



End of life care in extra care housing

Learning resource pack for housing,
care and support staff





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Foreword

Most residents of extra care housing schemes see it as their home for life.

For many, that means it is also where they would choose to die. After all, surveys consistently show that most of us would prefer to die at home rather than in a hospital or other care setting.

The sector is rightly proud that its residents are less likely than other older people with care needs to move into institutional care.

Dying at home is a realistic option for extra care housing residents if that is their choice.

However, achieving that ambition for many individuals requires sensitive discussion, good care and support planning and effective communication between support staff and the individual and their family. It also means working closely with all the professionals and organisations involved in their care and support.

We hope this document equips people working in extra care housing with some of the skills and knowledge they need to ensure that such care at the end of life is a reality for more residents.

This resource is a unique partnership between our two organisations, reflecting shared values of independence and choice for older people and our recognition that these values should extend to the end of life. We are grateful to authors Chloe Carter and Dylan Kneale from the International Longevity Centre-UK for capturing that ethos.

The result is a practical toolkit for managers and care and support workers in extra care housing schemes. The resource pack illustrates how extra care housing staff can talk about end of life care with residents and work to ensure their wishes and preferences are met.

Extra care housing is built on the foundation of providing individuals with choice and control over their lives. We are confident that this document will extend those vital concepts to residents' end of life care and, eventually, their death.

Claire Henry

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About this resource pack

The original version of this resource pack, published in 2009, was piloted with a range of staff in different extra care housing settings. An evaluation was undertaken that captured the views of extra care housing staff and residents. This version builds upon that work.

Focus groups with extra care housing staff – including housing, care, nursing, commissioning and wellbeing staff – from sites across England have taken place to inform the development of this version. Interviews with experts have also taken place. All of the quotes and case studies in this pack have come directly from extra care housing staff. Some residents' names have been changed.

For the purposes of this resource pack the term '**resident**' is tenure-neutral and is used to refer to someone who lives in extra care housing. Some extra care housing sites use other terms, including 'service user' and 'customer'.

If you would like to offer any comments or feedback that will improve future editions of this resource pack, then please contact information@eolc.nhs.uk

How to use the resource pack

This resource pack is designed for anyone who is caring for or giving support to someone with a life-limiting, life-threatening or progressive condition in extra care housing. This includes giving care to residents in the last 6-12 months of their life who may have chronic conditions, such as heart failure or respiratory problems; residents with dementia; residents with a terminal illness including cancers; and resident who may be experiencing non-specific frailty and decline. Many people develop general frailty and other health problems as they get older, which can lead to or expedite the end of life.

This resource pack is not a medical or nursing handbook. NHS Direct provides comprehensive information, advice and guidance on these areas of end of life care and can be contacted 24-hours a day, 365 days a year by calling: 0845 4647. Information is also available on the NHS Direct website: www.nhsdirect.nhs.uk. In an emergency you should always call 999. If a situation is urgent, but not an emergency, then in some areas you can use the NHS 111 service by calling 111. This service is projected to replace NHS Direct across England by October 2013. You can check which areas currently have the service, by visiting the relevant NHS information webpage here: www.nhs.uk/111.

There are a number of roles within extra care housing, including housing, care, support, nursing and managerial roles. Your role will affect the boundaries you have in terms of delivering end of life care and support to residents.



The Core Steps

The Core Steps are intended to reflect the journey of a resident living in extra care housing towards the end of life. It is based upon the end of life care pathway used in the National End of Life Care Strategy (2008), but has been adapted to reflect the extra care housing setting.

Every resident's journey is different and these steps are only intended to be a guide. People have individual responses to approaching the end of life and distinct fears, wishes, needs and attitudes are likely to require different approaches from staff.

The structure of this resource pack tracks these Core Steps. You may wish to read through the whole resource pack, but it is designed to be easy to navigate so that you can quickly and easily find the sections relevant to you.

The steps may occur in an alternate sequence, and some steps may not occur at all. While these steps aim to capture a possible experience of end of life care, you will likely come across scenarios that are not represented here.

Systems, policies and practices in relation to extra care housing and end of life care can vary across areas and providers. Where locally-specific knowledge is needed, the guidance in this pack is intended to help you find out the relevant information.

This pack is intended to be a practical tool which gives useful information and guidance to all staff working with residents of extra care housing. It could be used within a learning and development framework, but it is not intended to replace training.

Disclaimer

All signposting, including hyperlinks, are accurate at the time of writing (July 2012). We cannot guarantee that links to external websites will work all of the time.

Neither the authors nor sponsors of this resource pack are responsible for the accuracy of material on linked websites. A link does not imply endorsement of that site or the views expressed there. We do not accept responsibility for the sites linked to, or the information displayed there.



Introduction and overview

End of life care in extra care housing

Extra care housing describes many forms of housing for older people, but usually comprises homely, purpose-built independent housing units that feature common spaces, facilities and flexible care services. For many residents their home in extra care housing will be their home for the remainder of their life. Fewer people living in extra care housing move onto institutional care than people living in the community in receipt of domiciliary care.

About 1% of the population die each year. At the beginning of the 20th century almost everybody died at home, but by the end of the century it was down to about 20% (National End of Life Care Intelligence Network, 2012). Nationally, around two-thirds of us would prefer to die at home.

It is difficult to predict when people are considered to be approaching the last 6–12 months of their life, but there are some ways to work with colleagues in health to improve recognition of people who are approaching the end of life and consider important issues that should be addressed at this time.

For more information – including factsheets – about extra care housing, visit the Housing LIN's website:

www.housinglin.org.uk/Topics/browse/HousingExtraCare

and see **Section 8: [Identifying when to initiate end of life care](#)**.

Although all of us will die at some point, the type of death will vary for each of us. There is a need to make sure that those people approaching the end of life, their informal carers, and family and friends are supported during the stages leading up to and during death.

“It is important that residents, their families and their informal carers understand that dying at home is a realistic option for residents of extra care housing. By empowering residents to understand their options, staff can enable them to have choice and control over their end of life care”.



Case study

Understanding that dying at home is a realistic option

“Extra care housing schemes often place an emphasis on promoting independent living. In our scheme, residents are encouraged to do as much as they can for themselves. They are reminded that the emergency pull-cords and pendant are for emergencies only, i.e. if they are taken ill, have a fall or if there is a fire or flood in their flat. The carer on night duty sleeps unless they are woken to deal with an emergency.

As the Estate Manager, I realised that many residents assumed that this would mean they would not get the additional care needed if they were approaching the end of life. As they couldn't use their pull-cord or pendant, residents had assumed that they would have to go into a hospital, nursing home or hospice if they required end of life care.

I now plan to approach this conversation differently with new residents so they know that end of life care in their own homes is a realistic option. I'm also exploring ways to have this conversation with existing residents”.

Hanover Housing Association

Death is not just a physical reality, but a social event too and it is important to address the emotional, social, cultural and spiritual needs of people and their families.

Providing effective, high-quality care for someone during the end of their life is a highly-skilled role and a challenging one. While it's a team effort and does not all fall upon the shoulders of one individual, without support and information, staff and informal carers can find the experience overwhelming.

“It's a fantastic set-up to enable people to die at home. You've got a lot of the resources onsite already, the flats are easy to carry out end of life care in, you've got the buy-in from GPs and other professionals. It's a real shame if people are dying in hospitals and hospices if it's not what they chose or would have chosen. It's terrible to get moved around if there's no reason to be.”



This resource pack is intended to help you to deal with the challenges of supporting someone who is dying. This includes approaching discussions about the end of life, enabling residents to have choice and control over their end of life care and identifying how and when you need to access specialist support from health professionals and other organisations or networks.

Case study

The impact of helping residents to die in their own extra care homes

The following is an extract from a letter received by one extra care housing manager following the death of a resident. Further examples can be found in Appendix D.

Dear [REDACTED]

As you will know by now my Mum passed away yesterday morning ([REDACTED], 2010).

I just wanted you to know how much I am thankful for the tender loving care she was provided with by all of your staff and also the support and care they gave to me. I am so happy that I got Mum home and it WAS worth all the hassle because it meant everything to Mum and made her last days comfortable and happy. The care staff were so concerned not to hurt her when they washed and dressed her and I know how difficult that was for them but they did it and with so much affection and caring and that's what she needed (and I needed!) after being in that hospital for so long and with no 1 to 1 contact. They sang to her to her favourite 'Jim Reeves' and she sang with them when she first came home.

It was a clean, comfortable, warm and loving end to her life and I and my family will always be grateful for that. She was never alone as I had my daughter and my friend overnight with her, and I was with her all day on Saturday when she slept peacefully all day. I am thankful to [REDACTED] who came in on Saturday and sang to her and I know she could hear him and all the staff who always spoke to her whenever they were with her.

I am glad that with a huge effort we were able to have the 'end of life' at home and I just hope in the future it will be made easier for families to do this.

Thank you again and please relay to all your staff how thankful we are and what a wonderful thing they did for my Mum and all of our family.

Best regards

[REDACTED]



“You wouldn’t talk about the end of life with the person who delivers your grocery shopping or reads your gas meter. Residents aren’t going to feel comfortable talking about it with staff who provide a service, but who they don’t know.”

Key elements of support planning

There is no prescriptive or exhaustive approach to support planning, as a personalised and person-centred plan will look different from one resident to the next. A general framework to support planning might include these elements:

- Timely and relevant information available beforehand so the resident knows what to expect from the assessment and support planning process, as well as how they can be at the centre of it.
- Knowing who is involved and what their roles are.
- Identification of clear goals and outcomes.
- An understanding of needs and how they may be met in order to help the resident achieve their goals and outcomes.
- Identification of the products and services (including nil cost ones) that are to be bought or commissioned in order to meet needs and achieve outcomes.
- Contingency and change planning and risk management.
- Identification of how and when the plan will be reviewed.

Source: www.peoplehub.org.uk/8.pdf



The principles of support planning:

Plans should be:	What to look for:
<p>Personal</p> <p>“My plan reflects who I am and it makes sense to me. Support to help me create it is light touch and tailored to suit me”.</p>	<ul style="list-style-type: none"> ● Increased variety of plans. ● Increased use of person-centred support planning tools. ● Increase use of plans by staff.
<p>Goal Orientated</p> <p>“My plan sets out what I want to change and achieve and describes ways I can do that”.</p>	<ul style="list-style-type: none"> ● Use of non-professional language to describe goals and outcomes. ● Goals are personalised and reflect what is important to the individual. ● Less emphasis on needs and tasks.
<p>Achievable</p> <p>“My plan is practical and achievable and says enough for me to understand how to put it into action”.</p>	<ul style="list-style-type: none"> ● The plan contains information about how to achieve goals and outcomes. ● The plan makes good use of the resources available. ● Plans are achievable within the resources available.
<p>Proportionate</p> <p>“My plan feels the right size for what I want to do”.</p>	<ul style="list-style-type: none"> ● Plans vary in length and detail. ● People decide how much to share in their plans. ● People decide who to share their plans with.
<p>Adaptable</p> <p>“I can adapt my plan if things change and I know I can get support with this if I need it”.</p>	<ul style="list-style-type: none"> ● Plans can be adapted to take different routes to achieve the agreed goals and outcomes. ● Residents understand where to go for additional support. ● Residents understand that their plans and support are flexible.
<p>Empowering</p> <p>“Developing my plan has helped me gain confidence to do more next time”.</p>	<ul style="list-style-type: none"> ● Over time residents take on more of the planning process. ● Residents who have created their own plans support others to feel confident to do the same. ● Good stories are shared.
<p>Social</p> <p>“My plan helps me think about how to maintain and improve relationships and networks that are important to me and give me a sense of belonging and purpose”.</p>	<ul style="list-style-type: none"> ● Plans consider resident’s social and community links. ● Reviews show residents are able to use resources to strengthen social and family networks. ● An increase in pooled budgets.



Support plans should include consideration of emergency situations, such as the illness of an informal carer or an unplanned hospital admission. It may be appropriate to include end of life care planning in a resident's first support plan, especially if they have moved into the extra care housing scheme with high needs, but **person-centred support planning provides a strong basis upon which to build end of life care planning at a later date.**

Top resources

A good starting point can be to develop a '**one page profile**' with each new resident. Helen Sanderson Associates have information, advice and resources to help with this. Each member of their staff has their own one page profile, so there are a number of examples on their website:

www.helensandersonassociates.co.uk. You may want to develop your own that you can share with residents; this can encourage them to create theirs and help you to get to know each other.

Another approach that is becoming quite well-known is BUPA's '**map of life**'. The form of the 'map' is up to the individual resident, but they are often pictorial representations of a person's life story and history through key events and themes, such as childhood, schooling, career, marriage and family. Be open and flexible when gathering information about a resident's life history and avoid assumptions about their family and relationships.

You can find resources to help with **person-centred planning** on the Helen Sanderson Associates website, as well as on the In Control website, where you will also find examples of best practice:

www.in-control.org.uk.

Life Story Network facilitates training around **telling and capturing life stories**. Their website has a number of resources: www.lifestorynetwork.org.uk.

An example of a support plan can be found in [Appendix B](#).



Case study

Jumping out of planes!

“Resident Bill Hodder, now in his seventies, was part of a team that raised over £3,000 when he leapt out of a plane from 13,000ft as part of a tandem parachute jump in aid of ExtraCare Charitable Trust’s Lark Hill Village. Chrishanti Thornton, who runs the Village’s Well-being Service, also took part in the jump.

Commenting on his active lifestyle at Lark Hill Village Bill said: “You don’t stop ‘thinking and doing’ at 65 – that’s why we’re here.”



ExtraCare Charitable Trust

Enabling residents to live life to the full can mean that conversations about the end of life and determining a resident’s wishes are an extension of focusing on outcomes, choice and control.

One of the possible challenges to enabling residents to achieve life goals can be convincing their informal carers, family and friends that things are possible. This can be especially difficult for families who are coming to terms with their loved one being at the end stages of life.

“It’s about reminding the families that the prognosis is not the end, even though they have started the grieving process of losing their parent, or sister, or other family member.”



As mentioned earlier, every resident's pathway is different. Sometimes people find it easier to focus on living life to the full when they have already considered the end of life and made decisions about their wishes.

"I think people can concentrate on having a sense of fun. if they have made the plan and the decision that they are going to be dying – when it comes – here; that there won't be a move to a residential home and then a nursing home and then onto the hospice. I think it's very important for people who want to make decisions. Not everyone does but taking away the anxiety and indecisions about what will happen is a huge part of starting the 'rock and roll' lifestyle."

Talking about, identifying and achieving life goals will not solve all of the challenges of starting conversations about the end of life, but it can be a good place to start.

"Finding out more about residents has reciprocal benefits. We have so many skills on site and a real sense of community. All we do is enable residents to get to know us and each other, and to find their niche. When I need advice, the first place I go to is the Committee of Residents".

The next section provides further information, advice and resources about approaching conversations about the end of life.



3. Approaching conversations about the end of life



Resident-centred conversations

Dying is an extremely personal experience. It may be one that a resident wants to share with loved ones, but any conversation about the end of life should be focused upon the resident and their wishes and decisions.

You should approach all conversations and decision-making with the presumption that the resident has capacity to take decisions about their end of life care and the things that are important to them. You can find out more about this in Section 6: [Decision-making and the Mental Capacity Act](#).

Approaching conversations about the end of life can be one of the greatest challenges for staff. Death and dying continue to be taboo subjects for many people. Extra care housing is focused upon independent living, which can make it feel out-of-place and uncomfortable to approach conversations about the end of life with residents.

Some extra care housing sites include considerations about the end of life in their support plans, especially with regard to key medical decisions including Do Not Attempt Resuscitation (see the [Glossary](#) for more information), but even when part of a formal process, some residents may make it clear that they do not want to talk about the end of life. Remember that they may reconsider if their circumstances change, or they may respond to a different approach, but there may well come a point – however frustrating it can feel – that it becomes clear a resident really does not want to consider the end of life.



“I think the major difficulty is knowing what the resident wants to happen. How you broach that subject with them is the stumbling block. Some people will talk about it and are quite open about it, but for others it’s almost as if they think ‘if I talk about it, it’s going to happen’.”

Sometimes it is easier for people to talk about death and dying when there is no urgency to do so. It can be empowering to have the opportunity to explore options and take thoughtful and unpressurised decisions. Including conversations about the end of life in support planning may not feel appropriate for all staff and residents, but situations do arise in extra care housing that can provide a natural opportunity to approach these conversations.

Situations that can lead to conversations about the end of life

- When a resident receives news that someone they know has died.
- When another resident dies.
- When a pet dies.
- When a resident experiences a time of change that takes them out of their ordinary routine, for example a hospital admission.
- When a well-known public figure dies, or even if there is a prominent storyline about dying in a popular TV programme such as Eastenders or Coronation Street. For example, a poll in 2009 found that 42% of people thought the publicity around the death of Jade Goody was helpful in making people think about death (Theos, 2009).

Openings to conversations about the end of life

Openings can arise in everyday activities and conversation

- “One of the things we always talk about – because we are pet friendly – is people’s pets. We bring into conversation ‘what would you want to happen’ and we have various options. That’s a good starting point. I think those conversations can be very reassuring for people.” (Hanover Housing Association).
- Residents can sometimes hint that they want to have a conversation about the end of life during their everyday conversation. For example you might ask a resident how they are today, to which they reply with something like ‘I’m just waiting to go now’. This may be intended as a flippant remark, or even as a joke, but it may stem from real feelings and fears about the end of life. Such comments can open up an opportunity to ask more questions and to listen.



- Residents may talk about the experiences of someone they know and reflect upon what was good and what was bad. This can present an opportunity to explore a resident's own thoughts and wishes.
- Film nights are popular at some extra care housing sites. Many films contain plots and subplots on the themes of death and dying. Talking about a fictitious experience can be a lot more comfortable than talking about a real one, but it can prompt people to reflect upon their own situations. The same goes for book clubs.
- As discussed in Section 2: [Enabling residents to enjoy life and achieve life goals](#), residents at some extra care housing sites have been developing 'bucket lists' of things to do/achieve before they die. Activities Co-ordinators, Wellbeing Advisers and staff with similar roles often lead these initiatives and can be well-placed to take a role in creating openings to conversations about the end of life.

"To be honest, I think a lot of the barriers to approaching conversations about the end of life come from staff. You find that residents are very frank about death and dying; perhaps because they are more reconciled with their mortality than we are. It's often the staff who worry about breaking a taboo by mentioning it. Once you've had your first conversation about the end of life, you'll feel more confident about your next one."

If you are visibly anxious, nervous or hesitant about talking about the end of life, then residents are likely to pick up on that. It may deter them from opening up and they may choose to avoid placing you in a situation that you find uncomfortable. Talking about the end of life is often something that gets easier with experience – both professional and personal – so you may find it helpful to seek advice and guidance from colleagues, or to ask them to assist you in approaching a conversation with a resident.



Top tips

It can be tempting to try and close a conversation down with comments like "don't talk like that – let's just see what happens", "I'm sure you've got a long time left" or "let's stay positive". However, someone who is coming to terms with their own mortality may feel anxious or frightened about things and want to talk about them. Even someone who feels at peace and in control may still want to have a conversation to help them work through their thoughts and emotions.

Top tips

Give residents time and try not to be put off by silence. Sometimes people just need a little time to put their thoughts together, compose themselves and find the strength to share their feelings.

Be aware that crying is a normal way of releasing emotion.

Don't be afraid to ask questions

Sometimes all you need to do is listen, but questions can be a good way of giving someone the forum they need to share their thoughts and feelings. Here are some ideas:

- How are you feeling?
- Is there anything that you're especially worried about?
- What's most important to you right now?

Questions to avoid include:

- Questions that require only a 'yes' or 'no' answer – these can block conversation.
- Questions that contain an assumption or judgement, for example: "You'll feel better when you see the doctor won't you?"

Top resources

The *National End of life Care Programme* have developed a **Communication Skills Work Book and DVD** called *Finding the Words*, which was developed by people with life-limiting conditions and people who have experienced the death of a loved one: www.endoflifecareforadults.nhs.uk/publications/finding-the-words.

Dying matters have worked in partnership with other agencies to create **five short films that explore why it's so important to talk about end of life care wishes**, under the banner 'I didn't want that', which can be watched here: www.dyingmatters.org/page/i-didnt-want-that. A number of other short films are available through the same site and copies of the film are also available to purchase on DVD.

The *National End of life Care Programme* have also developed a guide specifically focused upon achieving quality end of life care for **people with learning disabilities**, which includes a section about approaching conversations about the end of life: www.endoflifecareforadults.nhs.uk/publications/route-to-success-people-with-learning-disabilities

Life Before Death is an award winning **documentary series** that explores death and dying across 11 countries. You can find out more about the films and purchase them on DVD here: www.lifebeforedeath.com/movie, or access the majority of the resources for free through the *Life Before Death* channel on YouTube: www.youtube.com/lifebeforedeathmovie.

You can find **fictional films that address death and dying** by searching the *Internet Movie Database*: www.imdb.com. Click on the arrow on the right-hand side of the search box and select 'Keywords' from the drop-down list. Then type 'death', 'dying' or any other keyword you're interested in in order to generate a list of films on that theme. The films will be automatically broken down into sub-themes, for example 'dying from cancer'.



“A peaceful death is what everybody would wish for and everything has to be in place to ensure someone has a peaceful death... it’s all got to be well in place before the time comes. Planning is essential”.

Extra care housing staff are well-placed to support residents with ACP.

An Advance Care Planning discussion with a resident might include:

- the resident’s concerns and wishes;
- their important values or personal goals for care;
- their understanding about their illness and prognosis; and
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

Advance Care Planning may lead to making:

- An Advance Statement (of medical and care wishes).
- An Advance Decision to Refuse Treatment (ADRT).
- A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision
The differences between these are explained in the table on the next page.
- Other types of decision, such as appointing a Lasting Power of Attorney (LPOA).
See Section 6: [Decision-making and the Mental Capacity Act](#) for more information.

With the resident’s consent, discussions should be:

- documented and ideally signed to avoid confusion later on;
- regularly reviewed;
- communicated to key people involved in their care and support; and
- if appropriate and agreed, shared and developed with their family and friends.

There is no set format to making a record of ACP discussions and decisions. Sometimes it’s helpful not to have a rigid prescriptive method of interview and of recording discussions, but it is important that decisions are well-documented for use in future care and support. A helpful example flowchart for staff when considering creating an ACP can be found in [Appendix C](#).



Case study

Having choices means understanding the options

“Graham suffers with chronic heart disease. He is on oxygen 24 hours a day. Graham knows that his time in our extra care housing scheme is limited. He attends the local hospice one day a week. This is to allow him to get used to the hospice, the staff and to learn what to expect nearer the end of his life. At first we thought that Graham had good control over his end of life care. Then we realised that Graham has assumed that when the time comes he will go to the hospice full time and spend his last days there. We are going to make sure he knows what options are available to him; that he could die in his own home if he chose to. It may be his choice to move to the hospice, but he needs to know that it isn't a necessity.”

Hanover Housing Association



The differences between general care planning and decisions made in advance

	General Care Planning	Advance Care Planning (ACP) – advance statement	Advance Decisions to Refuse Treatment (ADRT)	Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)
What is covered?	Can cover any aspect of current health and social care.	Can cover any aspect of future health and social care.	Can only cover refusal of specified future treatment. May be made as an option within an advance care planning discussion.	Only covers decision about withholding future CPR.
Who completes it?	Can be written in discussion with the individual who has the capacity for those decisions or Can be completed for an individual who lacks capacity in their best interests.	Is written by the individual who has the capacity to make these statements. May be written with support from professionals, and relatives or carers. Cannot be written if the individual lacks capacity to make these statements.	Is made by an individual who has capacity to make these decisions. May be made with support from a clinician. Cannot be made if individual lacks capacity to make these decisions.	Completed by a clinician with responsibility for the person. Consent is sought only if an arrest is anticipated and CPR could be successful. Can be completed for an individual who does not have capacity if the decision is in their best interests.
What does it provide?	Provides a plan for current and continuing health and social care that contains achievable goals and the actions required.	Covers an individual's preferences, wishes, beliefs and values about future care to guide future best interests decisions in the event an individual has lost capacity to make decisions.	Only covers refusal of future specified treatments in the event that an individual has lost capacity to make those decisions.	Documents either <ul style="list-style-type: none"> • that CPR cannot be successful and should not be attempted • an individual's advance decision to refuse CPR.
Is it legally binding?	No – advisory only.	No – but must be taken into account when acting in an individual's best interests.	Yes – legally binding if the ADRT is assessed as complying with the Mental Capacity Act and is valid and applicable. If it is binding it takes the place of best interests decisions about that treatment.	Yes – if it is part of an ADRT. Otherwise it is advisory only i.e. clinical judgement takes place.
How does it help?	Provides the multidisciplinary team with a plan of action.	Makes the multidisciplinary team aware of an individual's wishes and preferences in the event that the patient loses capacity.	If valid and applicable to current circumstances it provides legal and clinical instruction to multidisciplinary team.	Makes it clear whether CPR should be withheld in the event of a cardiac or respiratory arrest.
Does it need to be signed and witnessed?	Does not need to be signed or witnessed.	A signature is not a requirement, but its presence makes clear whose views are documented.	For refusal of life sustaining treatment, it must be written, signed and witnessed and contain a statement that applies even if the person's life is at risk.	Does not need to be witnessed, but the usual practice is for the clinician to sign.
Who should see it?	The multidisciplinary team as an aid to care.	The person is supported in its distribution, but has the final say on who sees it.	The person is supported in its distribution, but has the final say on who sees it.	Clinical staff who could initiate CPR in the event of an arrest.

Source: *The differences between general care planning and decisions made in advance*, published in May 2012 by the NHS National End of Life Care Programme and available via their website:

www.endoflifecareforadults.nhs.uk



“We also need to increase people’s awareness about flexibility possibilities. They don’t have to have things set in stone – things can change, there are choices and people will be flexible.”

Advance Care Planning – specific things you can do to help

- Make sure that residents know exactly what your extra care housing scheme has to offer. For example, some schemes do not have waking night support, but it can be brought onsite for end of life care. Residents may assume otherwise and rule it out as an option for their ACP.
- Make sure that you know what is available in your local area and what the features and areas of expertise are of these services. For example, some hospices may specialise in palliative care for one type of disease only (for example cancer), although the majority of hospices do provide palliative care for patients with a variety of conditions.
- Strongly encourage residents to: document decisions; have them added to their files so that they are available if necessary to team leaders and night staff; and communicate their decisions with their families and friends.
- Encourage residents to nominate their next of kin and possibly a ‘named responder’ who they want to be contacted in the event of an emergency. The named responder should be the person the resident trusts most to take a lead and act in their best interests if required to do so; it does not have to be the same person as their nominated next of kin.

Planning beyond care

There is no set format to making a record of ACP discussions and decisions. Sometimes it’s helpful not to have a rigid prescriptive method of interview and of recording discussions, but it is important that decisions are well-documented for use in future care and support. A helpful example flowchart for staff when considering creating an ACP can be found in Appendix C.

- Who, if anyone, the resident would like to be notified when they approach the final days of life and who they would like to be with them in the final hours.
- Whether there are any elements of their setting that they would like to be personalised, for example they might choose to have photographs of their loved ones beside them, or scented candles that evoke happy memories. They may have particular music that they would like to be played in their last hours of life.
- There may be more practical things that need to be considered, such as the care of a pet if the resident is unable to maintain this. It might be very important to them that their pet stays with them right to the end, but arrangements might need to be made in advance to ensure that this can happen.



Case study

Mervyn's story: The importance of advance care planning

Mervyn moved into extra care housing in 2009. At that time he was 84 years old and very independent in spite of being an amputee. He also had cancer which worsened over time. No-one in Mervyn's immediate family lived locally, most of his relatives that he was regularly in touch with had moved to Canada.

About a year after Mervyn moved in, the manager noticed his health was deteriorating and also that he was starting to forget things. She arranged for him to be assessed for dementia. His physical health was deteriorating too, and the manager felt it would be an appropriate time to broach the issue of an advance care plan (ACP) for Mervyn whilst he still had mental capacity. She organised a residents meeting to show the DVD (that accompanied the original version of the end of life care resource pack). Some residents on watching the film decided they wanted to complete an advance care plan; others said they would think about it and probably complete one later. Mervyn was very clear that he wanted to complete an ACP so the manager assisted with this. Mervyn's ACP documented plainly that he wanted to die at home, he did not wish to be resuscitated and he wanted to be cremated.

As Mervyn's cancer got progressively worse, the manager or care staff would accompany him to hospital for chemotherapy treatment. Initially, Mervyn was allocated appointments for radiotherapy at a hospital which was over 30 miles from the extra care court. The manager negotiated with the consultant and successfully got Mervyn's treatments reallocated to a local hospital. On one of his visits he signed a 'Do Not Resuscitate' document. This was also captured in the advance care plan. The manager was successful in applying for Continuing Care funding and also got the local GP and District Nurses involved. The hospital consultant praised the court manager and said "I wish everyone was like you. You really got to know this gentleman and put his wishes into practice".

In the last few weeks of his life, district nurses were coming in 3 or 4 times a day and Mervyn was on a peg feed. He did get agitated and depressed from time to time, but was very clear he wanted to be at home when he died and the manager, staff and local health professionals all worked together to achieve this outcome for him. He died peacefully at home in accordance with his wishes. Subsequently, Mervyn's family in Canada have written to the manager to praise the care that he got from her and the staff. "You treated him as if he was the only person who lived there". The manager worked hard to co-ordinate and deliver such a complex, personalised care package alongside caring for the 40 other residents but was extremely happy that Mervyn's preferences were met at the end of his life. The manager says now that 'being able to advocate on that person's behalf is key' and the advance care plan gives a record of a person's wishes if there are any difficult decisions to make.



“One of our residents was adamant that her family were not going to see her without her wig. We were under strict instructions to make sure she was wearing it, even in her final hours.”

Residents' wishes for care after death

Residents may wish to consider:

- Clearly communicating wishes about organ donation, or donations to medical science.
- Deciding on a burial or cremation.
 - Choosing and arranging a burial plot.
 - Wishes for the scattering of ashes.
- Planning their funeral.
- Paying for their funeral.
- Planning for the clearance of their home.
- Ensuring all wishes and plans are well-documented and known to family (and ideally to staff – especially those that are time-dependent, such as organ donation).

One of the main things that an extra care housing resident may wish to consider is whether they want to be buried or cremated after death. Some people include details of their wishes in their will, but these are not always found and/or read until after the funeral, when it is too late to act upon them.

Planning a funeral can be very difficult for loved ones, who usually have less than two weeks to organise everything (considerably less in some faiths and cultures). While funeral directors can greatly assist with the administration, it is usually very important to the resident's family and friends that the order of service reflects their life and character. Approaches will vary, but in general family and friends will want to feel that they have 'done their best' by the resident and 'given them a good send-off', which often means personalising elements of the funeral, like music, hymns and readings.

If residents plan their own funerals, it means family and friends can be confident that it will be personalised according to their wishes, which can alleviate much of the stress and strain at what will be a difficult time for them. If residents wish to make plans for their care after death, then they can make these known to staff, but it is important to remember that the executor of the estate of someone who has died (who will usually be their next of kin) does not have to follow the deceased's wishes for the funeral, even if they are formally documented. A resident's wishes may come as a shock to the family, for example they might find it difficult to come to terms with the idea of a cremation, or be overwhelmed by the complexity of organising a burial.



You may therefore want to encourage residents to discuss their wishes with their loved ones in advance. These conversations can be difficult. Sometimes, even when the resident is comfortable talking about their death, their loved ones may not be.

Residents may wish to formalise their wishes by planning and paying for their funeral with a funeral director. Most local funeral directors will offer advance planning and pre-paid funeral plans. It is again important to remember that the executor of the estate of someone who has died does not have to follow their wishes – even if the funeral is planned and paid for – but it is rare for someone’s wishes to be overturned when they are formalised in a pre-paid plan.

Planning for care after death – specific things you can do to help

- Accompany residents to appointments with a local funeral director (It may not feel comfortable, or be appropriate to stay for the duration of the appointment, as finances and very personal wishes will likely be discussed).
- Enable a resident who expresses a wish to be buried in a plot of their choosing to visit cemeteries and make the arrangements.
- Document wishes and keep them on the residents’ files.
- Encourage residents to discuss their wishes with their families and friends.
- Some extra care housing schemes have arranged information sessions with local funeral directors for residents to find out more about planning their own funeral, which have proven to be popular when sensitively handled.
- Reassure residents that you will work to advocate for them after death – especially if they have no next of kin – but be careful you don’t make promises that you are unable to keep. Remember that the executor of a resident’s estate (usually their next of kin) can override all decisions; even those that the resident has already arranged and paid for.

Case study

Supporting residents who don’t have family: example of a frequently occurring scenario

Carol has no family. She decided to plan for her funeral. The Scheme Manager assisted Carol to make the appointment and went with her to introduce her to the Funeral Directors near the extra care housing scheme. The Scheme Manager then left Carol to discuss the personal details and finances involved. She’s chosen her poem, her music, the clothes she’s going to wear and it’s all paid for. Although Carol has now sorted this out she has no-one to communicate her wishes to. Therefore at the moment only the Scheme Manager is aware of these plans.

Possible approaches:

Encourage Carol to discuss her plans any friends who visit, or with someone else she trusts. Encourage Carol to leave the funeral arrangement details in a safe, but prominent place in her flat. Ask Carol if she would like the information put on her care file. Suggest to Carol that she discusses her wishes with her Care Manager.



“I don’t think it’s until a resident sees the property of a deceased resident being cleared – until it’s really pointed out to them – that they realise they should have a think about their possessions.

They may well have this attitude of ‘when I’m gone it won’t matter because I won’t be there’, but they’ll have accumulated some very personal things over the years and if they make no plans then a lorry might be brought in to sweep it all away.

It may just be picking a few things out and saying who they want to have them. It might seem too small to put into their will, but they should write it down – prominently – somewhere”.

Top resources

Resources on the NHS National End of Life Care Programme’s website include:

- Capacity, care planning and advance care planning in life limiting illness: A Guide for Health and Social Care Staff
- Advance Decisions to Refuse Treatment – A guide for health and social care professionals
- Planning for Your Future Care
- Practical Guidance for Best Interests Decision Making and Care Planning at End of Life

www.endoflifecareforadults.nhs.uk

Compassion in Dying is a charity that provides information and advice about the end of life, **free Advance Decision documents**, as well as the guide *Your Rights at the End of Life*:

www.compassionindying.org.uk

Advice and guidance about **arranging a funeral** – including lists of funeral directors – can be found on the Direct Gov website: www.direct.gov.uk/en/governmentcitizensandrights/death/whattodoafteradeath/dg_10029667

Decisions relating to cardiopulmonary resuscitation

www.resus.org.uk/pages/dnar.pdf

Age UK has a number of **factsheets and guides** about many aspects of the Mental Capacity Act, including how to appoint a **Lasting Power of Attorney**: www.ageuk.org.uk/money-matters/legal-issues/powers-of-attorney.

A leaflet on **Do Not Attempt Cardiopulmonary Resuscitation** is available from the East Midlands Ambulance Service. Available free on a first-come, first-served basis in boxes of 600 (a charge of £10 for postage and packing applies). Email jo.baggott@nhs.net or visit www.emas.nhs.uk to find out more.

A short document *On the Pulse* includes **case studies** as to how housing can achieve **better health and social care outcomes** for older people: www.housing.org.uk/publications/find_a_publication/care_and_support/on_the_pulse.aspx

See also the **top resources** box of section 6: [Decision-making and the Mental Capacity Act](#).



It is important to take into account religious, spiritual and cultural beliefs when it comes to:

Diet

Dietary restrictions and practices according to religious beliefs are unlikely to change at the end of life in most cases. However, it is important to be aware of these preferences in advance. Some people may follow Halal, Kosher or meat free diets. Some people may observe vegetarian or pescetarian diets; others may follow certain diets on specific days or at festival periods.

See the top resources box at the end of this section for more information.

Language

Language can be an issue for some residents. Some residents may feel more comfortable reverting to their first language when discussing sensitive issues; dementia and other conditions may also interfere with a resident's ability to communicate in English. At times, some residents may need the help of a translator and local community groups or religious organisations may be able to help. Families can also help in translating, although families should not be used for translating information on prognoses or other sensitive information. As is appropriate, communication (for example eye contact) should be directed at residents even when a translator is present.

Names

It is important that the resident's wishes in how they would like to be addressed are observed at all points in the delivery of end of life care (for example first name, or title and surname).

Washing and care

There are a number of practices that residents and families may wish to be observed. These should be established in advance. These practices extend into treatment after death, and there are large differences between the major religions in, for example, whether to wash the body after death.

Modesty

Modesty this is an area that needs to be treated with the greatest respect at all times. Residents who follow some religions may not wish to be in close contact with staff of a different gender; some religions also forbid the body to be touched by non-believers after death. Residents' and families' preferences should be established in advance.

Community

Some residents and their families may view the end of life process and death as being a private time for close family or close friends alone; others may regard the end of life, and particularly death as being a time for openly celebrating a resident's life. It is important that the residents' wishes in particular are respected in this regard.

Neighbours and other residents in extra care housing will also be affected by the death of a resident. It is important that staff consider the impact of a resident's death on the scheme as a whole. This may mean helping other residents celebrate a neighbour's life in their own way.



Attitudes to medical, care and housing staff

Most residents and their families will accept conventional qualified medical opinion. However, conventional medical opinion may be less important compared to traditional forms of medicine in some cultures and religions.

Some residents and families may perceive medical, care and housing staff that broach and discuss end of life openly as being cruel, uncaring and ignorant. While this pack advocates transparency and openness in terms discussion about the end of life, focusing on enjoying life and setting goals may be one way of overcoming perceived cultural differences.

It should also be borne in mind that many residents from minority groups, including residents from: minority ethnic; religious; sexual and gender identity; and disabled groups and their families, may have experienced discrimination or hostility from service providers in the past. These experiences may shape the way in which residents and their families react to discussions of end of life care and the role of staff in this process.

Some residents and families may be inexperienced in matters surrounding end of life care and may expect to be given a steer on many of the important decisions by staff. In other cases, residents and their families may have very clear wishes. In either case, it is important to consider the wishes of the residents, and not to impose your own beliefs, or those of the family, onto the resident.

On occasion, it may be necessary to get advice from someone of the same ethnicity, background or identity as a resident, who may be a colleague or someone from the wider community. However, it is important not to disclose personal or sensitive information to an outsider.

Family and relationships

Everyone knows that people's families and relationships are different. While for some, close family may mean a small number of kin consisting of siblings and children, close family for others may include a multitude of relationships from children through to second cousins. Similarly, some people and groups, for example older lesbian, gay, bisexual or transgender (LGBT) people may be less likely to have close ties to children, although may have other relationships and friendships that are equally as important to them. It is important to base the way that families and friends are involved in decisions on the end of life on the wishes of the resident (where possible) and not on your own judgement about who is 'close' family or friends.

The stress of the end of life process can exacerbate family tension. It is important to be aware of the potential for conflicts between individuals and family members, arising from different religious, cultural or lifestyle perspectives and work with those involved to reach agreement. Advance care planning with the resident, and where appropriate the family, can be one way to help avoid conflict, through setting out plans and wishes early on.

Death

Death is probably the most sacred ritual for all people, regardless of background. There are many rituals and customs that vary along family, religious, cultural and even individual lines. It is important to get advice from appropriate organisations, especially in the case of residents whose culture or religion you may be unfamiliar with. If your organisation has a diversity policy or coordinator, this could be a good source of information; alternatively you could speak with local community, cultural or religious groups.



After death

Different practices also exist after death. These can include differences in terms of the treatment of the body or arrangements for organ donation. Again, it is important to know of these in advance; this may also require speaking with your diversity coordinator or local religious or cultural groups.

Within extra care housing settings, there may be an expectation that some part of the funeral, such as the wake, will take place within the scheme; either within an individual home or within a communal area of the scheme. In addition, given that extra care housing is a home, it is likely to be the setting for other stages, such as the start of the funeral procession. There may be a need to liaise with other residents as to the impact that this is likely to have, as well as to facilitate any practical arrangements, such as parking spaces.

Practical advice – 3 golden rules

1. It is important to ask extra care housing residents, their families and even religious leaders where appropriate, whether standard practices exist to comply with religious, spiritual and cultural conventions of the resident.
2. It is particularly important not to make assumptions about people's religious and cultural preferences – people craft their own versions and have different ideas about the end of life, suffering and what is a good death.
3. It is important to find out in advance about a resident's religious, spiritual and cultural preferences. Where possible these should be recorded. Having the resident sign these is one way to avoid ambiguity or conflict at a later date.

Case study

Learning about diversity as a way of starting conversations about the end of life

"At a retirement housing estate, the Estate Manager organised a shared reminiscence session with residents and older members of a local Chinese community. The discussions were based around important 'life' events including birth, marriages and deaths and with the aid of a translator some really open and interesting comparisons were made between the different cultures – for example, Chinese people traditionally wear white to a funeral and don't face the coffin....this was a great way not only to build awareness of each other's cultures, but also to explore thoughts and feelings about the end of life."

Hanover Housing Association



Case study

The importance of discussing and confirming wishes with residents, friends and family in advance

"I had a lady who we supported with end of life care. She was a staunch Catholic, who took Communion on site every month. But the family just went ahead and had her cremated; there was no Catholic Church or service, or anything. I did, as gently as I could, say "do you not think...", but they were going to organise the service and pay for the funeral – they weren't going to listen to me and it was difficult to know how far to get involved there."

Hanover Housing Association

Top resources

A great **guide on end of life care practices of different religions and spiritual beliefs** produced by the Merseyside and Cheshire Cancer Network can be found here: <http://queenscourt.org.uk/spirit/>. It gives an overview of some of the practices in terms of beliefs, diet, death and dying and some of the key issues of major religions and spiritual groups.

You can find **advice about fasting** – especially during Ramadan, the ninth month in the Islamic calendar – and health on the NHS Choices website: www.nhs.uk/Livewell/Healthylamadan/Pages/faqs.aspx.

The National End of Life Care Programme has an excellent resource: **The route to success in end of life care – achieving quality for lesbian, gay, bisexual and transgender people**: www.endoflifecareforadults.nhs.uk/publications/rtg-lgbt



Even if a resident is assessed as not having capacity to make one or more key decisions about the end of life, they can still have an input into those decisions and must be at the centre of them. Any decision taken must be in the resident's best interests. Information and guidance about making decisions in someone's best interests can be found in the Mental Capacity Code of Practice (see the top resources box for more information).

Assessing capacity

Each assessment of capacity will vary according to the type of decision to be made. The more complex or difficult the decision, the greater the level of capacity required.

The person making the individual decision needs to be able to:

- a) Understand what the decision is, why it needs to be made, and the likely consequences of making or not making the decision.
- b) Retain the information long enough to make the decision.
- c) Use or weigh the information as part of the process of making the decision.
- d) Communicate their decision (whether by talking, sign language, or any other means).

While everyone working in extra care housing must comply with the Mental Capacity Act, different schemes have different policies, procedures and organisational structures. Ask your manager what the policies and procedures are at your scheme and which member/s of staff are responsible for assessing capacity.

Independent Mental Capacity Advocate (IMCA) service

- The IMCA service helps people who lack capacity and who are facing important decisions made by the NHS or Local Authorities about serious medical treatment or changes of residence, for example moving to a hospital or care home.
- NHS bodies and Local Authorities have a duty to consult the IMCA service in decisions involving people who have no one unpaid (such as friends or family) who can be consulted about a best interests decision.

Lasting Power of Attorney (LPoA)

As well as thinking through, talking about and documenting their wishes for the future, residents can appoint a Lasting Power of Attorney to take decisions in their best interests if they lose the capacity to do so.

An LPoA is a statutory form of power of attorney that gives another individual the legal authority to look after specific aspects of your financial affairs or health and welfare should you lose the capacity to do so.

There are two types of LPoA: one that can cover decisions about money matters, known as a property and financial affairs LPoA, and one that can cover decisions about healthcare, known as a personal welfare LPoA. A key difference is that a property and financial affairs LPoA can be used while someone still has capacity, whereas a personal welfare LPoA can only be used once they have been assessed as having lost capacity. A person administering a property and financial affairs LPoA can make decision on things such as buying and selling your property, dealing with your bills, running your bank accounts and investing your money. If they have a personal welfare LPoA, they can generally make decisions about where you should live, how you should be treated medically, what you should eat and who you should have contact with.



Forms and guidance are free from the www.justice.gov.uk/forms/opg/lasting-power-of-attorney#individual or by calling 0300 456 0300. Registering the document can take up to three months and costs £130 per LPOA, so £260 to set up both types. Most people on benefits or a low income can get an exemption or reduction. Residents may choose to seek legal advice if arranging an LPOA, but they do not have to do so for it to be valid.

You can provide information and advice to residents about LPOAs, but it is a conflict of interest to be appointed as a resident's LPOA. Protocol in most schemes forbids staff from witnessing documents such as LPOA applications or wills. Talk to your manager if you ever find yourself in a position that is inappropriate or feels uncomfortable.

It should be recorded on a resident's file (with consent) if they have an LPOA in place.

Top resources

This section of the resource pack is only a brief overview of some aspects of the Mental Capacity Act, but more resources are available

The full **Mental Capacity Act 2005** can be found on the UK Government's *Legislation* website: www.legislation.gov.uk/ukpga/2005/9/contents

Good Decision Making – The Mental Capacity Act and End of Life Care from the National Council for Palliative Care www.ncpc.org.uk/publications

Legislation can change and evolve over time as judicial rulings on individual cases set new precedents. The Direct Gov website is perhaps the best place to go to stay up-to-date on **how the Mental Capacity Act is being applied**. The site includes explanations about making a Lasting Power of Attorney and the role of the Court of Protection: www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw

The Mental Capacity Act **Code of Practice** can be found on the Ministry of Justice's website. It contains practical guidance about how to apply the Act: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act. You will also find an information booklet for family, friends and informal carers, which can be downloaded in a version designed for easy printing.

Age UK has a number of **factsheets and guides** about many aspects of the Mental Capacity Act, including how to appoint a **Lasting Power of Attorney**: www.ageuk.org.uk/money-matters/legal-issues/powers-of-attorney.

As well as information and advice, *Age UK* also offer free consultations to find out about **legal advice**, support and how much it will cost you to proceed with legal services: www.ageuk.org.uk/products/products/financial-products--services/legal-services.

A free **Advance Decision pack** can be found on the *Compassion in Dying* website: www.compassionindying.org.uk/advance-decisions.

The Housing LIN have a useful set of resources in relation to extra care housing, including **guidance on capacity and tenancies**: www.housinglin.org.uk/Topics/browse/Housing/Personalisation/?parent=3695&child=1940

See also the **top resources** box of the section 4: [Supporting residents to have choice and control](#).



The following provides a summary of professional roles. See Appendix A for more details, including how they are involved in end of life care.

Advocate

An advocate can help a resident to become an active member of society and ensure that their voice is heard and their best interests are met. Your local Council and/or PCT may have a contract with an agency to provide advocacy services, or local voluntary provision may be available.

Community Matron

Highly experienced, senior nurses who work in people's own homes to provide, plan and organise their care.

Continuing Care Co-ordinator

Usually a joint-post between the local Council and PCT, they co-ordinate assessments of people to see if they are eligible for Continuing Care (also known as fully-funded NHS care).

Dietitian

A dietitian (or dietician – alternative spelling) is a health care professional who can provide practical information about food and nutrition.

Discharge Co-ordinator and Planning Team

People and teams responsible for planning safe and timely discharges from hospital and ensuring there is care and support in place for discharged patients.

District Nurse (sometimes called Community Nurse)

A nurse who has completed a degree-level specialist practitioner programme and who is appointed to attend patients within a particular district; usually within the person's home.

Faith Leader

A leader of a religious order, or a person who guides and inspires others in their spirituality.

General Practitioners (GP)

A physician who does not specialise, but who has a medical practice in which they diagnose, treat and make onward referrals for a range of illnesses.

Macmillan Nurse

Nurses specialised in cancer and palliative care, providing support and information to people with cancer and their families, friends and informal carers, from the point of diagnosis onwards.

Marie Curie Nurse

Nurses who provide practical, hands-on nursing care during the terminal stages of cancer and other conditions in a person's own home, including overnight.

Occupational Therapist (OT) – Local Council and NHS

A healthcare professional who can help someone to overcome the effects of disability caused by physical or psychological illness, ageing or accident.

Pharmacist

An expert in medicines and their use who can advise health and social care professionals on the selection and appropriate use of medicines, and can advise individuals as to how to manage their medicines to ensure optimal treatment.

Physiotherapist

A healthcare professional who is concerned with human function, movement and helping people maximise their abilities.

Social Worker

A social worker can co-ordinate care and support, but also provide emotional and psychological support, especially at difficult times in people's lives. Someone who performs social work functions, but who isn't a qualified social worker is sometimes known as a 'care manager'.



Local directory of key contacts who can help in the delivery of end of life care

This section should be completed by scheme managers, or senior care or support staff – ideally from a centrally-held and up-to-date list of contacts.

Professional / service	During normal working hours (Mon-Fri, 9-5pm)	Out-of-hours
Advocacy Services		
Benefits Advice		
Bereavement Support		
Carers Centre (or similar)		
Community Matron		
Continuing Care Co-ordinator		
Discharge Co-ordinators and Planning Teams		
District Nurses (Community Nurses)		
Equipment Store		
Faith Leaders		
Funeral Director(s)		
GP Surgeries		



Professional / service	During normal working hours (Mon-Fri, 9-5pm)	Out-of-hours
Homecare		
Hospice		
Macmillan Nurses		
Marie Curie Nurses		
NHS Direct		
Occupational Therapy – Council		
Occupational Therapy – NHS		
Pharmacy		
Physiotherapy Services		
Registrar		
Specialist Palliative Care Team (if applicable)		
Social Services		
Solicitor(s)		
Urgent Care Centres		



8. Identifying when to initiate end of life care



It is difficult to predict when a resident is approaching the end of their life, especially when their health is deteriorating due to ageing rather than a specified and diagnosed illness. That said, around three-quarters of deaths are 'predictable', in that they follow a period of chronic illness, such as cancer or heart disease, where people may need access to end of life care.

(Source: Public Accounts Committee, 2008).

When should end of life care begin?

When end of life care begins will depend upon individual residents' needs.

The General Medical Council considers that people are approaching the end of life when they are likely to die within the next 12 months. This includes people who are expected to die within the next few hours or days, and those with advanced incurable conditions. It can also include people who have:

- general frailty and co-existing conditions that mean they are likely to die within 12 months;
- existing conditions, if they are at risk of dying from a sudden crisis in their condition; and/or
- life-threatening acute conditions caused by sudden catastrophic events, such as an accident or a stroke.

End of life care may last a few days, or for months or years.

Frailty can be difficult to identify, but indicators include signs of impairment in day-to-day functioning and a combination of weakness, slow walking speed, low physical activity, weight loss and self-reported exhaustion.

It is perfectly possible for end of life care to be initiated, but for the resident's health to improve and the prognosis to change.



It can be difficult to manage expectations at the end of life. This includes the expectations of the resident, their family, partner and friends, other residents and of health and social care staff. People have different outlooks on life and some people's outlooks will be more positive than others'.

It can be difficult to accept that curative measures are no longer viable and that there will be no recovery. Equally though, it can be too easy to assume that because someone is dying, nothing more can be done for them, when in reality some elements of their health condition/s can still be treated and their symptoms (including pain) can be managed. It can be a difficult balance to strike, but realism is important.

Remember that for some people – sometimes including the resident themselves – initiating end of life care means initiating the grieving process. You can find out more about the natural grieving process on the website of the Royal College of Psychiatrists:

www.rcpsych.ac.uk/mentalhealthinfo/problems/bereavement/bereavement.aspx

Top resources

The Prognostic Indicator Guidance developed by the National Gold Standards Framework includes a number of tools to help you determine when someone is approaching the end of life:

www.goldstandardsframework.org.uk/LibraryofResourcesPresentationsandLinks

While not a fail-safe method of identifying when to initiate end of life care, some staff find it helpful to ask themselves the question “would I be surprised if this resident were to die at some stage in the near future; i.e. within the next six months to a year”.

Macmillan Cancer Support, working with NHS Camden & NHS Islington, have developed a **Quick guide to identifying patients for supportive and palliative care**:

www.endoflifecareforadults.nhs.uk/publications/quick-guide-to-identifying-patients-for-supportive-and-palliative-care



9. Considering funding options for end of life care



This section is not intended to be a comprehensive guide to all funding options, but to provide signposting to further sources of information.

Your local Citizens' Advice Bureau (CAB) can provide advice, guidance and in some cases advocacy on a range of end of life care-related financial matters, including benefits and care and support costs. You can find your nearest CAB by using the 'Find your local bureau' function on their website:

www.citizensadvice.org.uk/

If your extra care housing organisation has a Benefits or Financial Inclusion Team, then encourage residents to notify them as and when there is a significant change to their circumstances. Having these types of services available (and sometimes even onsite) is something that sets extra care housing apart from residential and community-based care when it comes to delivering good quality end of life care.



Case study

The importance of holistic advice on financial wellbeing and welfare benefits: Experiences from Housing 21

Some organisations who provide extra care housing have an in-house benefits advice/financial wellbeing team whose role involves providing tailored one-to-one advice and support to older people and practical help with navigating the benefits system and making claims. Lessening money worries is a key concern for people who are terminally ill and their families. It is a difficult time for people to have to think about filling in claim forms, and many older people find it hard to understand that entitlement to specific benefits isn't automatic.

Many people who are terminally ill may qualify for Attendance Allowance and if a doctor or approved medical professional confirms a diagnosis that a person has less than 6 months to live, then they can often be fast tracked to receive Attendance Allowance under 'special rules' set by the Department of Work and Pensions (DWP). The process from making the claim to having it assessed, approved and in payment should be no more than 3 weeks. AA under special rules is always paid at the higher rate so this can make a significant impact on the financial wellbeing of people at an immensely difficult time. Qualifying for AA can also passport people onto some other benefits and if the dying person lives with a partner, they may be eligible for Carer's Allowance. This remains in payment for a period of 8 weeks after the person they are caring for dies.

"Recently one of the team visited a couple in their own home with their daughter. Whilst Peggy, diagnosed with terminal cancer and four months to live, had accepted her prognosis and was able to talk in a quite matter of fact way, it was clear that her husband and daughter were distressed. The Financial Wellbeing Manager supported them through the claims for Attendance Allowance and Carer's Allowance as Peggy's husband Alan was her full-time carer. Alan had worked in the motor industry, so a quick search of occupational benevolent schemes led to a suitable fund being identified. Alan qualified for support and was able to pay off a credit card bill of several hundred pounds that had built up whilst he had been caring for his wife. As a result of the advice, Peggy and Alan were over £140 per week better off which at least helped to alleviate financial worries at a traumatic time for the family."

Housing 21

Funding from Adult Social Services

Some, or all, residents may already be in receipt of care and support through the local ASS department, but private tenants and owners of their extra care housing property may wish to pursue a referral. Most ASS departments have a team that manages referrals, but your council's switchboard should be able to advise.

Councils have a duty under the NHS and Community Care Act (1990) to assess people if they appear to be in need of community care services. All Adult Social Services departments in England and Wales must follow the Department of Health's **Fair Access to Care Services guidance**: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113154

Councils have the discretion to choose which level of needs they meet, based on available resources. A number of Councils have raised their eligibility thresholds in recent years.

Where a resident is found to have eligible needs then products and services can be arranged to meet those needs. This should be done through a person-centred support plan and Personal Budget.



There are charges for social care services, though some people on low incomes are exempt. A number of Councils have increased their charges in recent years.

Funding from the NHS: known as Continuing Care, Continuing Healthcare or Fully-funded NHS Care

Continuing Care is a package of ongoing healthcare provided outside of hospital, arranged and funded solely by the NHS, for people with ongoing healthcare needs.

To be eligible for NHS continuing healthcare, a resident must be assessed as having a “primary health need” and have a complex medical condition with substantial and ongoing care needs. The resident’s health will need to be assessed by a nurse, social care practitioner, GP or other health professional who will decide whether they are eligible. This will be based on the type of condition or treatment required, the different symptoms that make it difficult to manage or control, how severe it is and any unexpected changes in condition that are difficult to manage and present a risk to the resident or to others.

Continuing Care is free. It is not means tested and is fully-funded by the NHS.

Continuing Care in a resident’s extra care housing home may include: services from a community nurse or specialist therapist, and personal care, such as help with bathing, dressing and laundry.

Case study

Negotiating ‘preferred providers’

“Social services wanted to bring another agency in to provide one of our resident’s care. It’s really difficult with ‘preferred providers’ as Social Services and/or the PCT often want any additional hours to be delivered by specific providers. We have staff onsite who know the resident and who really want to provide their care and to support them through. Yet sometimes – especially with Continuing Care funding – there’s a point where they have to withdraw so that someone else can come in. Residents just want consistency of care and to be supported by the people they know.”

Places for People (Housing Association)

While people do not have a legal right to choose who delivers their care and support, choice control and dignity are key elements of person-centred care. Generally this should include being able to choose to receive care and support from a provider you know over a provider you do not know, especially when it comes to intimate care.

Top resources

NHS Choices have full details about Continuing Care funding on their website, including the tools that professionals use to assess eligibility:

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/NHSContinuingCare.aspx

Age UK have a number of factsheets and advice guides on their website:

www.ageuk.org.uk/health-wellbeing/doctors-hospitals/nhs-continuing-healthcare-and-nhs-funded-nursing-care/



10. Unforeseen events, including admission to hospital



Flexible care and support planning

Even the best-laid plans can be disrupted by unforeseen events. For an extra care housing resident approaching the end of life, these may include an unplanned hospital admission, or the death of their informal carer. Sometimes plans will need to be flexible so that they can be responsive to change. Developing care and support plans that are focused on goals and outcomes (rather than services) can help. If everyone knows what the end goals are that a resident wants to achieve, then they can work together on developing a support plan that enables them to get there. Their care and support services may need a small tweak, or they may need a radical overhaul, but it's important that they remain centred on the resident and what they want their life to be like, even at the end of life.

Extra care housing provides a supportive environment for residents when they are discharged from hospital, but sometimes professionals need a gentle reminder as to just how much extra care housing has to offer.

“We’ve had cases where we’ve delivered our services and the Rehabilitation Team have delivered theirs too – with major overlap. It’s only because we had gotten to know the team manager that we’ve been able to say ‘this is crazy’ and arrange to deliver the care ourselves.”



Things you can do to help

- Ensure that staff within your scheme get to know your local hospital staff, especially Discharge Planners / Co-ordinators. Ensure that they understand what extra care housing has to offer its residents upon discharge from hospital.
- Extra care housing staff involved in the development of this resource pack identified a number of challenges that they had faced around hospital discharge. They reported that they had been able to mitigate the majority of future occurrences by working with hospital staff. Reported challenges to timely discharge included:
 - Extra care housing properties are purpose-built and are therefore well-designed to receive equipment (such as specialist beds and hoists), but the timely and appropriate delivery and set-up of equipment in the resident's flat can be a challenge.
 - In many areas people qualify for 6-8 weeks of free rehabilitation services upon discharge from hospital. This can be especially useful for those residents who are self-funding, but local authorities and PCTs often have 'preferred providers' for this service. This can mean that residents can find themselves receiving care and support from carers they don't know, or receiving a mixed care and support package, with some care provided by their regular carers and some provided by a new agency. These arrangements can often be negotiated if extra care housing staff (especially managers) have developed good relationships with the statutory staff responsible for co-ordinating it.
 - Make sure all notes and files are up-to-date, just in case the hospital discharges a resident out of normal hours and the night staff have to settle them back in.



Demystifying next of kin

It can be a concern for some residents that someone close to them will be denied visiting rights and information because they are not seen as 'next of kin'. Issues of confidentiality and information sharing may arise, especially if tensions exist within the person's network as a person approaching the end of life.

The term 'next of kin' is used widely in health and social care, but it lacks clear definition and does not have any legal status. There is a common misunderstanding that next of kin refers to and needs to be a person related by blood, or marriage or civil partnership.

In reality there are no rules about who can and cannot be next of kin and an individual can nominate anyone in their personal network. A next of kin does not have automatic rights to access medical records, or have information on a person's condition. Where there is evidence that the person did not want information shared, this must be respected.

If a person has nominated a next of kin prior to losing capacity, then information can be discussed with them and they can provide valuable information to health and social care workers. An individual can nominate their partner, member of their family or a friend.

"Sometimes I think the reason a resident talks to you is because they know there is likely to be a clash between their daughter and their son... for family it can be quite distressing to see someone die and I think it's important that everyone has as much support as possible so you can enable the resident's wishes to be followed through. You may need to enable the family to let the resident have what they want".

A time of high emotion and anxiety

Supporting a loved one through the end of life can feel like being in a pressure cooker: you have feelings and thoughts that you haven't yet had time to process, as well a need to find release from your stress, anxieties and grief. You may also be extremely tired because of the physical and emotional demands of supporting someone through the end of life.

Families may also find their roles changing. They may need someone to step into the role that the dying resident used to hold, but not know who should do that. All families are different and will find themselves in subtly different and nuanced situations, but remember that this shifting of roles can be disorientating and confusing.

The grieving process can start for informal carer/s, family and friends when they are told that someone is dying; don't assume that this process will only start when the resident has died.



Fear, anxiety, anger, guilt, sadness and loneliness are just some of the emotions that informal carer/s, family and friends may feel. These are likely to be reflected by the resident themselves, who will also be coming to terms with the situation.

All of this may manifest in the way informal carers, family and friends speak and behave. They may become overly-dependent on each other or on staff for reassurance. They may become short-tempered. Try not to take this to heart; it is likely to be a release of this 'pressure' and unlikely to be deliberately targeted at you. You may well receive an apology immediately or shortly afterwards.

If at any point you feel threatened, unfairly singled out, or uncomfortable about continuing to work with a resident's informal carer/s, family, or friends, then you must report this to your manager.

A role for informal carer/s, family and friends

It's easy for loved ones to feel at something of a loss as to what to do when someone is dying. This can be the case for less-established acquaintances too, such as a resident's neighbours in extra care housing, who may feel like they want to help and to be involved, but don't know what their role might be and don't want to 'tread on the family's toes'.

Possible roles might include:

- Sitting with the resident: perhaps reading to them from their favourite magazine or book, enjoying music with them, or chatting about your day.
- Offering to run errands, such as bringing their favourite items (CDs for example), so that they don't have to ask.
- Writing letters and making phone calls if it's not possible to be there in person. You may also be able to assist relatives to communicate via Skype.

Top resources

When a resident is dying, he or she becomes the focal point for their loved ones. This is normal, but it can place a great physical and emotional burden on everyone involved. Encourage informal carer/s, family and friends to be considerate and meet their own needs too.

Find your nearest **Carers' Centre**:

www.carers.org/carers-services/find-your-local-service, where anyone who supports a loved one can access a wide range of local support services.

Counselling and bereavement services can be accessed in most areas through an individual's GP.

An excellent '**top ten tips to help someone who is dying**' can be found on this blog, written by 'a woman, mother, teacher, living in London', who is dying from cancer: <http://womanlyparts.blogspot.co.uk/2007/12/10-top-tips-to-help-someone-dying-of.html>

The National End of Life Care Programme have a useful guide, **When a person dies: guidance for professionals on developing bereavement services**:

www.endoflifecareforadults.nhs.uk/publications/when-a-person-dies



Things you can do to help

Examples of questions you may wish to work through with residents during support planning and review

- Who is important in my life and what role might I ask them to play at the end of my life?
- Who do I want to say goodbye to, and how?
- What does/will a good day and a bad day look like for me?
- How can I have more good days towards the end of my life?
- What is working and not working in my life and what do I want to change?
- 'If I could, I would...' what would I still like to do or experience or achieve?
- What do I want and not want in the future around my treatment and care?
- What is my history...my important memories and how would I like to be remembered?
- What decisions need to be made and how must I be involved?
- Are there any risks involved? How can I manage those risks? (being overly risk averse can prevent a person from achieving their goals – there is a delicate balance between empowering risk taking and safeguarding vulnerable adults).

Source: www.peoplehub.org.uk/8.pdf

Reviews

Reviews need to consider what is working and what is not working, which should be explored from a range of perspectives, including the resident's, in all cases where this is possible. Even if a resident has been assessed as not having the capacity to take decisions about their care and support, that does not necessarily preclude their involvement in the assessment, support planning and review process. Reviews should be flexible, proportionate and focused on reviewing outcomes. They should take into account various factors including lasting powers of attorney and anticipatory prescription of 'just in case' drugs.

Case study

Increasing the levels of care over time

"We had a gentleman who was diagnosed with lung cancer and though he wasn't yet receiving support, he confided in me because he knew me from doing his wellbeing assessment. We initiated a Level 1, low level support package, where I just went in every now and again to say 'Hi, how are you doing' and supported him with that to build up a relationship and his trust. As the months went by his health deteriorated, so we worked with him, his family and the GPs to review his needs and increase his care. Eventually, last spring he did get to the Level 5 status of needing high level nursing intervention, with two members of staff, the EoLC Team coming in to support the family and sitters from Marie Curie, Macmillan and Treetops providing additional support as he went onto the Fast Track programme. The GPs were good: knowing his diagnosis and prognosis, they were able to say 'right, he goes onto the Fast Track Programme now'".

ExtraCare Charitable Trust



Pain management

When someone is dying, any type of pain can feel significant and overwhelming. It may be necessary for a number of medication changes to be made towards the end of a resident's life to ensure their pain is managed.

Drugs used to treat pain are known as analgesics. Some analgesics work directly on pain, while other medication has an indirect action, such as antidepressants.

Opioids are the largest group of direct analgesics used in end of life care. Weak opioids include drugs such as codeine and strong opioids are drugs such as morphine.

Common side effects of analgesics can include:

- Drowsiness: usually wears off a few days after commencing medication.
- Sickness: anti-sickness medicines help and this usually settles after a few days.
- Constipation: everyone taking a strong analgesic needs to take a regular laxative.

Myths and facts about morphine

Some common misunderstandings about morphine and other opioids:

Myth	If I take morphine I will become addicted and won't be able to stop.
Fact	Very few people who use opioids for pain relief ever become addicted or 'psychologically dependent'. However, it is important to be aware that anyone taking opiates for more than 2 weeks should not stop taking them all at once. They should ask their doctor about weaning off so that their body is able to adjust.
Myth	If I take Morphine now, it won't work later on when my pain is worse and I really need it.
Fact	Tolerance (needing higher and higher doses with diminishing pain-relieving effect) does not occur except in rare cases where it has been administered through an IV, though some physicians consider even those instances of tolerance to be unproven. There is no upper dose limit to the use of morphine that can be used safely and no reason to wait until your pain is unbearable. If your pain increases over time, your morphine dose can be increased as needed; this is true of very few other medications. Using it when it is needed early in the course of a terminal illness does not mean that it won't continue to work later in the disease.
Myth	I've heard that Morphine has lots of side effects, including making people comatose. I feel bad enough already.
Fact	All opioids can cause nausea, drowsiness and constipation. However, all side effects will generally stop after a few days, as your body adjusts, and constipation can be easily treated. Morphine can cause some sedation initially, but this effect decreases within a few days. Due to its effects to decrease pain and ease breathing, it often enables people to catch up on sleep that has been lost due to pain and/or shortness of breath. If someone notices a difference in their alertness, then they can choose somewhat-less-than-perfect pain control as a trade-off.



Myth	The fact that morphine is being prescribed means that death is imminent.
Fact	The choice of pain medication is related to the severity of pain rather than life expectancy. When a patient of any age has severe pain, opioid medications will likely be utilised in order to control pain.
Myth	Professionals are at high risk of expediting death if they administer morphine.
Fact	Morphine would have to be administered at doses that would cause identifiable toxic effects such as 'pinpoint' pupils, rashes and skeletal muscle flaccidity with cold or clammy skin before causing death. Accidental overdoses do occur when morphine is used recreationally, which has led to a false understanding about its dangers when used for pain control. Professionals do of course need to be trained, but overdoses of morphine administered by professionals are extremely rare.

Alternative therapies

Few comprehensive and rigorous studies have been undertaken to explore the benefits of alternative therapies at the end of life, but though their impact is largely unproven, individual residents may find them to be useful, as well as requesting alternative therapies on religious or cultural grounds.

Acupuncture and massage, including aromatherapy can be pursued for pain control and relief. Psychological therapies, including cognitive behavioural therapy (CBT) have been used in the control of some pain and as an entirely non-invasive therapy this may be appealing to some residents. Water therapy, if viable, has also been used to bring some pain relief, though this is usually short term. Acupuncture and breathing retraining are pursued by some people to address shortness of breath, while others pursue acupuncture to relieve nausea.

Gentle osteopathy and chiropractic techniques are pursued by some people to relieve muscular-skeletal pain.

It is important to restate that some of the techniques described above lack evidence on their efficacy. A resident's GP should first advise as to safety of alternative techniques, and particular the interaction with other treatments, should a resident wish to pursue an alternative therapy.

Assistive equipment and adaptations

Occupational Therapy services (contactable through your local Social Services, or through a resident's GP) can advise residents as to what equipment and adaptations may enable them to safely and more-easily carry out their day-to-day activities and remain as independent as possible. The majority of equipment and adaptations can be purchased privately if a resident wishes and is able to do so. Some items can be bought at the larger homeware stores.

- Equipment might include things like seven-day pill boxes, stools for use in the bath and shower, and mobility aids such as rollators.
- 'Minor' adaptations include things like grab rails, raised toilet seats and bed levers (used to support a resident's transition out of bed). 'Major' adaptations are generally considered to be those that cost in excess of £1,500 and include widening doorways to enable wheelchair access and full bathroom refits, for example replacing a bath with a walk-in shower that is large enough to take a shower seat. Extra care housing is usually ergonomically designed to enable adaptations to be made relatively easily, indeed many extra care housing properties are designed with adapted bathrooms and wide doorframes, for example, from the outset.



Top resources

Information about adapting your home, including distinctions between tenures and sources of funding can be found on the Direct Gov website:

www.direct.gov.uk/en/disabledpeople/homeandhousingoptions/yourhome/index.htm

Information on the design principles in extra care housing are set out in the Housing LIN factsheet No 6.

This can be found at: www.housinglin.org.uk/Topics/browse/Design

Harrow Council have created an online shop of the care and support available in their area, which includes useful photographs and explanations of a number of equipment and adaptation options:

www.shop4support.com/S4S/UI/Content/MyCatalogue/CatalogueProducts.aspx?Id=11090

Other resources about **Enhancing the Healing Environment** can be found on the King's Fund's website: www.kingsfund.org.uk/current_projects/enhancing_the_healing_environment



Common symptoms in the last days of life:

- Changes in breathing – usually a slowing down in breathing. Some residents may find it harder to clear congestion which may mean that breathing becomes more raspy or ‘rattling’.
- Circulation slows down. The skin may feel cool to touch, especially at the extremities, and may become bluish in colour.
- Dry mouth or cracked lips.
- Changes in bladder functions – incontinence and decreased amounts of urine which may be darker in colour.
- Physical restlessness.
- Continued disorientation. Some residents may experience hallucinations; although these are normal they can be disturbing to residents and those around them.

Supporting the resident

There are some steps that can be taken to support extra care housing residents in the final days of life. Many of these are outlined fully in **the Liverpool Care Pathway for the dying patient**. This was developed by the Marie Curie Palliative Care Institute (in Liverpool), and the pathway is recommended by the Department of Health. Further information is available here: www.mcpcil.org.uk/liverpool-care-pathway.

The care pathway helps healthcare professionals to deliver care in the final days of a resident’s life. There are some steps that all staff can take to ensure that the resident is supported in the final days. Formal training, which should be provided to all staff involved in providing end of life care, will cover these aspects and more, although some of the steps that will help to support residents include:

- Attending to the spiritual, religious and cultural needs of the resident. Some residents may find comfort from community or religious leaders at this time. With forward planning, the spiritual, religious and cultural needs of the residents can be established in advance (see Section 5: [Diversity in dying: culture, spirituality and religion at the end of life](#)).
- Making sure that the resident is comfortable in other ways – this can include being comfortable in terms of clothing, food, temperature. It could also involve other aspects such as ensuring that the resident see flowers or photographs, hear music or prayers, or that the resident receives a massage. Even a smell can be very evocative, for example spraying their favourite perfume.
- Most residents experience a loss of appetite at the end of life. Planning ahead with catering staff can ensure that special dietary requirements can be accommodated – this could help support the resident’s dietary needs in terms of their spiritual, religious or cultural background (see top tips box). Some staff even report that residents’ dietary needs can be quite different at the end if life:

“Some people can be ‘absolutely full of life’ right at the end, for example asking for sausage, egg and chips!”



- Helping the resident change positions can help them to be most comfortable. However, it is not generally appropriate to disturb someone who is obviously in a comfortable position in the last hours of life. Using special mattresses, foam cushions, and talcum powder, among other things, can help to reduce pressure sores.
- Elevating the resident's head or turning their head to the side can help with breathing in some cases.
- Using blankets (not electric) and keeping their extremities covered can help the resident stay warm.
- Different people offer different advice on how the best way to keep residents' mouths and lips moist in the last days. Using glycerine swabs, lip balm, pineapple juice and Vaseline are all things that the extra care housing staff that we spoke to found can help.

Top tips

Suggestions and ideas from extra care housing staff on supporting the resident's needs in the last days of life

Remembering the resident
 "I ask people to really think about someone's tastes and personality at the end of life. Hearing is usually considered to be the last sense to go, but that doesn't mean someone wants to be forced to listen to a radio station they have no interest in, just to 'keep them company'. A resident is an individual right to the end".

Top tips

"Sometimes a resident just doesn't want to eat any more. However it's worth having a conversation with them about what they would consider eating if it were available and working with catering staff to provide it. I had one lady who only wanted organic food in her last few days. Another wanted a traditional Caribbean meal as she was reminiscing about her childhood and told me she was preparing to join her family again".

One consistent tip offered by extra care housing staff in delivering end of life care is to maintain a degree of flexibility and not to forget the personality and wishes of the resident – to really embody a person-centred approach.

Smoking and drinking are often a cause of conflict in delivering end of life care – neither is a behaviour that would be promoted in terms of healthy living – and the rules on smoking and the workplace in an extra care home are ambiguous. However, many staff use their discretion in terms of allowing residents to smoke and drink and afford some degree of flexibility.

Similarly, a flexible approach can help find solutions to challenges that occur when residents are not mobile and at the end of life, for example in terms of washing a resident's hair in their bed.



“What helps you deliver end of life care?”
 “Sense of humour. Sounds awful, but it is so important.”

Case study

A flexible attitude in delivering end of life care in the last days

“We looked after a coroner and his wife who had spent the entirety of their lives drinking Chardonnay. When she was dying there was a real battle with the staff because – for all the right reasons – they went into protective mode. The lady’s condition deteriorated to the point that she couldn’t hold the glass of Chardonnay herself. People were nervous about giving morphine sulphate tablets with the Chardonnay. It had to be myself and the senior staff who had the confidence to give her her last days in the way she had lived the last 60 years. People were scared that they might do more harm than good. We train our staff to do everything by the book and then they’re cautious – which is good – but at the same time it needs to be balanced with person-centred care.”

ExtraCare Charitable Trust

Supporting family, friends and neighbours

Death is a very rare occurrence for many of the people who do not work with older people and indeed even among some of those who do. Most people will be inexperienced and will be unprepared for what’s likely to happen in the last hours, at the point of death, and immediately afterwards.

The last days are usually a signal of gradual decline. If you are comfortable in doing so, you can offer to talk to the family about what’s likely to happen to the resident from that point onwards, or arrange for a nurse or doctor to talk through what is likely to happen.

Often there is a change in the care that a resident receives once there are indications that their death is imminent. For example, medication may cease to be administered to residents, or pain relieving medication with sedative side-effects may be administered. The reasons for that decision should be explained clearly to a resident’s family.

Families and friends are likely to have many questions about what’s likely to happen. Do seek the support of colleagues and other staff involved in providing end of life care if you need to.

Simply sitting with a resident, gently touching or holding their hand, can be of tremendous support for residents at the end of life. This is a role that close family and friends can assume, which in turn can also provide comfort for them. However, it is not uncommon for someone to die when they have been left unattended for the briefest of periods. Some people believe that the individual – consciously or otherwise – wants to spare their loved one the moment of death itself.

Finally, it is often said that people’s hearing is ‘the last to go’. It is critical that all involved around the resident in their last days remain respectful right until the very end.



To check whether someone has died, you should listen to the heart for one minute and feel for a pulse for one minute. You can examine for signs of breathing, look at the pupils to check there is no response to a shining light and, if you're not certain, you can rub on the breastbone with your knuckles, which is a very painful procedure. This is exactly what the registered medical practitioner (usually a GP) who certifies the death will do.

A few hours after death the body will start to stiffen, which is known as rigor mortis and which after a while starts to reverse. If a time of death needs to be established then a forensic scientist can estimate the time of death by whether rigor mortis has come and gone.

Death today is handled very differently from the way it was in the past. For example, in the Victorian period it was common practice for people who had died to be kept in their home, in an open coffin. Relatives paid their respects and would see a dead body more frequently than we do today. It can be an upsetting experience to see someone's body – whether it's someone you cared for very much, or someone you didn't know that well. When someone views the body of a loved one in a funeral parlour or chapel, the body has usually been embalmed and been carefully tended to by an embalmer and/or a funeral director. This means they look more 'like themselves', for example the embalming fluid returns natural colour to the skin and has a plumping effect. It can be a shock to see the body of someone who has very recently died, as rigor mortis can make them look uncomfortable and the body may have started to take on a bluish tinge because the blood has stopped being pumped around it. Be assured that this is unlikely to be how family will see their loved one if they choose to say a final goodbye before the funeral.

The death of a resident can be a shock, even when it is expected and has been a 'good death'. **It's important to remember the positive experiences that the resident had while living in extra care housing and to focus on your role in those.** Not every death is a good death, but it is important to put into perspective the months – usually years – of good quality care and support (and often fun and friendship) that the resident benefited from while living in their extra care housing home.

You may find it helpful to talk about and reflect upon your experiences with colleagues, family and/or friends. If you don't wish to speak about your experiences with someone you know, or if you are finding it difficult to cope with the death of a resident, then you might find it helpful to speak with your manager, with your GP, or with a confidential service such as the Samaritans who can be contacted 24 hours a day by calling 08457 90 90 90 (there is a charge for using this service).

Top resources

The Liverpool Care Pathway team have developed a number of leaflets about **Coping with Dying** (including some designed for children): www.mcpcil.org.uk/patients-carers/index.htm



After the resident has died, you should contact **the resident's GP or out of hours doctor**. The GP will usually issue a death certificate which can be used to register the death. In some cases, a District Nurse will verify the death when they have been involved closely in the care of the resident. It is only in (rare) cases where the GP is unsure of the cause of death, and is unable to issue a certificate, that a coroner will need to be informed. Usually, the next of kin register the death following the GP issuing the certificate. In cases where the resident has no next of kin, staff may need to register the death – In England and Wales this needs to be done within 5 days of the death and will result in two forms – the 'green form' allowing for the burial of the resident and the 'BD8' form for stopping receipt of pension and other state allowances

Other extra care housing staff will need to be informed of the death of a resident. It is inevitable staff will grieve for residents with whom they have built up close bonds. Team leaders may need to provide support to staff when a resident passes away. Team leaders may also be those who have to inform other staff of the death of a resident. Some extra care housing schemes keep a register of whether staff want to be told immediately of the death of a resident, or whether they want to be told when they return onto their shift.

Extra care housing schemes are communities where residents can build close bonds with one another and the dynamics of an extra care housing site can change when a resident dies. Extra care housing staff can help with the death of a resident by **keeping other residents informed** and through offering a sympathetic ear if needed. Some schemes liaise with families before informing neighbours, while others don't; some residents may have express wishes about the way the news is communicated to neighbours, which may be raised during initial conversations on end of life care. In cases of an unusual or sudden death (for example suicide), additional support may need to be provided to residents and staff. The Data Protection Act does not apply to the deceased, but your organisation may have a Duty of Confidentiality policy that sets out boundaries around sharing information when someone has died. Any information communicated to other residents should be relevant and considerate of the deceased resident's family and friends. You must not share information about the deceased resident's family, friends or any other living individual without their express permission.



"I get told off by residents for using the terminology 'passed away' all the time of other residents. They say "why don't just say he's snuffed it and be open about it?"



Case study

Informing residents when someone has died

"I became very aware of the varying emotions amongst residents when another resident died. This seemed to be focused by the manner in which they were told, or not told, as the case may be. Whilst accepting that their neighbour, friend or acquaintance's 'time had come', they were less accepting of being told this via a noticeboard, or from the residents' grapevine, or by meeting the resident's relatives etc.

As an Estate Manager I had ample opportunity to find out how residents wanted to be told of another resident's death and what was important to them in the process. Of course all actions had to be in line with the Data Protection Act and family's wishes, but in most cases the Care Manager and I – with maybe the Support Worker or Care Team Leader – would divide up the extra care housing court and take one floor each and tell all the residents individually. Ideally we would do this in the morning so that residents were not left brewing on the news with no one to talk to about it.

Whilst this may take almost an hour out of the day and not all staff would want to follow this approach, it proved to be an invaluable opening for residents to chat about death, funerals, ageing and any related concerns. It valued how they felt and respected the passing of their fellow resident, which meant that residents also knew that that was how their death would be treated – should the time come – which was important to them."

Hanover Housing Association

Case study

The impact of not being able to share information with residents

"I had a family who said they didn't want anyone to know that their mother Jean had moved into a residential home from hospital and then passed away.

That can be very difficult for the new resident who moves into the flat. When a lady moved in and took over the flat, other residents were asking where Jean was and there were tears and all sorts when they realised she'd gone. It wasn't a very nice welcome for the new resident."

Hanover Housing Association



The body

Some residents will have specific requests about the way that the body is treated after death including requests related to their religious, spiritual or cultural beliefs. It is important to establish these preferences early on in the process of planning end of life care. Some residents may have included these preferences in their wills and these wishes also need to be stored elsewhere for easy retrieval upon death.

In reality, however, each death and what to do with the body immediately after death differs for a variety of reasons. Many people may not have even seen a dead body before, and dealing with a dead body, particularly for the first time, can be distressing. It is a good idea to talk through and ask questions about what is likely to happen to each resident in advance with other housing, care, and medical staff, especially if this is something new for you.

The main thing to remember about dealing with the body is that it is part of the ongoing process of providing end of life care to the resident and to be approached in the same way: to be planned ahead in advance ensuring that the dignity and wishes of the resident are upheld.

What's been your experience of dealing with a body after death?

"I had to put her red wig on because she always had it on unless she went to bed. I thought she couldn't go out of here without her wig on."

"Expelling of air when you move a body – very traumatic if you don't expect it."

"You can't remove a resident's dressings etc. if they have died and a Coroner needs to visit. It can be very difficult and disturbing."

"There can be a terrible mess. There are a number of deaths on the toilet because people having a heart attack can feel the urge to empty their bowels."



Some residents will want to donate their organs for transplant and it is important to find this out in advance. Unless the death occurred within hospital with the resident on a ventilator, internal organs are not transplanted, although other organs such as skin, corneas, heart valves and bones can be donated.

Further details and contact numbers can be found on the UK organ donation website: www.organdonation.nhs.uk/ukt/default.asp. Similarly, some may have chosen to donate their body to medical research. In the experience of a number of staff included in this research, residents who had this wish were usually upfront in their wishes, although having a record of who or where to contact is useful.

Making arrangements

The property

Lettings and tenancy policies of extra care housing are not direct replications of those in other care settings – each extra care housing provider will have different policies on what happens to the property after the death of the residents, which will also depend upon whether the resident was a tenant or a leaseholder. The processes and procedures you need to follow will be a mixture of national legislation and locally-developed policies. Regardless, tenancies generally don't end on the death of the resident, but pass onto a resident's estate. In situations where residents do not have wills and have no relatives (and did not hold a joint tenancy), the estate passes to the Crown, which can add complexity after death.

Ensuring that residents have made plans and have made wills beforehand is essential in order to facilitate a 'good death'.

Extra care housing does differ from other care settings, as it constitutes an independent home for residents, and needs to be treated in this way after death – for example, just in the same way that an older person's home in an average community setting is unlikely to be emptied within a couple of days of death, the same policies should apply within extra care settings. Families may request assistance with helping to empty a property. If a resident's partner is also resident in the same unit, depending on their security of tenure, a different set of policies and succession rights need to be applied.

If the next of kin need help in organising the financial affairs after the death of a resident, the following guide from Age UK can offer a good starting point: www.ageuk.org.uk/money-matters/legal-issues/what-to-do-when-someone-dies

In many cases, the family of a resident may turn to staff for advice, questions and discussions about the property and the tenancy. You should not feel pressure to provide an answer unless you are in a position to do so, although you should be ready to refer the family to the most appropriate person at the scheme to speak to and to help make sure that the family does speak to this person.

In all cases, staff should consult company policy, and where appropriate seek legal advice, before making decisions or giving advice about the extra care housing property itself and the resident's security of tenure and/or property inside this.



The funeral

The funeral is usually something concrete that residents will have focussed on. By now, after the prior planning of end of life care (see earlier sections), much of the funeral arrangements should have been organised in terms of the resident's wishes, and communicated, where appropriate, with the family and next of kin. Above all, it is useful to have a signed record, where possible, of the resident's wishes for their funeral – this will enable staff to continue to advocate on behalf of other residents after death.

The funeral itself may involve other residents. Some families will want other residents to attend and may expect extra care housing staff to help communicate details of the funeral arrangements to other residents. Usually, families will liaise, with some assistance, with funeral directors to plan the ceremony. It is also useful for staff from the scheme to have some discussions with the funeral directors in advance in order to know the impact of the funeral on the scheme – for example does space in the car park need to be reserved for the hearse? In some cases, especially those where the resident has no family or next of kin, much of the arrangements with the funeral directors may need to be made by staff or neighbours of the resident.

Case study

Thinking about other residents

"We had a lady who prepared her funeral 15 years-ago; she'd paid for it and she knew what she was having. She was adamant that she had come in through the front door and that she was going out through that front door, even though there was a side exit. But obviously we had to prepare people in and around the extra care village for what they could see if they were around. We do have to accommodate for different diversities and choices, but we do need also need to be sensitive to their impact on other residents."

ExtraCare Charitable Trust

Case study

Advocating for residents after death

"I remember a resident who had a nephew as her next of kin. She had always said to the staff that she wanted to be buried with her husband in their previous church and that was exactly what she wanted, which we documented. When she had passed and the family attended, they were going to cremate her. We said 'this is what your aunt's wishes were' and they said 'no, no it's much easier to have a cremation' and we had to negotiate to make it happen the way she wanted. When you are aware of someone's wishes you can be their advocate; even after death. I think it's important because it's the last thing that we can do for someone."

ExtraCare Charitable Trust



Top tips

As part of a plan for care after death that is available for all staff to consult:

1. Make a checklist of people who need to be informed of the resident's death in advance.
2. Make sure you are aware in advance of any special consideration for the care of the resident's body after death including organ donation or any religious conventions to be followed.
3. Make sure that you have a copy of the resident's preferences for their funeral (preferably signed by the resident).
4. Familiarise yourself with the key people that families can speak to about any issues arising with the death of a resident such as legal issues or funeral arrangements.
5. Make sure you understand the policies and succession rights for joint tenants in your extra care housing scheme.

Top tips

The National End of Life Care Programme has published Guidance for staff responsible for care after death, which includes detailed guidance around post-death personal care: www.endoflifecareforadults.nhs.uk/news/all/neolop-publishes-guidance-for-staff-responsible-for-care-after-death



One of the top sources of information, advice and guidance is the National End of Life Care Programme's website (www.endoflifecareforadults.nhs.uk), along with the 150+ free to access e-learning sessions on end of life care available at: www.e-lfh.org.uk/projects/e-elca/index.html. A small sample of sessions are available without the need for registration at: www.endoflifecareforall.com. You will also find the Core Competences and Principles for health and social care staff working with adults at the end of life here: www.endoflifecareforadults.nhs.uk/publications/corecompetencesguide.

The National Institute for Health and Clinical Excellence (NICE) have also published a Quality Standard for end of life care for adults. These set out aspirational, but achievable, markers of high-quality care: www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp. They have been developed by health and social care experts, including patient representatives (a summary can be found in Appendix E).

A key element of staff development, as well as staff wellbeing, is taking the time to reflect upon experiences. These may include personal experiences, or experiences staff had in previous roles (if these are appropriate and staff are comfortable sharing them). You may find it helpful to discuss a resident's end of life journey in a team meeting and to reflect upon what went well, what could have been done differently and what you can learn as a team. Mentoring schemes – where more experienced members of staff support less experienced members – can also aid this reflection process.

“It can be quite overwhelming for staff. One of the things we did recently was have The Samaritans come in, because we had some concerns that our Estate Managers – who are all things to all people – didn't have anything that was instant access where they could talk through their feelings.”

There may come a time when you find that you are supporting someone who is approaching the end of life in your personal life, or a loved one may die suddenly and/or unexpectedly. Grieving is a natural process and there are no set timescales, but the first three months of a bereavement are likely to be especially painful. If you find it difficult to provide care and support to residents during the last days and hours of their lives because of your personal circumstances, then it is quite legitimate to discuss this with your manager and see if additional support, or the option to change cases, is available.



Case study

Reflecting on and learning from personal experiences

"I had a personal experience of end of life care with a family member, which I found to be a big learning curve that informed my work. I discovered several things that were good and others that could have been better.

I think it's so important for the person who is dying to have the people around them that they like and respect. Imagine that the last thing to go is your hearing and you're hearing a person you don't really like, or who doesn't mean anything to you, just chatting away at your bedside.

Carers and nurses are essential to support medical needs, but those roles are also about empathy, understanding and being able to support family and friends who are stressed and upset. When I was putting a palliative care team together for work, I really drew on my personal experience and recruited people with these crucial skills and characteristics.

If your death is known – and we all know that we will die at some point – then advance planning is the key; I really believe that. It can be such a relief to friends and family that someone has detailed their wishes.

My death is all planned and on a CD to music! It's the little things that matter and will really make the difference. Just like we are different and individual, so is every end of life experience".

Hanover Housing Association



Appendix A: people and services who can help in the delivery of end of life care

Advocates

An advocate can help a resident to become an active member of society and ensure that their voice is heard. Advocacy is a process of supporting and enabling people to:

- express their views and wishes;
- defend and promote their rights and responsibilities;
- have their interests represented;
- access information and services; and
- explore choices and options.

How an Advocate can help:

Advocates can be especially important at the end of life, when a resident has been assessed as not having the capacity to take some or all of the decisions about their care and support. See Section 5: Decision-making and the Mental Capacity Act for more information.

How to find an Advocate:

- Your extra care housing scheme may already be linked-up with an organisation that provides advocacy, so check first with your manager.
- A resident's social worker/ care manager may be aware of advocacy organisations that the Council has arrangements in place to work with.
- Your local Citizen's Advice Bureau should also be able to help.

Community Matrons

Community Matrons are highly experienced, senior nurses who work closely with patients (mainly those with a serious long-term condition or complex range of conditions) in a community setting to directly provide, plan and organise their care. Not all residents with a long-term condition will have access to a Community Matron.

As well as providing nursing care, Community Matrons act as 'case manager' – a single point of contact for care, support or advice, typically for a caseload of around 50 very high intensity users.

How a Community Matron can help:

Community Matrons can help in the delivery of end of life care by:

- Carrying out physical examinations.
- Using their expert knowledge and clinical judgement to identify the potential diagnosis.
- Referring patients for investigations.
- Where appropriate, make a final diagnosis.
- Decide on and carry out treatment, including prescribing medicines, or refer patients to an appropriate specialist.
- Plan and provide care that meets patients' health and social care needs.
- Ensure the provision of continuity of care, including follow-up visits.
- Review residents and their care, adjusting it as appropriate (NHS Careers, 2012).

**How to find a Community Matron:**

Your local Health Centre or GP surgery will have the contact details. A resident will need to be referred to a Community Matron, usually by their GP, District Nurse, Consultant or Social Worker.

Continuing Care Co-ordinators

To find out more about Continuing Care, see Section 10: Considering funding options.

How a Continuing Care Co-ordinator can help:

Your local Continuing Care Co-ordinator works for the NHS and will be able to arrange an assessment of a resident to see if they qualify for Continuing Care (sometimes referred to as 100%, or fully funded NHS care). They should keep you up-to-date on the progress of the assessment and whether the funding has been improved (a decision usually taken by a Panel of NHS senior staff).

How to find a Continuing Care Co-ordinator:

You can find out the name of your local co-ordinator by asking the resident's GP, or contacting your local Patient Advice and Liaison Service (PALS), which you can find here: www.pals.nhs.uk/members/officeSearch.aspx.

Dietitians (Dieticians – alternative spelling)

A dietitian is a health care professional who can provide practical information about food and nutrition. They work with people to promote wellbeing, prevent food related problems and to treat ill health. Dietitians work in a variety of settings including hospitals, health centres, schools and GP practices and also can visit people in their own homes.

How a Dietitian can help:

- Provide advice about: the quantity of food; most appropriate type of food; and the best consistency of food for a resident.
- Provide advice about the type and timing of meals offered, for example 'little and often' rather than three meals a day.
- Provide advice and guidance when people use non-oral methods of eating and drinking.
- Liaise with other professionals.

How to find a Dietitian:

Through your GP or Social Services. Dietitians may work privately and freelance, but they must have a recognised degree, MSc or post graduate diploma in nutrition and dietetics.

District Nurses (sometimes called Community Nurses)

District nurses are qualified nurses who have completed a degree-level specialist practitioner programme. They play a crucial role in the primary health care team. They visit people of all ages in their own homes, providing care for patients and support to family members. District nurses provide a 24-hour service dependent upon the patient's needs.



How a District Nurse can help:

- Avoiding admissions and readmissions to hospital, working with hospital and community teams to ensure patients can return home as soon as they are well enough or when a decision has been made that an individual is to die at home.
- Assessing and evaluating a resident's needs and developing support plans; working with the resident, their family and extra care housing staff. Modifying that support as appropriate.
- Supplying medical equipment, for example beds and mattresses to enable care and support to be delivered within the resident's own home.
- Recommend a Marie Curie registered nurse or Marie Curie Healthcare assistant, depending on the patient's needs.
- Deliver palliative care interventions, for example pain/symptom control monitoring and evaluation.
- Give psychological support to residents and their families.
- Offer support in bereavement.

How to find a District Nurse:

Contact your local GP practice – referral to the district nurse is usually via a resident's GP. In some areas district nurses are based within GP practices.

Discharge Co-ordinators and Planning Teams

The teams are normally based in hospitals and are often made up of nurses and social workers.

How a Discharge Co-ordinator and Planning Team can help:

They usually become involved in planning safe discharges from hospital and ensuring there is adequate care and support for individuals when they leave hospital. They need to receive a referral from ward staff to become involved with someone's discharge.

It is sometimes helpful for scheme managers to meet with hospital discharge teams to ensure they have a clear understanding of your extra care housing scheme and what care and support can be provided and facilitated on site.

How to find a Discharge Co-ordinator and Planning Team:

They should contact a resident who has been admitted to an acute hospital ward and will sometimes work with patients on rehabilitation wards.

Faith Leaders

Faith Leaders can provide religious, spiritual and often cultural information and advice to both residents and staff.

How a Faith Leader can help:

To find out more about the aspects of a resident's end of life care that may need consideration as to religious, spiritual and cultural preferences, see Section 4: Diversity in dying: culture, spirituality and religion at the end of life.

How to find a Faith Leader:

You can find local Faith Leaders through the local places of worship (which should be listed in your locally-distributed telephone directory).



General Practitioners (GPs)

GPs provide a complete spectrum of care within the local community: dealing with problems that often combine physical, psychological and social components. They increasingly work in teams with other professions, helping patients to take responsibility for their own health.

How a GP can help:

The End of Life Care Patient Charter, launched in June 2011 and co-produced by health professionals and patients, represents an ideal of best practice that patients should be able to seek from their primary healthcare team. GPs in England are expected to work to the Charter, but that is not say that GPs in other regions are not working to the same principles.

"We [GPs and nurses] want to offer people who are nearing the end of their life the highest quality of care and support. We wish to help you live as well as you can, for as long as you can.

Therefore, if and when you want us to, we will:

- Listen to your wishes about the remainder of your life, including your final days and hours, answer as best we can any questions that you have and provide you with the information that you feel you need.
- Help you think ahead so as to identify the choices that you may face, assist you to record your decisions and do our best to ensure that your wishes are fulfilled, wherever possible, by all those who offer you care and support.
- Talk with you and the people who are important to you about your future needs. We will do this as often as you feel the need, so that you can all understand and prepare for everything that is likely to happen.
- Endeavour to ensure clear written communication of your needs and wishes to those who offer you care and support both within and outside of our surgery hours.
- Do our utmost to ensure that your remaining days and nights are as comfortable as possible, and that you receive all the particular specialist care and emotional and spiritual support that you need.
- Do all we can to help you preserve your independence, dignity and sense of personal control throughout the course of your illness.
- Support the people who are important to you, both as you approach the end of your life and during their bereavement" (Royal College of General Practitioners & Royal College of Nursing, 2011).

You can find out more about the role of GPs in end of life care by visiting the Find Your 1% Campaign, which is an advice and information service for GPs that also encourages the sharing of best practice:

www.dyingmatters.org/gp

How to find a GP:

You can find details of your local General Practices by using the NHS's 'Health Services Near You' tool:

www.nhs.uk/servicedirectories/Pages/ServiceSearch.aspx?ServiceType=GP



Macmillan Nurses

Macmillan nurses specialise in cancer and palliative care, providing support and information to people with cancer, and their families, friends and informal carers, from the point of diagnosis onwards.

Macmillan Nurses do not carry out routine nursing tasks, such as personal hygiene, changing dressings and giving medicines, and do not focus on non-cancer patients. Macmillan Nurses usually work normal office hours although this can vary.

How a Macmillan Nurse can help:

Macmillan Nurses work closely with GPs, district nurses and other health care professionals to:

- provide support at diagnosis;
- manage pain and symptoms;
- help with investigations and treatments;
- provide information and advice to both residents and staff; and
- offer psychological support to residents, their families and friends.

How to find a Macmillan Nurse:

A resident will need to be referred by their GP, hospital consultant, district nurse or a hospital ward sister.

Marie Curie Nurses

Marie Curie Nurses provide practical, hands-on nursing care during the terminal stages of cancer in patient's homes and will often be available for a morning, afternoon or all night, so that the family carers are able to rest. Their core service is one-to-one overnight nursing from a Registered Nurse or Senior Healthcare Assistant in a resident's home, usually for eight or nine hours. Registered Nurses can give any medication prescribed and perform technical nursing procedures including the management of syringe drivers; Healthcare Assistants do not usually administer medication. In some parts of the UK, they can also offer shorter shifts, evening shifts and day shifts.

How a Marie Curie Nurse can help and how Marie Curie Nurses are different to Macmillan Nurses:

Marie Curie Nurses care for people in the last few months or weeks of their lives. Macmillan Nurses care for people with cancer from when they are first diagnosed. Marie Curie Nurses generally spend several hours at a time in a person's home providing nursing care and emotional support, often overnight. Macmillan Nurses usually spend up to an hour in a person's home providing advice on pain management and symptom control together with emotional support (Marie Curie Cancer Care, 2012).

How to find a Marie Curie Nurse:

The Marie Curie Nursing Service can only be accessed through the resident's district nurse. Contact the district nurse to find out if there is a Marie Curie service in your area.

Occupational Therapists (OTs) – Council and NHS

An OT is a health care professional who can help a resident to overcome the effects of disability caused by physical or psychological illness, ageing or accident. They assess, rehabilitate and treat people using purposeful activity and occupation to promote independent function. Their aim is to enable people to achieve as much as they can for themselves. OTs work in a number of settings, including within people's own homes. Occupational therapy interventions focus on adapting the environment, modifying the task, teaching the skill, and educating the resident and their family in order to increase participation in and performance of daily activities.

**How an Occupational Therapist can help:**

- Assess a resident's abilities.
- Give advice on how the home environment can be changed to promote and maintain independence.
- Help residents learn how to do things as their abilities deteriorate.
- Provide adaptive equipment, for example grab rails, toilet risers, mobility aids and adapted cutlery.
- Assist a resident with social and psychological issues such as low self-esteem, decreased confidence and coping skills.

How to find an Occupational Therapist:

Through your GP, district nurse or Social Services. OTs can work for the NHS or for the local Council. NHS OTs can be critical in enabling timely discharge home from hospital.

Pharmacists

A Pharmacist is an expert in medicines and their use.

How a Pharmacist can help:

They advise medical and nursing staff on the selection and appropriate use of medicines. They can advise residents as to how to manage their medicines to ensure optimal treatment. Some pharmacists can also prescribe medicines for specific conditions.

How to find a Pharmacist:

You can find details of your local Pharmacies by using the NHS's 'Health Services Near You' tool: www.nhs.uk/servicedirectories/Pages/ServiceSearch.aspx?ServiceType=Pharmacy. Some pharmacies operate 24-hours a day.

Physiotherapists

A physiotherapist is a health care professional who is concerned with human function, movement and helping people maximise their abilities. Physiotherapists do far more than fixing muscle, joint problems and sports injuries. They assess and treat people with physical problems caused by accident, ageing, disease or disability by using physical approaches. Physiotherapists work in a variety of health settings including hospitals, health centres, GP practices and also visiting people in their own home.

How a Physiotherapist can help:

- Posture management.
- Mobility issues and balance problems.
- Chest therapy.
- Assessment for specialist equipment such as wheelchairs.
- Moving and handling advice.

How to find a Physiotherapist:

Through your GP, district nurse or by directly contacting your local physiotherapy department.



Social Workers

Social workers can co-ordinate care and support, but also provide emotional and psychological support, especially at difficult times in people's lives.

How a Social Worker can help:

- Assess the resident (they have a right to an assessment, even if they are found to be ineligible for care and support that is funded or co-ordinated by Social Services).
- Enable the resident to make choices about their care and support.
- Support the resident to create a person-centred support plan.
- Co-ordinate their care and support with providers.
- Review their care and make changes as appropriate.

How to find a Social Worker:

You can contact your local Social Services directly or contact them through your local Council's main switchboard. GPs and other health professionals can also make referrals. In most areas referrals will also be accepted by voluntary sector providers such as your local branch of Age UK.



Appendix B: example support plan

Source: p.17 of the Department of Health's End of life care planning with people who have a personal health budget: discussion paper (2010): www.peoplehub.org.uk/8.pdf

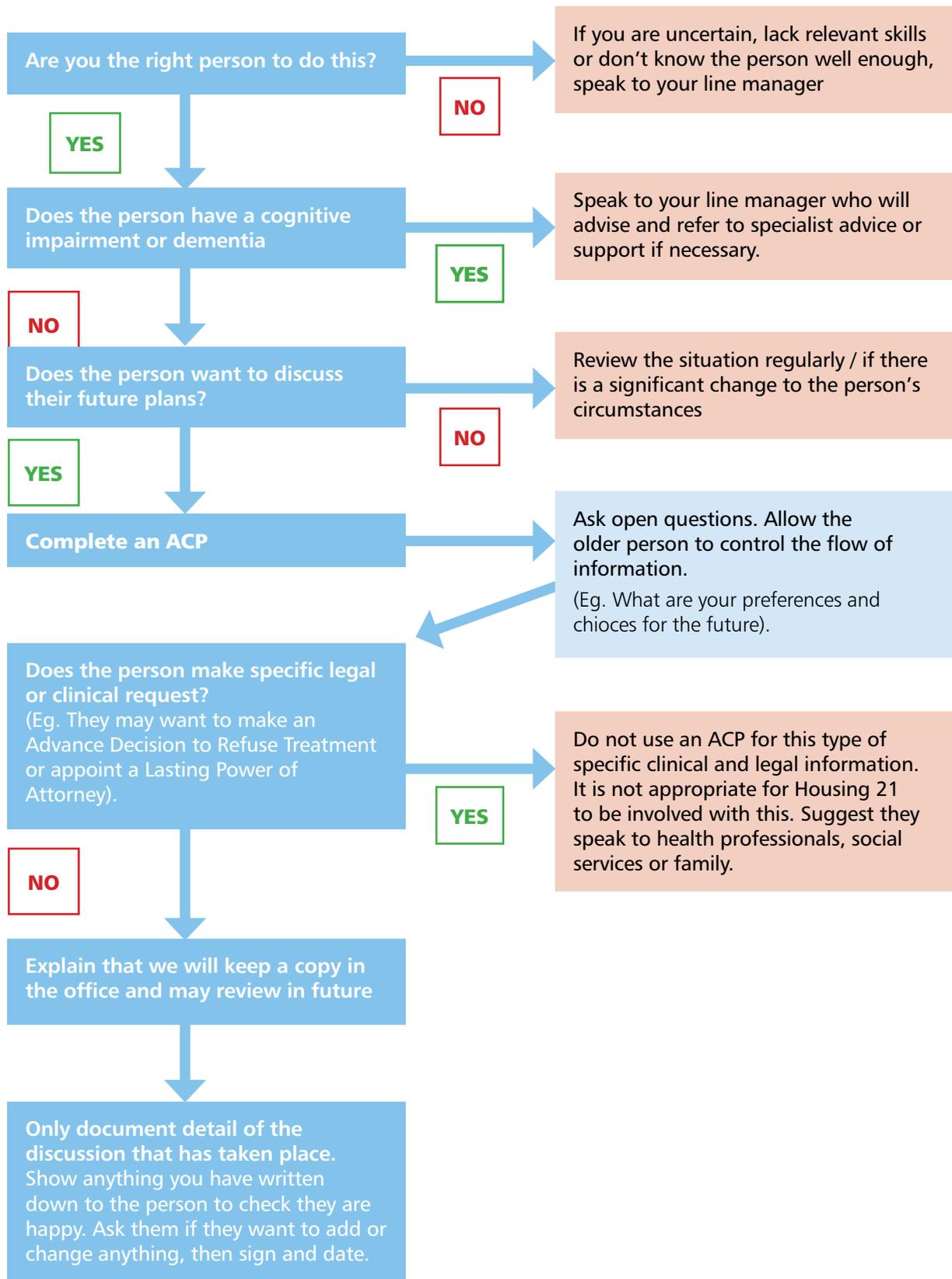
Edna's Journey





Appendix C: example advance care plan flowchart for staff

Source: Reproduced with kind permission of Housing 21.





Appendix D: Case studies of end of life journeys

Source: *Reproduced with kind permission of Housing 21.*

Arthur's story

Arthur moved into extra care housing in 2007; fairly independent and determined to keep his independence for as long as possible. At that point he needed help with his socks, footwear, and lower clothing, as he was unable to bend down far enough to put them on.

Arthur enjoyed spending time in his flat, but also enjoyed the communal lunch and afternoon activities, as well as the local day centre, which he attended three times a week. Within a year Arthur's mobility had declined considerably and he struggled to find the correct words when communicating, which – as a highly educated and intellectual gentleman – he found extremely frustrating. This resulted in Arthur shouting loudly at times to try and disperse his frustration. His team of support workers had gotten to know him quite well and they were able to reassure him as much as possible and make him laugh. The consistent and trusted team were able to know and recognise what Arthur wanted even when he said the incorrect words.

As Arthur's health deteriorated, he gave up the day centre because he found he was too tired in the mornings to get out of bed in time for it. Then he started to need a wheelchair to get about.

About six months later Arthur became very unwell and it was confirmed that his organs were shutting down. The district nurses ordered a hospital bed and popped in daily to see if they could support the staff team with anything. Arthur's GP was fantastic as he also popped in two or three times a week.

Arthur found the hospital bed to be very comfortable and this facilitated bed care to commence. The GP advised that it was likely Arthur had gone into kidney failure and it appeared at times that he was in discomfort. He started to refuse medication as he had difficulty in swallowing the large tablets, so his medication was changed to a syrup form which was much easier for him to manage.

Arthur's health then deteriorated quite quickly. His GP organised and set up a syringe driver and gave the Scheme Manager his personal mobile number in case we needed to contact him out of his normal working hours. The district nurses also gave contact numbers, but they still popped in every evening to check the syringe driver. As the syringe driver started to take effect, Arthur became more settled and did not appear to be in discomfort anymore.

The staff team continued to provide personal bed care and this gradually became intensive end of life care. Support workers ensured Arthur was comfortable and gave him personal care, mouth care and pressure care, which included turning or repositioning him every three hours to ensure he did not develop bed sores. The staff continually encouraged Arthur to drink fluids and eat sweet soft foods.

Gradually Arthur started to sleep quite a lot. He passed away peacefully in his own home, which had been his wish. Support workers were with Arthur when he passed away.

The staff team contacted Arthur's GP who came out to confirm the death, and then the undertakers. Staff supported the undertakers, including making sure that other residents were busy when Arthur's body was taken from the building.

In addition staff had continually supported Arthur's friend. Throughout Arthur's care his friend was informed about what his care and support plan was and all parties concerned were in agreement that Arthur was in the best place to receive the care he needed.



Brian's story – extra care housing in a rural setting

Brian came to the extra care housing scheme after his wife died. Initially Brian was reluctant to move into extra care housing as he had farmed all his life and was used to living on the farm.

Brian settled into the extra care housing scheme very quickly and enjoyed mixing with other local farmers who had also moved into the scheme. He also liked the company of people from the local community who came in to visit or to use the scheme facilities such as the restaurant, shop and hairdressers.

The extra care housing scheme was developed and built in two phases and Brian originally moved into the scheme following the first phase of the development. When the second phase of the scheme was built, he applied to move flats to one that overlooked the farm he had worked on all his life. Brian was now able to look out of his upstairs window and keep watch over his farm, as well as watch his son at work harvesting and bringing the cows in for milking.

Initially Brian did not receive a package of care, but after a while he was diagnosed with a degenerative disease and he unfortunately became unwell. As a result of his illness he began to require some help and support from the care team, so a personalised care package was developed to meet his needs. As his illness progressed, his health worsened and his care packaged increased.

Staff would pop in regularly as we were passing the flat to make sure he was comfortable and to have a chat. He enjoyed seeing familiar faces and it was important that there was some kind of normality in his life. Although Brian was poorly he regularly thanked the Court Manager and care staff for their support saying 'how can I ever repay you for letting me have this lovely flat with views over my land'?

Brian was familiar with the care staff and got on very well with them, so when his health needs became critical, it was important to him that he was able to remain living in his own home and that he did not have to move to another setting to get the care he needed and to have to face 'getting used to new faces and people'.

Brian had lots of support from a variety of people and organisations including his family, the care staff, the district nurses, as well as support from the Macmillan nurse who came in every week to see him. When Brian became really poorly, he was able to remain in his home because of this support and he died overlooking the dale where he farmed and had lived his whole life, with his family around him. Staff at the scheme say that they could not deliver good quality end of life care in a rural setting without the strong partnership working that had been developed, especially with the district nurses.

Produced with thanks to Housing 21 and North Yorkshire County Council



Joe's journey

Joe had been suffering from early-onset dementia when he and his wife moved into the extra care housing scheme. Joe's wife was beginning to struggle at home and was attracted to extra care housing and knowing that there were carers constantly on site.

For the first three or four months Joe only required one daily visit, and this was for personal care. After this, and up until two weeks before his death, Joe received two daily visits: one for personal care in the morning and one to help his wife to get him ready for bed in the evening. The staff had a close relationship with Joe and his wife, which proved to be crucial when Joe moved towards the end of his life and needed more care.

The months running up to Joe's death saw a rapid deterioration in his health. He lost the ability to mobilise and developed skin problems due to losing interest in food and drink.

Two weeks before he died, Joe was bed bound; unable and unwilling to eat and drink, needing two hourly turns to protect his skin. At this point intensive care was offered to Joe and his family. The staff were able to offer visits every two hours, where skin and mouth care were attended to and Joe's family were fully supported in caring for him. For the last three days of his life Joe was also supported by the District Nurse team, who set up a syringe driver to alleviate his agitation.

With the close working relationship between family, extra care housing staff and District Nurses, Joe was able to remain in his flat until he died. Being able to have a home for life had been very important to both Joe and to his wife.

The carers felt proud of what they had been able to achieve, but recognised this would not have been possible without the intensive care element or the support and close working relationship with the District Nurses and the General Practitioner. Also, the close relationship they had fostered with Joe's wife and family was paramount in a successful outcome.

Following Joe's death the family wrote a very appreciative letter to the care staff, excerpts included: "Every single member of the team was superb, they treated Joe with the greatest respect, maintaining his dignity; they were gentle and kind... they washed and dressed his body and prepared the room so that his family could say their goodbyes... this was above and beyond what we expected and we are so proud and grateful."

Produced with thanks to Housing 21 and Cheshire End of Life Care Services Model



Appendix E: National Institute for Health and Clinical Excellence's *End of life care for adults quality standard*

- 1.** People approaching the end of life are identified in a timely way.
- 2.** People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.
- 3.** People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.
- 4.** People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.
- 5.** People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.
- 6.** People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.
- 7.** Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.
- 8.** People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.
- 9.** People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.
- 10.** People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.
- 11.** People in the last days of life are identified in a timely way and have their care coordinated and delivered in accordance with their personalised care plan, including rapid access to holistic support, equipment and administration of medication.
- 12.** The body of a person who has died is cared for in a culturally sensitive and dignified manner.
- 13.** Families and carers of people who have died receive timely verification and certification of the death.
- 14.** People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.
- 15.** Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.
- 16.** Generalist and specialist services providing care for people approaching the end of life and their families and carers have a multidisciplinary workforce sufficient in number and skill mix to provide high-quality care and support.



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National End of Life Care Programme

The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy.

www.endoflifecareforadults.nhs.uk

Housing Learning and Improvement Network

The Housing Learning and Improvement Network, formerly responsible for managing the Department of Health's (DH) Extra Care Housing capital programme, is the leading 'learning lab' for a growing network of housing, health and social care professionals in England involved in planning, commissioning, designing, funding, building and managing housing with care for older people.

www.housinglin.org.uk

International Longevity Centre

The International Longevity Centre-UK is the leading think tank on longevity and demographic change. It is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change. We develop ideas, undertake research and create a forum for debate.

www.ilcuk.org.uk



Glossary

Advance Care Planning (ACP) is a voluntary process of discussion and review between an individual (with capacity) and their care and support providers, irrespective of discipline. ACP differs from general care planning in that the aim is to identify and record the individual's wishes in the context of an anticipated deterioration in their condition in the future, including approaching the end of life and/or losing capacity. See Section 4: [Enabling residents to have choice and control](#).

An Advance Decision to Refuse Treatment (ADRT) is a decision made by an individual (with capacity) to refuse specified treatments. Specified situations for the refusal of treatment can also be decided upon. An ADRT only applies to a future time when the individual lacks capacity to give or refuse consent to treatment. Careful assessment of the validity and applicability of an advance decision is essential before it is used in clinical practice. An ADRT is legally binding if valid and applicable. It is sometimes also known as an Advance Refusal or Advance Decision. See Section 4: [Enabling residents to have choice and control](#).

An **Advance Statement** is any decision other than an ADRT about how an individual would like to be treated. An Advance Statement is not legally binding. An Advance Statement is usually known as an Advance Care Plan, or sometimes as an Emergency Healthcare Plan. See Section 4: [Enabling residents to have choice and control](#).

An **Advance Directive** is a term in use prior to the Mental Capacity Act. It has now been replaced by *Advance Decisions to Refuse Treatment and Advance Statements*.

Under the Mental Capacity Act, any decision made, or any action done for a person who lacks capacity to make specific decisions must be in accordance with their best interests. There are minimum standards that must be met in order to work out someone's **best interests**. See Section 6: [Decision-making and the Mental Capacity Act](#).

Having **capacity** means being able to make and communicate your own decisions. See Section 6: [Decision-making and the Mental Capacity Act](#).

A **Do Not Attempt Resuscitation (DNAR)** document (which can form part, or all of an Advance Decision to Refuse Treatment), states that resuscitation should not be carried out in certain circumstances, which are defined within the document. A DNAR is not legally binding, but does sit within legally binding guidelines that health professionals must follow. See Section 4: [Enabling residents to have choice and control](#).

Extra care housing describes many forms of housing for predominantly older people, but usually comprises homely, purpose-built independent housing units that feature common spaces, facilities and onsite flexible care services. See: [Introduction and overview](#).

The **Gold Standards Framework (GSF)** is a systematic, evidence-based approach to optimising the end of life care that is delivered by frontline generalist staff in any setting (www.goldstandardsframework.org.uk).

The **Housing Learning and Improvement network (or Housing LIN)** is the leading national network for promoting innovative new ideas in enhancing the housing choices for older people and supporting change in the delivery of housing and related care and support services (www.housinglin.org.uk).



The International Longevity Centre – UK is the leading think tank on longevity and demographic change. It is an independent, non-partisan think-tank dedicated to addressing issues of longevity, ageing and population change (www.ilcuk.org.uk).

A Lasting Power of Attorney (LPOA) is a statutory form of power of attorney that gives someone the legal authority to look after specific aspects of another individual's financial affairs, or health and welfare should they lose the capacity to do so. See Section 6: Decision-making and the Mental Capacity Act and Section 4: Enabling residents to have choice and control.

The Liverpool Care Pathway (LCP) takes the best of hospice-based care and makes it transferrable to other settings, including people's own homes in extra care housing. It is an integrated care pathway that is used at the bedside to drive up sustained quality of care in the last days and hours of life (www.mcpcil.org.uk/liverpool-care-pathway).

The term **Living Will** does not have a legal meaning, but can be used to refer to either an Advance Decision or an Advance Statement (see above). Note that the term is not used widely across all professions. See Section 6: Decision-making and the Mental Capacity Act.

The Mental Capacity Act 2005 came into force on 1st October 2007. It creates a framework within which to both empower and provide proper protection for people who cannot take all decisions for themselves. See Section 6: Decision-making and the Mental Capacity Act.

The National Council for Palliative Care is an umbrella charity for organisations involved in palliative, end of life and hospice care in England, Wales and Northern Ireland (www.ncpc.org.uk).

The National End of Life Care Programme works with health and social care services across all sectors in England to improve end of life care for adults by implementing the Department of Health's End of Life Care Strategy (www.endoflifecareforadults.nhs.uk).

Person-centred Planning / Person-centred Care: the process of developing a support plan that is focused upon the individual, the goals and outcomes they would like to achieve and how they are going to utilise products, services and networks to achieve them. Person-centred Planning does consider health and social care needs and how they will be met, but the main focus is very much on achieving goals and outcomes.

Preferred Priorities for Care (PPC) is a process that provides the opportunity to discuss concerns that may not otherwise be addressed with regard to end of life care. A PPC document is an Advance Statement; however it is not the appropriate place to record an Advance Decision to Refuse Treatment. See www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare, as well as Section 4: [Enabling residents to have choice and control](#).

Scheme Manager or Estate Manager: The individual with overall responsibility for providing a housing management and support service to residents living in extra care housing. Terminology differs between providers.



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