. Her son, however, was refusing to agree to her returning to the Court. He wanted instead to move his mother to a nursing home nearer to where he lived. No one had asked the tenant what she wanted, and the son would not discuss matters with the Manager. Some months later, after her son discovered (because of the specific circumstances) he would have to make all the arrangements for the nursing home place himself, the tenant returned to her flat where she was very pleased to spend time with her very close male friend, also a tenant at the Court. At the time of the second evaluation visit, it seemed likely she was approaching the last few months of life. She had started to say she didn't want to die on her own.

This last case also helps to emphasise that the Courts do not 'own' the person – and neither do their family. Managers cannot insist that the tenant returns to their flat. Nor can they insist that they are kept up to date with tenants' progress whilst in hospital. It is entirely up to the tenant and any family to what extent they include the Manager or other Court staff in their plans and in otherwise sharing information.

Particular problems can arise in situations where the tenant has not lived in the scheme for long, as has been discussed. In these cases, staff may feel they neither know the tenant nor any family sufficiently well to have yet asked about their wishes, or to be able to gauge these from earlier conversations. The findings of the quantitative study highlighted again that such tenants were far more likely to be admitted to hospital than those who had lived in the schemes for longer. This too highlights the importance of taking early opportunities to discuss with new tenants, and their families, what they would like to happen in the event they are unexpectedly taken very ill.

What can help?

- Making sure that tenants know the scheme will do everything it can to support them to stay in their flat until the end of their life, if this is what they want.
- Creating early, and regular, opportunities for tenants and their families to ask about what level of care can be supported if circumstances change, and providing information that answers those questions.
- Recording tenants' wishes, and supporting them to share this with any relatives if they so choose.
- Having information about what support local specialist services can offer and how to access these; and about arrangements such as Lasting Powers of Attorney, and making advanced decisions.

2. Staff support and skills development

Everyone taking part in this evaluation emphasised the importance of the skills and attitudes of extra care staff. This went beyond training and education, to include what was variously described as 'the knack' or 'the gift' of positively supporting people's individuality in compassionate, sometimes innovative ways. That these skills and attitudes are so important is reflected in the views of tenants' families. For example, one relative commented about her mother's death:

> *"By the time I got here* [just after she had died], *they had bed bathed her, changed her nightie in the bed, so she was clean and comfortable*
>
> *I am so glad she was here at the end* [the tenant died in her flat at the scheme] *because she had real love. Sometimes I would be in the other room and the staff didn't know I was there, and the way they spoke to her, it was like she was their own mum."*

These inherent abilities should be acknowledged and supported, not least because staff may play down their natural abilities, especially if they believe they are in fact unskilled since they lack training. Being gentle, holding someone's hand, and moistening their lips, are an important – and skilled - part of supporting the person as they die. Other aspects of staff support include:

- Bereavement support when a tenant to whom a member of staff has been close, dies;
- Support in the form of a professional 'de-brief' after someone has died – to look at what had gone well, what had been a problem, and whether anything could be changed for the future;
- Practical recognition and support on occasions that staff become emotionally overwhelmed in their work supporting a dying tenant or his or her family.

One very important part of supporting staff lies in acknowledging that a few people may have what might be called ‘bad’ deaths. This might include unexpected deaths, where it was not possible for someone to receive the end of life care they had chosen.

Training

Training and skills development were still key in spite of the caveats outlined above. Staff identified very clearly the information they had received that was helping them:

- An understanding of what symptoms to look for, to indicate a significant change in the person’s underlying health that might suggest they were reaching the end of their lives. This included symptoms such as breathlessness, and weight loss;
- Knowing what other services could offer locally, including community equipment; Macmillan and Marie Curie nurses; and local hospices – and knowing how to access these;
- Understanding what sort of information was useful for them to track, record and share with health colleagues, and why – for example, recording the specific type of incontinence.

Staff appreciated ‘bite sized’, short sessions of ongoing training. They especially wanted training that was based on actual local events and situations – national case studies, they felt, could not give sufficient local detail to help them apply that information to their own working lives. This was particularly true in terms of knowing which service to contact (including the actual telephone number and, in some cases, named professional), since organisations and services vary considerably around the country. In addition, discussing what had happened for an actual tenant would, they felt, prove more useful as they would likely know something about the person and feel more able to contribute to the session.

There was a great deal of enthusiasm for training and education in its broadest sense. Providing an overview of palliative care; signs and symptoms to look for; an explanation as to why certain aspects of a tenant’s health needed recording at the end of life; and the range of local services, were all key components of being introduced to the subject. Managers felt this would be helpful to deliver as part of the overall induction training for staff. Other sessions that had proved useful included training in bereavement and loss.

It was important to make use of whatever local facilities were available including training sessions provided free of charge, since the cost of training might be one barrier to taking part. Other barriers included freeing up staff for training sessions, providing locum cover for staff attending sessions, and ensuring that training need were met even during periods where the retention and subsequent recruitment of staff might be causing short-term difficulties. In addition, although good links were being established between, for example, Court B and local End of Life educators, there were ongoing problems for both in finding sufficient time because of existing demands.

In such circumstances, it is important to look at what can be delivered quickly (and perhaps for free) as well as what will require booking future dates into busy diaries over the longer term. For example, if a local educator is to visit to see the scheme and discuss possibilities, the opportunity can be taken not just to show them around but for them also to speak for 10-15 minutes to available staff to introduce themselves and their work.

If district nurses, Community Matrons or other health professionals (including GPs and Macmillan nurses) are already visiting tenants and discussing their care needs and health situation with care staff, asking them to include within this exchange some additional relevant information about end of life care issues means that care staff could learn more broadly from these experiences.

Another option was to regularly include the subject at staff meetings, partly to review any current situations and share these experiences about caring for tenants at the end of life in the scheme, and partly to discover where there are problems or gaps in knowledge. In addition, any broader information gleaned from other health and social care colleagues could be shared at these meetings – keeping everyone up to date with local changes.

Everyone involved in health, housing and social care services needed to know how their part of the system worked, as well as something about how it overlapped with other elements. It was remarkable how easy it was for organisations to overlook the need for their colleagues elsewhere to be kept up to date when anything changed.

For example, in Court A, some problems had arisen when the local authority changed the system of contacting social workers, but had not explained this in advance to the scheme's Manager or care staff. Similarly, problems regarding delays accessing equipment via social services had been resolved by the Court's staff simply asking the district nurse team to make any referrals for equipment, which were always quickly met. In fact, in this case there had been a much broader problem around the ways in which social services were using the system, which the Community Equipment Service had since addressed but which outcome was not known at the Court.

Links between housing management and care delivery

The links between the housing and care aspects of extra care, and especially the ethos within which both were delivered, were clearest for Court Managers who managed the care staff. In these cases, staff and Managers felt it should be the Court Manager who discusses with new tenants and their families, issues about care if they became very ill (including end of life care). Staff simply needed to know that this discussion had taken place, and where it had been recorded.

For Court Managers who do not manage the care staff, their role is essentially that of landlord. In broad terms, this involves what might be described as a concierge service, managing the domestic support to the building and tenants (including the laundry service), and reporting repairs and similar issues.

Even in these ‘landlord’ situations, however, Managers were often heavily involved in providing information and reassurance to tenants. Holding a resource pack in their office, and making sure tenants and families knew to ask questions about staying supported in the scheme during any ill-health, were important roles.

Where Housing 21 provides the domestic support and landlord function but does not manage the care services, a close and complementary relationship with the care provider is clearly key, to ensure the landlord and care service are not contradicting each other, in terms of what is said or what is done – or how support is delivered. This is one area where it is particularly important that those commissioning extra care services can translate a clear understanding about the extra care role into the detail of the contract – see section 4, below.

Changing roles and responsibilities

Managers of extra care schemes need a range of skills and competencies, which they often need to develop very quickly. The very nature of extra care housing as a relatively new service means that few come from existing schemes. Instead, they come into the profession with a wide variety of career histories. Some have worked in sheltered or supported housing, or have a nursing background, have managed residential care services, or have worked in the hospitality industry.

Ironically, the very range of skills they go on to develop as Court Managers opens up new possibilities to further their careers, and many soon move on to other management positions.

Staff retention is therefore a key challenge in terms of promoting continuity of good practice arising from service improvement projects such as this. Management arrangements in all three pilot schemes had changed or were about to change by the end of July 2008. None of the three Court Managers in post in January 2008 were in those same posts when the project finished. Similarly, the roles of the NHS Facilitators also changed over the course of the project.

There are three aspects to this that are particularly important to note. All those involved remained very committed to the piece of work and continued to act as a network in their respective areas, regardless of their changed roles. Keeping such contacts current forms important part of ensuring that good practice is supported and spread. In addition, it is important to ensure that a sense of the work's importance and of lessons learned becomes embedded into organisations' work and approaches.

What can help?

- Including an introduction to end of life issues in induction training for staff
- Regular short training sessions – covering aspects such as symptoms to look for, and knowing why recording and sharing certain information is helpful
- Training that is based around actual local cases
- Discussing cases at meetings; offering debrief and other support
- Acknowledging staff's natural skills and aptitudes
- Being supported by management and health colleagues.

3. Extra care and its links to wider health and specialist resources

The evaluation identified what seems to be a general lack of understanding over what extra care housing is, and is not. This was proving challenging in several respects.

An upmarket care home? Competing perceptions and expectations

Those health and social care professionals whose perception of extra care is simply as an upmarket residential care home may wrongly assume that the schemes offer the same amount and type of overnight care as is provided in residential care. For example, district nurses at one scheme did not realise until after the event that staff were coming in on a voluntary basis overnight to supplement the night-cover care staff because a tenant was dying. If a similar situation arose again the nurses would instead arrange for the local Marie Curie overnight sitting service, as they would for other patients living in their own homes.

Secondly, sometimes community and district nursing services hold such high opinions of the extra care staff that they assumed they can carry out complex caring tasks. This can create significant stress for some staff, who may feel under qualified and lacking in sufficient experience to adequately manage tasks other than in an emergency. It can also cause problems for the scheme and Housing 21 if the tasks do not fall within the existing domiciliary care regulations.

This can work well, however, if all parties are clear that health staff are training and supervising specific tasks in order to support a particular tenant to remain at home until their death.

For example, a husband and wife moved into one extra care scheme after the wife's cancer had resulted in her having one leg amputated. As her condition worsened, she was prescribed Ketamine (a short-acting, powerful tranquilliser, which can also be used illegally in place of ecstasy). Initially, the pharmacy refused to allow Housing 21 staff to collect this prescription, insisting that a relative collect it instead. The local social care regulator (from the relevant Commission for Social Care Inspection office) agreed that, if the district nurse assessed the senior care staff regularly and was happy with the competency of staff to administer this drug orally, they could provide this service. The tenant remained in her flat until she died.

Support from all the involved staff and organisations is an essential factor in achieving someone's wishes at the end of their life:

> *"It was Maggie's choice to remain in her own home. She was fully aware of her illness and a Do Not Resuscitate (DNR) policy had been agreed with her, her family, GP, Macmillan nurse etc. She was cared for by staff who were familiar to her and understood her needs."*
> [quote from quantitative study]

Relationships with health, housing and social care professionals and services

Given that at least some extra care staff are at the scheme at all times, and given that health and other social care colleagues are not, staff play a vital role in acting as what might be called a 'caring conduit' between the tenant and his or her family, and health staff – particularly for the district nurses and Community Matrons.

This role – providing clear up to date information about someone's condition, and alerting health staff to any sudden or other significant change – was welcomed by local NHS staff and also acted as a reassurance for relatives, especially if they lived some distance away:

> *"With one lady, her daughter lived in Canada so it was even more important she felt confident about what was happening for her mother. The family knew if they rang us up they would be speaking to someone who had actually seen their relative and was giving them an accurate picture."* [Court Manager]

This role appears better fulfilled when staff have a good understanding as to why they should be looking for or recording certain signs or symptoms, and who to contact.

The district nurses and Community Matrons particularly stressed the importance of this role. It meant they could be confident about the information they were receiving about tenants; that they would be called out because there was a specific problem or concern rather than simply as a result of staff being uncertain whether anything was wrong; and that their patients would receive any necessary input at the earliest signs of difficulty.

In contrast with the good reported relationships with community health staff, some problems were reported with hospital admissions and discharges, and in accessing community equipment. Extra care staff cannot directly access community equipment, but must go via either social services or the district nurse team. Problems arose in one Court when attempting to access equipment via social services, because of significant delays in receiving equipment. In one case, a tenant who was terminally ill did not receive a specialist mattress cover and sheet (to help with turning her in the bed) in time. There were no delays with the district nurses' requests, however, so Court staff had simply begun asking the nurses for all equipment requests.

During the course of the evaluation it became clear there had been a much wider problem in terms of how social services' personnel were using the assessment system. These problems had been addressed by the relevant Community Equipment Service, and any delays were now significantly reduced.

This also raised the issue that care staff and the Court Manager were not always certain under which circumstances they should ask health, or social services, colleagues to assess for and request equipment. In this case, they had taken the pragmatic approach of simply asking the particular professionals who appeared to make the system work best for tenants. Raising this issue helped to clarify for all concerned that, in the event of needing equipment for a tenant who was terminally ill, the request should always go to the local health team.

Where relationships between extra care schemes and health and social care professionals were particularly good, these appear to have developed over a period of involvement. In other words, the staff have seen each other 'in action' within the scheme in supporting particular tenants.

It is the nature of this close involvement together that seems to be more important than the length of time colleagues have known each other.

These relationships develop further in situations where opportunities for ongoing discussions are taken, whether these discussions are about care for particular tenants, or about changes within the extra care scheme, within local health and social care organisations, or in terms of the latest national developments.

For example, the local Marie Curie team were invited to run an information stall at Court B prior to a local meeting to discuss the project and evaluation, attended by a broad range of interested health and social care colleagues. This created an opportunity to discuss broader initiatives across the local area, the role of specialist staff and other services, and an introduction to extra care housing – including looking round the scheme, seeing this for the first time for some. It also again identified the general lack of understanding about what extra care housing can offer.

Promoting better understanding of extra care

Several reports were shared of hospital staff informing families that the tenant now needed nursing care and so could not return to the extra care scheme, as this did not offer nursing services. This raised two issues: firstly the lack of knowledge about extra care housing; and secondly, a distinct lack of partnership working across the acute and community health sectors. These conversations did not involve either the scheme manager, or the district nurses or Community Matrons – who between them may have been able to offer and organise sufficient support for the tenant to return home.

> *"Last Christmas a lady was in hospital and the social worker said she had to go to a nursing home, no discussion with us here, and before we knew what was going on she had moved and given up her tenancy. We might not have been able to support her but we wanted the chance to at least talk about it if not try it out with her agreement.*
>
> *Tenants have rights under their tenancy; a social worker can't just spot purchase a place in a* [nursing] *home and move them on."*

That there remains some lack of understanding amongst those working closely with – or whose decisions directly affect - extra care schemes, creates some cause for concern, in particular because it is so easy for this misunderstanding to be passed on to tenants and their families.

One major barrier seems to be the lack of understanding as to what the 'extra' in extra care housing means in practice – especially the 'extra care' aspect. In contrast, the 'extra' housing element is better understood as providing a self-contained flat as well as shared amenities, although there is still a tendency for tenants in the schemes to be described '*as if* the person is living in their own home', rather than fully comprehending that it *is* the person's own home.

The Court Managers are, however, perfectly clear that the ‘extra’ care element consists of *how* any support is provided – in other words, it is the way this care is approached that is key:

> *“When people need care they get a care plan from social services. The 'extra' that Extra Care Housing delivers is how you then support that care plan, so if the care plan says 'a wash every day' then you find out do they prefer a bath, or a shower, or a mix in the week, and what time of day they prefer this. Some people like an evening bath, or a shower before teatime – not everyone wants it mornings.*
>
> *Then you find out the other stuff that would support the person, so you ask them and encourage them - are you coming down to the lounge, would you like a cup of tea, are you going to the restaurant today, what are your plans for the day, did you have a good time yesterday?*
>
> *And then you add other extras like if the care plan says ‘do laundry’ but the person can't do the ironing, then you'd do the ironing, because what's the point of putting on clean clothes if they're creased? Where's the respect or dignity in that?*
>
> *The staff just do it. I can't explain it, they don't need telling. But this extra is continuous all the time, so if I pop my head round someone's door to pass on a message for them, and I can see the bin in their lounge needs emptying, then I’ll ask - should I do it or leave it for later?”*

This approach mirrors much of what is at the heart of expected changes within social care provision, in terms of providing personalised support. It will likely form an important part of how services are increasingly commissioned, valued and evaluated over the medium- to long-term.

Knowing about each others’ role and work is an essential part of providing good quality end of life care. Poor experiences can have a negative impact over the longer term – and if organisations are unaware of the impact this may have on others’ work, they are unlikely to let affected colleagues elsewhere know when problems have been resolved. For example, the delays in social services’ accessing Community Equipment Service previously described had largely been resolved towards the end of the evaluation. The Community Equipment Service had changed aspects of its service, the local authority had identified failings on its part, and request from social services were being fulfilled within the time limits set by national targets. None of this was known, however, by the scheme staff - who continued to believe that the district nurses were somehow able to make the system work, where social services could not.

One of the effects of this kind of project work is that it can in itself act as a way of re-energising links between extra care schemes and wider health and specialist resources; help to create new links; and provide explanations about roles and responsibilities to all parties. In the Community Equipment instance, above, for example, the evaluator was able to share information about the positive changes with the Court Manager, care staff, and the district nurse team.

So much changes so quickly within health, housing and social care for older people, that sustaining these links, and ensuring that, on occasion, conversations with colleagues from other organisations go beyond discussing one tenant's situation to exchanges of wider news and developments, is an important yet often unrecorded part of providing a good quality of care, through life as at end of life, for older people.

What can help?

- Open days, meetings at schemes, and other opportunities for professionals to see the facilities and meet staff
- Creating ongoing opportunities for all health and social care staff, including hospital personnel, to understand what is (and is not) possible at the scheme – and equally, understanding their roles
- Sharing information and talking about broader shared areas of work as well as about particular tenants.

4. Commissioning and funding

It was clear from discussions that although End of Life care issues were relatively new from a commissioning and funding perspective, the opportunity better to understand and plan for these needs was much appreciated – especially for those working in housing and social care.

Commissioners contributed time and ideas to the evaluation, and were clearly interested in and enthusiastic about discussing best practice examples:

> *"The Extra Care Housing environment almost automatically puts together the components needed for tenants and their families at the end of life - like not being alone, not being frightened or lonely, and having the flexibility of care"*
> [Local authority Commissioner]

> *"The GP would like me to say that the standard of care at the scheme is very good - but if there is an issue about end of life care it is how to change the*

> *care response quickly without waiting for the social services assessment. This is an issue for the commissioners as well as the providers."*
> [District nurse team]

Flexibility to change the care provided, and the ability to do so quickly if someone's care needs radically change at the end of their life, are key elements. On occasions when a tenant's situation does deteriorate very swiftly, extra care teams need either an existing, blanket, permission to increase support immediately (even if subsequently this has to be reviewed and reassessed) or need to receive specific agreement to do so within a matter of hours.

For example, one tenant who was aged 101 was diagnosed by her GP with pneumonia 4 days before Christmas. Senior staff rang social services, and faxed a request for more hours of care for her, setting out what the new care plan would be. The social worker immediately agreed to extend the package of care from 21 hours to 36 ¾ hours per week during the pneumonia without further assessment, taking the scheme's word for this need. Despite the holiday shutdown and lack of postal deliveries over the bank holidays, written confirmation of this new care package was received in the post from social services 4 working days after the request was made; the tenant died the next day.

Alongside agreement, however, the team need physically to be able to deliver additional hours. In some instances, this may be achieved only if those already working within the team agree to do so. In other words, responding quickly means – at least to some extent – employing staff willing to translate attributes such as dedication, compassion and loyalty into taking on extra hours' work at very short notice, in order to support a tenant at the end of his or her life.

These personal and professional attributes need to be understood and recognised as an important part of what is funded, and commissioned, overall. Although the 'extra housing' element is relatively easy to understand, there are still gaps in comprehending that the 'extra care' element is not simply that staff are physically present at all times; it is also very much concerned with how staff, through their behaviour and attitudes, ensure the delivery of the service's ethos.

It is particularly important for those commissioning extra care schemes to achieve a match between the ethos of the housing element, and that of the care component, if these are to be provided by different organisations. The growing interest amongst commissioners in providing extra care schemes so that older people with higher levels of disability and illness may also remain in their own homes for the rest of their lives means making sure this includes palliative and end of life care.

What can help?

- Commissioners would appreciate detailed case study examples of supporting tenants at the end of their life – explaining something about the tenant's situation and how long they had lived in the scheme; what was needed; what was provided and by whom; what worked; and what was a problem. This they felt would help their understanding of how best to commission such flexibility.
- Ensuring that funders and providers agree what the ethos of the service should be, and how this ethos will be delivered, in terms of both the extra housing and extra care components.

Conclusions

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.

It is of some concern that these changes are taking place in the context of what seems to be a general lack of understanding about what extra care schemes are, and are not; in particular, a lack of understanding of the range of situations Housing 21's Courts could support throughout the lifetime of their tenants.

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.

For Housing 21's tenants, delivering these and other policy imperatives is dependent on a number of factors, including:

- Recognition of the ethos of the service – in particular, the actual manner in which staff support tenants
- Partnership working at local, regional and national levels, making sure professionals and services work together to achieve the best outcomes for tenants.

What is especially important, however, is finding practical ways of successfully delivering such factors. For example, successful partnership working for tenants means everyone involved – even at the periphery – with the changing care needs and ongoing living arrangements of tenants has a good working knowledge and understanding of how an extra care scheme might be able to assist the meeting of that tenant's wishes at the end of their life.

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.

Despite this lack of understanding, however, 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.

It can be tempting to ‘wait’ until the ‘right’ form, approach, or priority has finally been agreed, before beginning to introduce new areas of work, or new ways of working. Yet the reality of much of health, housing and social care for older people is that these situation and issues are constantly changing. This requires the kind of flexibility that lends itself to working successfully within a fluctuating, changeable system of forms, services, organisations, approaches and personnel. In other words, having the ability to make existing arrangements work as well as possible can be as important as introducing any change.

In terms of end of life care, this includes identifying existing opportunities for training and sharing knowledge. It is not necessary to exactly replicate another organisation’s resource folder, for example: the critical factors such as identifying skills, training to increase technical knowledge, understanding what is available, and sharing experiences broadly amongst health, housing and social care colleagues, can be achieved in any number of ways. 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 clear; this is likely to become even more so over the next 2-3 years.

This is perhaps at the heart of this kind of effective working: that everyone involved has 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.

Working together in this way involves seeing each other as equal but different. 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

This section of the report highlights a series of recommendations for specific groups, together with overall proposals and suggestions for positive change. It aims to provide some practical ideas for service improvement that could be applied for and by anyone involved in any capacity at the end of life for extra care housing tenants.

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:

General Recommendations

- Opportunities need to be found to bring together professionals to talk about who does what and how things might need to change to improve the outcomes for tenants. This includes ensuring that extra care colleagues are involved in relevant local Forums and working groups, and that schemes offer to host external colleagues' meetings at the schemes, combining this with looking round the scheme.
- 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.

Information and knowledge

- Clear, concise information about extra care housing is needed for and by tenants, families, and health/housing/social care professionals and organisations.
- The NHS End of Life Care Programme, possibly in conjunction with other relevant bodies like the Department of Health's Care Services Improvement Partnership (CSIP) should produce a simple resource pack for extra care housing as an on-line resource.
- Extra Care Housing providers should review current policies and procedures to explore how best to incorporate end of life care issues. For example, a question on advanced care planning could be linked to an existing care or support plan.

Equality and diversity issues

- 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. Housing 21 is already taking steps to address the gap in end of life care services for people with dementia, by starting to deliver a new specialist nursing service. From late 2008, an End of Life Dementia Nurse will work with family carers and care staff to ensure people with dementia are able to die at home with dignity if this is their choice. The nurse will link to local health care services to ensure that palliative services are accessible to people with dementia and will also support care staff in specialist skills development work. The service will initially be available in London, and will be evaluated with support from the King's Fund.
- Ensure that information produced is made available in accessible formats; for example large print for people with visual impairments.
- Any information or materials produced – either by housing providers or the NHS End of Life Care programme should meet with equality and diversity requirements and be developed with input from user groups.

Supportive skills development for staff

- Provide a basic introduction to end of life issues as part of induction training for new staff, so that a 'home for life' is understood to include the end of life.
- Hold and share a range of information and materials about services and systems for tenants and staff – such as factsheets and leaflets from local and national organisations.
- Tailored training should be developed for those working in extra care housing; this should include short 'bite-sized' sessions, and be based on local case study examples of tenants. The importance of existing staff skills in supporting tenants as they are dying should be acknowledged and highlighted.
- Specific training for extra care staff and Managers 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.
- Existing resources should be utilised wherever possible, seeking and taking advantage of local free training, planned e-learning packages from the NHS End of Life Care Programme, and ongoing input and support from general and specialist health colleagues, including local Marie Curie, Macmillan and hospice personnel.

For Extra Care Scheme Managers (“Court Managers”)

- Court Managers’ conversations with tenants about their future life in the scheme (at around 6 weeks after the tenant has first moved in) should include an early and simple question about health, and a record made of the tenant’s wishes should they be taken very ill. Staff should be informed that the conversation has taken place.

  This is a topic for Managers and staff to return to in more detail at opportune moments such as:
  - when the tenant raises it
  - after a period of illness
  - if the tenant has been admitted to hospital, after they come home.

  Managers should seek the input of local district nurses and Community Matron colleagues in situations where the discussion has moved to death and dying as discussion and recording of Advanced Care Planning options may become appropriate.
- Introduce staff to resources such as Help the Aged’s educational guide to End of Life, *Planning for End of Life Care*, drawn up with the help of older people as part of a peer education project, in which older people suggest ways of tackling and discussing this subject.
- ‘Spread the word’ about extra care schemes – by running short Open Day-type sessions; offering meeting space for health, housing and social care organisations; joining local Forums; inviting professionals to visit the scheme informally (and visiting their service in return).
- Find out about health, housing and social care locally – including encouraging visiting professionals to share wider news of relevant changes and developments in their professional field, as well as in their organisation – and share extra care news with them in turn.
- Write up case studies – anonymised as needed - for local service commissioners, and for discussion/ training amongst extra care staff.

For extra care staff

Care and support staff working in extra care housing need to:

- Be able to demonstrate, in practical terms, their understanding of the ‘extra’ they are delivering and how this relates to end of life care regardless of type of employer.
- Explore ways on having difficult conversations with older people, including using the Help the Aged materials.
- If not employed or managed by the extra care housing provider, regularly raise any training needs with line managers.

For wider health, housing and social care services

Colleagues and organisations need opportunities to:

- Meet together for discussions around shared interests such as End of Life care
- Share changes and other developments with extra care teams on an informal basis
- Ensure that extra care colleagues are part of local Forums and other partnership working groups and discussions.

In addition, colleagues need to become more aware of, and so avoid, the potentially negative impact they may have on tenants and families by either insisting on a hospital admission or discharging a tenant to a new care facility without first ascertaining the tenant's wishes and discussing solutions with Court Managers.

For commissioners and funders

- Detailed case studies should be developed and used by commissioners in order to gain a more in-depth understanding of what is needed for commissioning or funding the flexible care needed in end of life situations.
- Translating the practical examples in this report of what a personalised approach or service ethos can mean for extra care tenants, into contracts and specifications for future services, to ensure a match between the approach of landlord and that of care provider.

For tenants and families

Tenants and families need repeated opportunities to:

- Discuss and record tenant's wishes. This includes discussions early on in a new tenancy, as well as ongoing discussions as situations change. Extra care housing providers should ensure there are opportunities for tenants and families to discuss and record future preferences. However, this should not be a 'one size fits all' approach, nor should it be a 'tick box' exercise. Such questions should be handled sensitively and not be compulsory, as not everyone will wish to talk about this.
- 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.
- Have information about living in the extra care scheme at the end of life, and about wider services available locally to support terminally ill people in their own homes. Many older people may be reluctant to talk about end of life

issues but this does not mean they don't think about death and dying. Information should include material that a tenant can keep in their flat to look at and reflect upon as and when they choose.

For regulators

From April 2009, the existing Commission for Social Care Inspection and the Healthcare Commission will merge to form the new Quality Commission. This new body will be responsible for the regulation of all social and health care services. It is hoped this change will help to support:

- Regulation that is increasingly activity based, not dependent on being delivered in particular settings - so removing the current regulatory distinction between care provided to those living 'in your own home' and those in a 'care home'.

For policy makers

It can be difficult to apply all the current strategies (eg housing; ageing population; Dementia Care; sustainable development; End of Life care) to practical situations, meaning that individuals and organisations sometimes feel they must 'tack-on' a new policy to existing arrangements with no real understanding how the policies might best mesh together :

- Pull together the relevant strategies around a case study to help all concerned understand more clearly how these need to work together to achieve the desired outcomes.
- 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.

Appendix 1 – people who took part

At Court A, East Anglia

Manager
Senior staff
Care staff
Tenants

And colleagues from:
District nurse team
Community Equipment Store
Hospital Macmillan team
Hospital Integrated Discharge Planning team
Marie Curie team manager
Commissioner, County Council
Social work department, County Council

At Court B, North East England and Court C, North East England

Court Managers
Senior and care staff at Court B
Care staff manager at Court C
Tenants

And colleagues from:
Community Matrons
NHS End of Life Facilitators
Marie Curie team
Domiciliary Care Manager and Assistant Team Manager, local authority
Strategic Health Authority Lead, NHS continuing health care
Joint PCT/local authority Development Officer
Commissioner, local authority

Appendix 2 – Questionnaire with results summarised

Extra care: circumstances of resident death questionnaire

Housing 21 and the NHS End of Life Care Programme are carrying out a service improvement project between January - July 2008. Over this period, we will be monitoring information we collect when extra care tenants die. After a tenant has died - either at home or in hospital or another care setting, I would be grateful if you would take a few moments to complete the following short questionnaire and return it to me via email. The information obtained will be entirely for the purposes of this evaluation project and personal details will not be disclosed to others.

Please complete the following questions as fully as possible. If you do not know all the answers then leave blank those you cannot answer and fill in the ones you can.

SECTION A: BASIC DETAILS

This section asks for a few details about the person who died and how long they were living at the court. Please complete this section as fully as possible.

Q1 Name of court

Q2 Name of resident (NB this will be kept confidential)

Q3 Date of death (dd/mmm/yy)

Q4 Person's age at time of death

Q5 How many hours of personal care did the person receive per week?

Q6 Where did the person die?

At home (in own flat)	24.6%
In hospital	70.8%
In a hospice	1.5%
In a nursing home	3.1%
Other (please state)	1.5%

Q7 How long did the person live at your court?

0 - 6 months	10.8%
6 months to a year	9.2%
1 - 2 years	44.6%
2 - 5 years	30.8%

Over 5 years	3.1%
don't know	1.5%

Q8 Did the person who died live alone ?

Yes	80.0%
No - lived with partner / spouse	18.5%
No - lived with other person	0.0%

Q9 Did the person have any long term health conditions or terminal illnesses? (Please tick all that apply)

Diabetes	12.3%
Cardio Vascular Disease (CVD) - Heart problems or stroke	29.2%
Chronic Lung Disease (Emphysema or asthma)	12.3%
Continence problems / UTIs	18.5%
Cancer	16.9%
Arthritis or osteoporosis	20.0%
High blood pressure (hypertension) or circulatory problems	15.4%
Parkinson's disease	7.7%
Sensory impairment (hearing or eyesight problem)	13.8%
Other health problem - please state	30.8%

Q10 Did the person have dementia?

Yes - diagnosed by doctor	15.4%
Yes - suspected but not diagnosed	3.1%
No	70.8%
Don't know	6.2%

Q11 Was the death expected? (For example, was the resident at an advanced stage of illness?)

Yes	35.4%
No	40.0%
Don't know / can't really say	20.0%

SECTION B: HOSPITAL STAYS

Answer the questions in this section ONLY if the person who died was in hospital at time of death. If the person didn't die in hospital, please go on to answer the questions in Section C: Dignity and Choice issues

Q12 When was the person who died admitted to hospital

Less than 24 hours before they died	4.6%
24 to 48 hours before they died	9.2%
3 - 7 days before they died	12.3%
1 to 4 weeks before they died	30.8%
Over 4 weeks before they died	10.8%

Q13 What was the main reason for the hospital admission?

Fall	13.8%
Chest infection	18.5%
UTI (Water infection)	12.3%
Other infection	6.2%
Heart attack / stroke (Acute admission)	9.2%
Planned admission (for surgery or treatment) with subsequent complications	1.5%
Don't know	7.7%
Other reason - please give details	20.0%

SECTION C: DIGNITY AND CHOICE ISSUES

It may be difficult to answer all of the questions here. Please try to answer as much as you can, using your best professional judgement and knowledge of the person.

14 Had the tenant been consulted about their preferences in terms of where they would like to be, should their care needs change or their health suddenly decline? (Please tick all that apply)

Yes - included in support plan	6.2%
Yes - covered in personal care plan	16.9%
Yes - "Preferred priorities for care " or similar advanced care planning record	1.5%
Yes - discussed informally with care staff	23.1%
Yes - discussed with family carers	41.5%
Don't know	41.5%
No	4.6%

Q15 Were the tenant's family aware of the tenant's preferences?

Yes	50.8%
No	1.5%
Don't know	43.1%
No family	1.5%

Q16 To what extent did what happened - where the person died and how they were cared for at the end of their life - meet that person's choices?

All or mostly	32.3%
Partly	7.7%
Hard to say	24.6%
Not at all	7.7%
Don't know	27.7%

Q17 Please tell us your main reasons for the answer you gave to Q 16 above