

# End of life care

Achieving quality in hostels  
and for homeless people -  
a route to success



A practical guide to implementing high quality end of life care for homeless people in our communities



<u>3</u>	<u><a href="#">Introduction</a></u>
<u>4</u>	<u><a href="#">Background</a></u>
<u>5</u>	<u><a href="#">Aim of the guide</a></u>
<u>6</u>	<u><a href="#">Key considerations for delivery of end of life care</a></u>
<u>7</u>	<u><a href="#">When to start thinking about end of life care</a></u>
<u>8</u>	<u><a href="#">End of life care pathway</a></u>
<u>9</u>	<u><a href="#">Step 1: Discussions as the end of life approaches</a></u>
<u>12</u>	<u><a href="#">Step 2: Assessment, care planning and review</a></u>
<u>15</u>	<u><a href="#">Step 3: Co-ordination of care</a></u>
<u>18</u>	<u><a href="#">Step 4: Delivery of high quality care in different settings</a></u>
<u>21</u>	<u><a href="#">Step 5: Care in the last days of life</a></u>
<u>24</u>	<u><a href="#">Step 6: Care after death</a></u>
<u>27</u>	<u><a href="#">Next steps</a></u>
<u>29</u>	<u><a href="#">Useful resources</a></u>
<u>31</u>	<u><a href="#">Appendix 1: Quality markers for end of life care</a></u>
<u>32</u>	<u><a href="#">Appendix 2: Support sheet Mental Capacity Act</a></u>
<u>34</u>	<u><a href="#">Appendix 3: St Mungo's palliative care service pathway</a></u>

According to the 2008 *End of life care strategy*, high quality end of life care “should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money.” (*End of life care strategy*, Department of Health, 2008)

This strategy poses particular challenges in relation to homeless people, who are often described as a hidden population. Homeless people are often overlooked when policies are developed, and often not engaged with service development.

So the complexity of life for homeless people is often mirrored by complexities around end of life care.



Photo courtesy of St Mungo's homeless charity



It is estimated that in England around 40,500 people are in the hostel system at any one time and that over the course of a year approximately 100,000 individuals move in and out of it. For some the lack of a settled home may be temporary and quickly resolved. Others may be homeless or living in insecure circumstances for longer periods and either sleep rough, in squats or on friends' floors when not in the hostel system. The homeless population is also very unevenly distributed among PCT areas.

The Department of Health noted in 2010 "There is abundant evidence that people who are sleeping, or have slept, rough and/or are living in hostels and night shelters, have significantly higher levels of premature mortality and mental and physical ill health than the general population." (*Healthcare for single homeless people*, Department of Health, 2010)

In addition, according to several sources, the average age of death among people known to be homeless is about 40 to 44. (Incidentally, it is important not to cite these figures as life expectancy rates. It simply means this was the average age of death based on samples of those who died while known to be homeless.)

**Some of this can be attributed to the fact that single homeless people have a high incidence of physical health problems compared to the general population. A 1994 study found that:**

- "Chronic chest or breathing problems and frequent headaches were twice as high among people in hostels and B&Bs and three times as high among people sleeping rough.
- Wounds, skin ulcers and other skin complaints were twice as high among day centre users and three times as high among soup run users.

- Musculoskeletal problems were twice as high among people sleeping rough.
- Difficulty in seeing was experienced by three times as many people sleeping rough as the general population.
- Mental health problems were eight times as high among hostel and B&B residents and eleven times as high among people sleeping rough as the general population. One in four single homeless people with mental health problems had been in a psychiatric hospital at some time in the past.
- In comparison with the general population heavy drinking or alcohol-related problems were found to be less of a problem among people in hostels and B&Bs than among those sleeping rough."

(Study by Wendy Bines of the Centre for Housing Policy reported in *Findings: housing research 128*, Joseph Rowntree Foundation, 1994)

Homeless Link's *Survey of needs and provisions 2010* revealed that more than half of homelessness projects across England see clients who experience some sort of disability.

**Disability can cover a range of conditions including:**

- Learning difficulties
- Mental health problems
- Mobility
- Sensory impairment
- Developmental disability.

It is likely that some homeless clients have an undiagnosed or unregistered disability. Learning difficulties are particularly under-reported and not always formally recognised by professionals or included in commonly used assessment tools.



*Photo courtesy of St Mungo's homeless charity*

The aim of this publication is to provide a practical guide which supports hostel staff to engage with key professionals in ensuring that those who may be in the last months of their life receive high quality end of life care. The guide may also be useful to health professionals who work or link with hostels in clarifying what measures need to be taken to ensure that people can access appropriate care.

Individuals approaching the end of their life need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to giving people the opportunity to have a dignified death and offering families, staff and other residents bereavement support following a death.

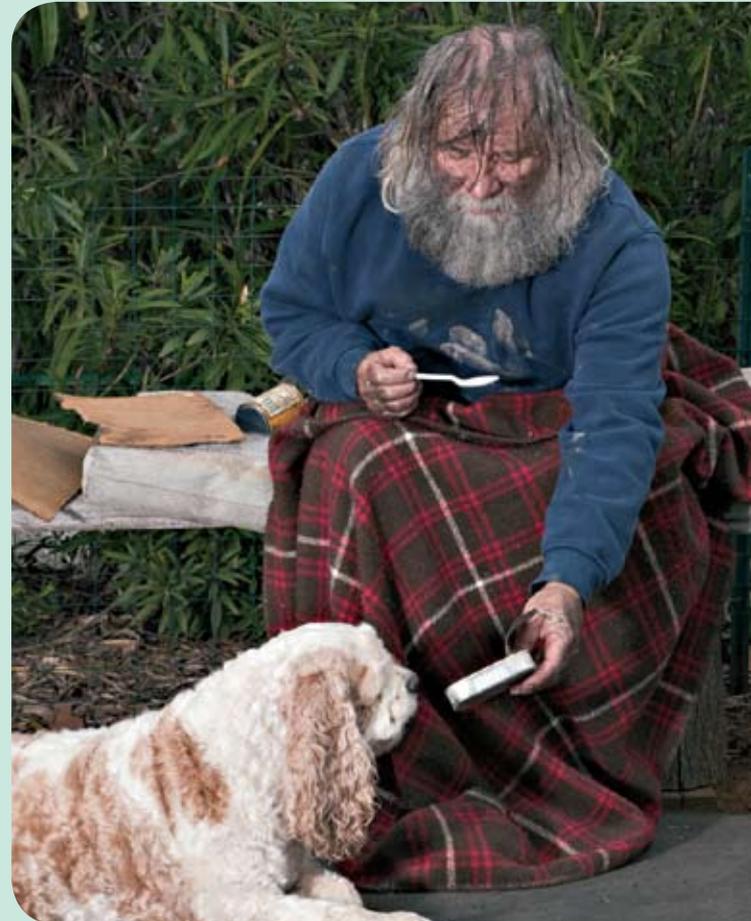
This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital, in the community or in any other setting. The

guide is intended to support practitioners and staff working in hostels to develop their awareness and understanding of the end of life care pathway and how it relates to people in the hostel setting who have life-limiting conditions. Of course, hostel staff are not usually health care providers. Few hostel staff possess specialist palliative care skills while some hostels will not be able to manage people with physical conditions or those approaching end of life. So this guide also offers signposting to more appropriate resources.

The guide has been developed by the National End of Life Care Programme in conjunction with a range of organisations working with homeless people, as part of its route to success series. It is intended to be a practical tool offering advice on what staff can do as well how and when to access specialist help.

# Key considerations for delivery of end of life care

- Care is client-centred and integrated
- Treat individuals with dignity and respect
- Identify and respect people's preferences
- Provide care after death
- Do other professionals fully understand the role of hostel staff?
- Misconceptions about roles can lead to mistaken assumptions. What can be done to assist understanding?
- The existing environment may not encourage privacy or be suitable for care and it may not be practicable to consider rebuilding or remodelling hostel environments. What other measures could be taken?
- Access to services may be problematic because of other professionals' misconceptions about an individual's background – for instance, homeless people are often stigmatised as non-compliant and unreliable. How can this be overcome?
- The homeless population often decline to engage with health services. What would encourage them to engage?
- Access to placement at end of life for people with substance misuse problems can be difficult because many care facilities do not accept people with drug or alcohol issues. Staff need to be aware of those providers who do accept and provide for this
- Some individuals give very low priority to their health needs. How will this be managed within your service?
- Some outreach services can have bureaucratic barriers. How can these best be overcome?
- Many hostels tend not to retain residents for a long time but help them move to supported or independent living. With collaborative working and planning this should also be possible for those with end of life care needs



- Many residents have very complex needs including a high incidence of learning difficulties, mental health problems and dependency issues. As a result hostels may not offer the best environment for end of life care
- In future, health care will be commissioned by localised GP consortia. It will be important for hostel staff to be aware who their local commissioners are and to be involved in helping to identify their residents' health and social care needs
- Residents are often reluctant to plan ahead but will inevitably see that other people in the same situation have poor outcomes. An open discussion about people's expectations can alleviate some of these concerns.

# When to start thinking about end of life care



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

Providing effective, high-quality care for someone during the end of their life is challenging. Without support and information, staff and carers can find the experience overwhelming.

Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone. It may be that on initial referral no specific action is taken, but a resident's future support needs and wishes may be identified and their illness progression can be monitored and reviewed when appropriate.

This resource pack is intended to help you deal with the challenges of supporting someone who is dying and identify how and when you need to access specialist support from health professionals and other organisations.

**It may be helpful to consider the following when referring a resident to the palliative care services or end of life care services:**

**Where an actual prognosis is known:**

- Who is the source of the prognosis (eg, consultant, GP, clinical nurse specialist, regional healthcare co-ordinator)?
- Is the resident aware of their prognosis?
- Is their prognosis months, weeks, days or imminent?
- What are the main reasons for referral (eg, physical, psychological, social, spiritual)?
- Is the resident aware you are making a referral to the palliative care service?



*Photo courtesy of St Mungo's homeless charity*

**Where a prognosis is not known but there are concerns that someone may be at end of life:**

- What is the primary/secondary diagnosis?
- Who is the source of the diagnoses (eg, consultant, GP)?
- What are the main concerns for the resident?
- Is the resident aware of your concerns?
- Who else is aware of these concerns?
- Have these concerns been discussed with any of the following: consultant, GP, clinical nurse specialist/district nurse, regional healthcare co-ordinator?

(Checklist devised by St Mungo's)

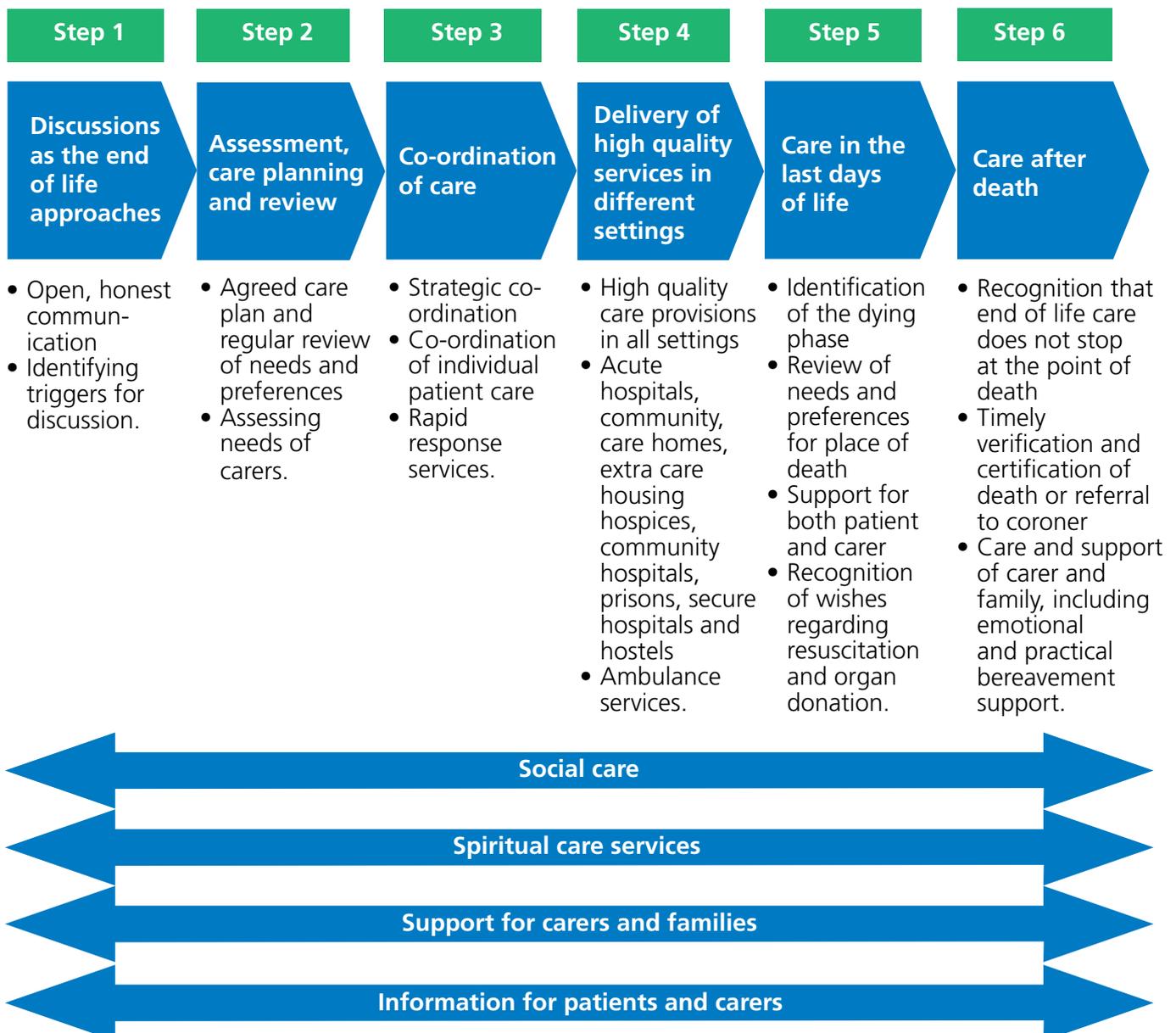
# End of life care pathway

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death.

Each section outlines the relevant step of the pathway, questions to ask about the individual's care and the practitioner's role in that care. (Reference can also be made to the relevant quality markers for end of life care. See Appendix 1 for full list.) We also include case studies highlighting best practice.

**The guide will reflect the need to work with other professionals in health and social care and assist hostel staff to:**

- Identify when someone is approaching the end of life phase
- Assess needs and develop a care plan
- Review care planning
- Help to review practice
- Support communication and team working
- Understand that staff and fellow residents may be affected by the death of a client and identify some measures to support them and provide information.





# Step 1

## Discussions as the end of life approaches

“It can be very difficult to predict when a resident is going to die. We tend to try to find informal and supportive ways to broach the subject with each and every one of them if possible. Sometimes this is about picking up on a comment or remark made about their mortality, and using this as an entry point to further discussion.” Hostel staff member

Identifying when people are approaching the end of their life can be complex. Many hostel residents may have conditions like liver damage and respiratory problems where the stages of deterioration can be unpredictable.

A key challenge is knowing how and when to begin a discussion with individuals about their wishes as they near the end of life and whether they should be referred to other services.



## Ask yourself

- How do you identify residents who are approaching the end of life?
- Are you aware of any triggers which indicate it is an appropriate time for discussion?
- Are you certain you know whether a client does or does not wish to have a conversation about their future care?
- What is your referral process to other services? Do you have a robust referral pathway?

## Your role

- Recognise when an individual's signs and symptoms have increased or condition has deteriorated
- Ask yourself the question "Would I be surprised if this person were to die at some stage in the near future?"
- Identify, with the help of health professionals, those who need to receive end of life supportive care
- Consider carefully whether the individual wishes to have open discussions about prognosis and possible future care options
- Identify whether it is appropriate to open a supportive discussion with the resident about their wishes for end of life care and the best time or circumstances to do that. Consider accessible information, particularly for those for whom reading may be an issue due to learning difficulties, lack of education and/or if English is not their first language
- Provide any relevant information required, whether that is about the individual's condition, financial support, access to specialist palliative care services or anything else.

## Top tips

- Death and dying should not be hidden from residents, relatives and carers. Building a trusting relationship will help facilitate conversations that may include end of life care. Consider who else needs to be involved
- Consider how to integrate conversations into existing activities and assessments such as substance use or general key worker discussions
- Recognise that greater attention and support may be required for those residents who struggle to communicate their needs because of learning difficulties, dementia or other health problems
- As a caregiver it is important you recognise how your own attitude to death and dying may influence the care you provide and your ability to talk openly about these issues
- Try to provide private spaces in which to break bad news or initiate end of life care discussions.

### Case study

Raising the subject of someone's approaching death is one of the most difficult conversations you can have with a resident, says Dave Millburn, but he has become accustomed to it over the 12 years he has managed 32 Bentinck Road in Nottingham.

The home offers long-term care and support for 21 residents, all of whom are 50 or over. Most were previously homeless and although some improve and move out, many others stay there till they die.

Dave and his fellow members of staff will not usually be the ones to break the bad news in the first place. But immediately afterwards they will be deeply involved in trying to help their clients focus on how and where they wish to spend their remaining time.

"It's a matter of trying to have an honest and realistic dialogue at that stage," he says. "I often encounter a degree of shock from the individual that at the age of, say, 50, they are dying. They say: 'How did I get here?'"

One of the keys, he says, is trying to connect with the individual and their particular tragedy. "They didn't plan for this way of life. It's invariably happened because of a series of misfortunes and you need to be able to understand this."

It is vital to get the timing and the tone of this conversation right, he says. Often there will be a chance after someone has been told they have a terminal condition to sit down over a drink and ask them where they want to go from here. "Most people seem to want to engage with that."

Dave says he tries to talk about practical matters as well as people's priorities. He also looks for catalysts such as, for instance, someone choosing a 'weepee' DVD that may offer an opening to talk about what's going on in their lives.

He notices a mood of "quiet observance" when someone is dying within the home. "The whole home feels it when that happens. It's just in the air. And it's something that has to be respected."



A photograph showing a person with long hair and a beard, wearing a dark jacket, sleeping in a metal bed frame. The person is covered with a grey blanket. The background is dark and appears to be an indoor shelter setting.

## Step 2

### Assessment, care planning and review

“People here find it hard to go to people to talk about their health. We need coaxing ... because we’re all messed up.” Cedars Road client

An early assessment of a resident’s needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as identifying any areas of unmet

need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each resident.



## Ask yourself

- Does your care plan assessment take into account all aspects of end of life care (social, emotional and spiritual) as well as physical?
- Who else needs to be involved in this process?
- Do you feel sufficiently confident and skilled in supporting residents to identify their wishes and preferences about their future care? Might additional training and support be valuable?

## Your role

- Consider how you can work with others to ensure that a holistic assessment can take place about the individual's end of life needs and preferences
- Assess and respond sensitively to the social, psychological and spiritual needs and wishes of a resident as well as their physical care needs
- If necessary, support an assessment of the individual's ability to make decisions about their care (guidance provided in the *Mental Capacity Act 2005 code of practice*, see Appendix 2)
- Work with others to identify, record and respond to an individual's personal wishes and preferences about their future care (advance care planning), implement regular reviews and verify this with their local GP if necessary
- Provide clients with a method of recording their wishes and preferences. If they choose to include an advance decision to refuse treatment appropriate advice should be sought
- Communicate information about personal wishes and preferences (with permission) to relevant people such as the GP and out-of-hours service.

## Top tips

- If a resident makes an advance decision to refuse life-sustaining treatment it must be in writing, signed by that person (or representative) and witnessed
- Holding an open meeting with residents can be a way of raising awareness about the possibility of expressing personal wishes and preferences
- Care planning discussions may need to take place in stages to avoid tiring the person. This may also be the case should the resident have learning difficulties or mental health issues
- Complete a key contact sheet as per hostel paperwork already in situ (or consider devising one) and keep in a readily accessible place
- Encourage hostel staff to have an input into care planning discussions when appropriate.

## Case study

The homeless charity St Mungo's and Marie Curie Cancer Care have set up the first palliative care service in the UK for homeless people with terminal illnesses. One of the chief aims is to enable clients to make informed decisions about how they would like to be cared for until they die.

### **Other aims of the service, which has been operating since September 2009, are:**

- Respect for an individual's cultural attitudes about death, enabling them to die with dignity
- Helping to deal with the psychological and emotional aspects of coming to the end of life
- Death occurring in the environment chosen by the service user.

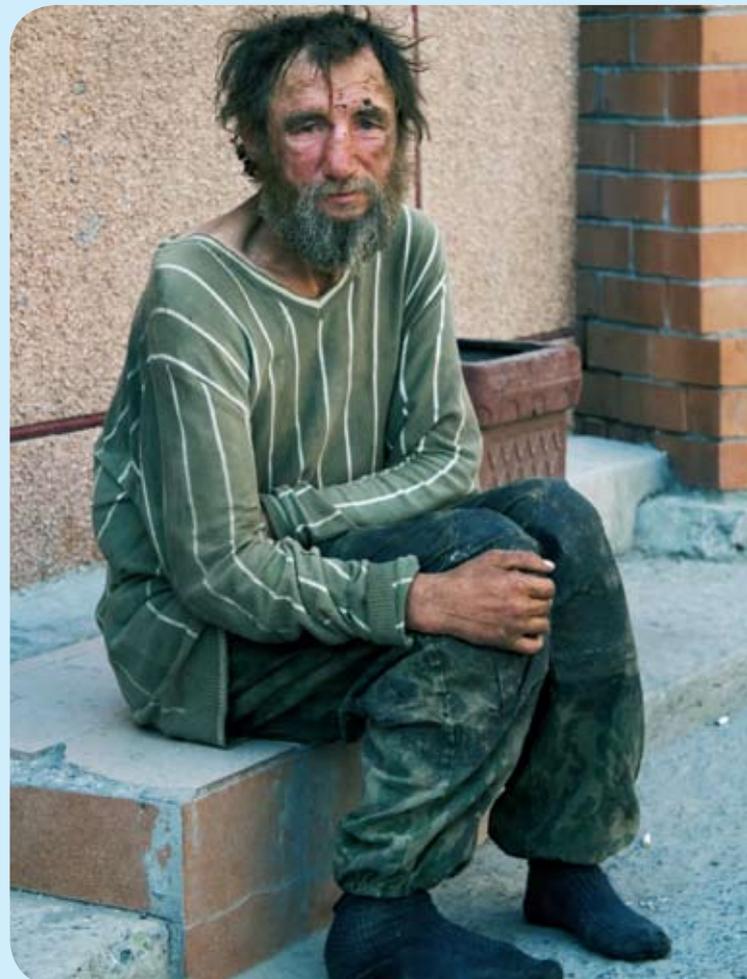
The service is led by Palliative Care Co-ordinator Peter Kennedy, whose role is to co-ordinate care between the resident, significant others, community palliative care services, medical consultants and St Mungo's staff. He also provides training and support to hostel staff.

Many residents' illness trajectories are difficult to predict, he says. "Over 90% of deaths in St Mungo's projects are perceived as 'sudden', although not necessarily unexpected. It is also difficult to assess the severity of people's illness, particularly those with advanced liver disease. The average age of death among residents in our projects is 46.

"Another challenge is that many clients approaching the end of their life have mental health and substance use problems. Working in partnership with statutory and non-statutory agencies is paramount in meeting the multiple needs of those clients."

The service's first step is an initial assessment to see if a client meets the end of life care criteria. The question "Would I be surprised if this person was to die within the next 6 to 12 months?" can help staff identify early on if someone is approaching the end of their life.

Once a client is seen to meet the criteria, the service can then begin to explore their understanding of what is happening and their preferences and wishes. Clients need to be told about appropriate support, particularly specialist palliative care support for dealing with the different aspects of end of life care. But above all they should remain in control of the choices around end of life issues, however difficult that is for staff.





## Step 3 Co-ordination of care

“One challenge is that many clients approaching the end of their life have mental health and substance use problems. Working in partnership with statutory and non-statutory agencies is paramount in meeting the multiple needs of those clients.” Peter Kennedy, St Mungo’s

Once a care plan has been agreed it is important that all the services the resident needs are effectively co-ordinated. Individuals should be asked for permission to share information with other services.

This is also an opportunity to establish contact details for anyone they would like to be notified if there is a change in circumstances – and can in certain cases be used to help re-establish links with families.



### Ask yourself

- Is there a communication system in place to keep all members of the hostel team as well as others such as friends and health and social care professionals fully informed of the end of life care plan?
- Has a key worker been identified within the hostel who can develop a strong working relationship with those key professionals who may be needed in order to meet the end of life care plan?
- Are systems in place for services to respond rapidly and appropriately, (out-of-hours as well as during working hours) to changes in circumstances as end of life approaches? For example, is there ready access to medication and special equipment?

### Your role

- Ensure local healthcare professionals are aware of those approaching the end of life. Some GP practices may be implementing an end of life care register. Is the hostel linked to this multidisciplinary team mechanism?
- Make sure good communication systems are in place with all relevant services
- Ensure you know who your key contacts are across the provider services, voluntary bodies and social care sectors
- Try to ensure that individuals have the benefits they are entitled to. These can be claimed for under special rules when someone is approaching the end of life. A doctor has to sign a special form to initiate this process (DS1500)
- Inform out-of-hours services of anticipated care needs
- Inform ambulance services of anticipated care needs.

### Top tips

- Find out which pharmacies your local hospice uses. These are more likely to offer out-of-hours delivery of drugs
- Building strong relationships with other services – for instance, GPs, palliative care teams and social care – can help you provide residents with good end of life care
- Remember: good communication systems need to work in both directions and meet the needs of those at the centre of the care
- Phone calls between a dying person and health professionals or relatives can maintain contact and resolve some issues without the need for a visit.



*Photo courtesy of St Mungo's homeless charity*

## Case study

Watching hostel clients in their final stages can often be a distressing and painful experience, says Danielle, a project worker at St Mungo's hostel in St Pancras, London.

Danielle works at a 'continued use' hostel, which means all 21 clients at the home are allowed to continue with their drink and drug habits while staying there. The principal aim is to provide them with a safe space while offering support to help them move forward in their lives.

Danielle works on a weekly or fortnightly basis with four of these clients, agreeing objectives – such as getting into meaningful activities, training or employment, moving into permanent accommodation or accessing health services – and then doing what she can to support them to achieve their chosen goals.

Given their substance abuse, health problems, such as liver damage in particular, are never far away and while some do manage to move on to lead more independent lives, others do not. Sadly, last year two of the hostel's clients died – one at the hostel and one in hospital.

In each case the end came quite suddenly – although staff had seen signs they were declining for some time before. The problem, says Danielle, is that most of her clients, being at the pre-contemplative stage, tend to deny what is happening to them so rarely have much time to prepare for their death.

One client was drinking heavily and vomiting and then bleeding. But every time he was admitted to hospital he was patched up and then discharged without any specific advice or support. "The only

thing the doctors said was that of course he was going to be like this because he was drinking so heavily." The man was eventually referred to the St Mungo's palliative care service while his health continued to deteriorate.

"We always try to make clear their choices," says Danielle, "but sometimes they decide they don't want to stop drinking. But it's difficult to see the decline and not to be able to do anything about it."

Staff do also see signs of improvement among other clients and many move on to more independent lives, which makes the job worthwhile. "They often say they dislike the place when they first arrive, but then after they leave you find them coming back to chat with staff and/or residents while they discuss where they're at, so that's when you know you've done a good job."



## Step 4

### Delivery of high quality services in different settings

“We always try to make clear the choices they have but sometimes they decide they don’t want to stop drinking. But it’s difficult to see the decline and not to be able to do anything about it.” Danielle, St Mungo’s

In the last year of life, residents and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless

of where they are being looked after. For some - such as those who are frequently in hospital - it may be useful to have a more proactive approach.



## Ask yourself

- Has a policy for the management of end of life care been developed within your organisation? For instance, is there a policy for what to do if a crisis occurs at a weekend or in the middle of the night?
- Can all staff access any internal or external training and support programme for end of life care?
- Does the environment within the hostel offer privacy, dignity and respect for individuals and their families as the end of life approaches?
- What process is in place for referral to other care settings if your hostel does not provide end of life care?
- What systems are in place to monitor and evaluate the quality and delivery of end of life care?
- Can you ensure that any transition from the hostel to a hospital is well co-ordinated and minimises any distress for your client?

## Your role

- Establish or be aware of the operational policy for implementing end of life care in your hostel
- Ensure you have awareness and understanding of end of life care core principles and values
- Promote or participate in the different aspects of end of life care training which may be available to you. There is no set format for the delivery of training
- Where possible, access training around communication skills, assessment and care planning, advance care planning, symptom management and comfort and well-being
- Give consideration to the environment in which end of life care and support is delivered. For example, is there access to a quiet room or other facilities for relatives?
- Use the experiences of relatives, staff or advocates to help provide constructive feedback to support continuous practice improvement
- Work with key professionals to find an appropriate place of care when it is no longer possible to provide care in the hostel.

## Top tips

- Don't forget the role that other residents, particularly those who have developed a close relationship with the person who is dying, may be able to play in the planning and delivery of care
- Staff training needs should include not only the physical aspects of care but also psychological and spiritual care
- Try to help the resident maintain the maximum level of independence, choice and control for as long as possible
- It might be worth discussing with community matrons and community urgent care providers when it would be appropriate to contact them. Ask for information and contact numbers
- Consider adapting end of life care tools - that is, guidance and support to help staff caring for people at the end of life - for use in the hostel environment.

## Case study

The Homeless Intermediate Care Pilot Project has provided care and support to a group of clients with life-threatening conditions at the St Mungo's Cedars Road hostel in Clapham, London over the last 18 months, reducing deaths and cutting hospital admissions.

The main purpose of the project, which began in January 2009, was to reduce mortality and morbidity while also cutting secondary care usage. In 2008 there were 7 deaths with an average age among those who died of 38. Since then there have been only 3 deaths.

The project team consists of a band 7 nurse, a health worker and a sessional GP, and offers intensive support to up to 10 clients at a time for 6 to 12 weeks. Its main activities include outreach, clinical interventions, liaison and referrals, screening and advocacy.

The level of illness and disease among the 34 clients cared for over the first pilot year was extremely high. 24% had had a diagnosis of HIV, 34% had past hepatitis B and 84% active or past hepatitis C. 83% had been intravenous drug users, 74% alcohol dependent and 88% had had mental health problems. Many suffered from serious conditions such as end stage liver failure, acute syphilis and pulmonary TB.

During that year the project has cut London Ambulance Service calls by 67%, hospital admissions by 77% and A&E admissions by 52%. Repeat attendances are also down. The length of admission has increased slightly, reflecting a reduction in inappropriate and self-discharges.

Nearly 4 out of 5 clients have undergone pre-detoxification. In addition, 90% of women received cervical and sexual health screening, 96% of all clients had a comprehensive health assessment and 87% had a full blood screen.

Key workers say they now feel better equipped to deal with health emergencies and have more knowledge about the conditions suffered by their most unwell clients.

The plan is to move towards residents dying in the place of their choice, usually the hostel, says project lead Samantha Dorney-Smith. However, because deaths are often sudden, this has not always been possible. "We do attempt to ensure death is as dignified as possible and to re-engage people with their families at the end."





## - Step 5 Care in the last days of life

“In principle you do want to be able to support someone around the point of death at home because the patient would want it rather than in hospital. The flip side of that is that death in the hostel can be very upsetting both for other clients and also for staff.” Samantha Dorney-Smith, Three Boroughs Homeless Team

A point comes when an individual enters the dying phase. For some this may appear to happen suddenly and without warning but for many others it can be a gradual process. It is vital that staff are able to recognise when

a person is dying and take the appropriate action. How someone dies remains a lasting memory for the individual’s relatives, friends and the care staff involved.



## Ask yourself

- Are you aware of the changes which may occur in an individual's condition during the dying phase?
- Are systems in place for involving friends, fellow residents and, where appropriate, families in aspects of the care-giving or in discussions as death approaches?
- Has the resident indicated any specific wishes or preferences for this time?
- Has the Liverpool Care Pathway (an end of life care tool for those in their last days or hours) or other equivalent pathway been implemented?
- Have you responded to any particular spiritual or cultural needs that have been recorded as part of the end of life planning?

## Your role

- Be aware of the processes which occur during the last days of life and be alert to the possibility that on occasions an individual's condition may improve
- Have open discussions with relatives, friends and other members of staff to ensure you all know what to expect during the last days of life, and offer support where needed
- Where possible adhere to an individual's stated wishes and preferences
- If someone lacks mental capacity, try to identify what they would take into account if they could make their own decisions
- Where possible have anticipatory prescribing systems in place or a system for rapid access to necessary medication
- Anticipate and be prepared for any specific religious, spiritual or cultural requests a resident may make.

## Top tips

- Discuss with medical staff the support which would be required for the resident to remain in the hostel
- Where possible, plan to have someone - a member of staff, health professional or volunteer - available to sit with the dying person. This will provide them with comfort and reassurance
- Consider ways to support any residents, friends or relatives that the individual wants to be present by providing, where possible, transport, accommodation, meals and emotional support
- Support people with the same respect you would want for yourself or a member of your own family.



*Photo courtesy of St Mungo's homeless charity*

### Case Study

Mary was a 44-year-old woman with learning difficulties living at a local authority hostel in Leicester when she attended the Homeless Healthcare's weekly GP service to have a cervical smear. The results were severely abnormal and an advanced cancer of the cervix was diagnosed, which required treatment with chemotherapy and radiotherapy.

Mary had no family contact but with her consent and with her input, her needs were met by co-ordinating all aspects of her care between the local authority, the local hospice and Homeless Healthcare. A member from the Homeless Healthcare team attended every hospital clinic appointment and all appointments for treatment with her to ensure she wasn't alone and unsupported.

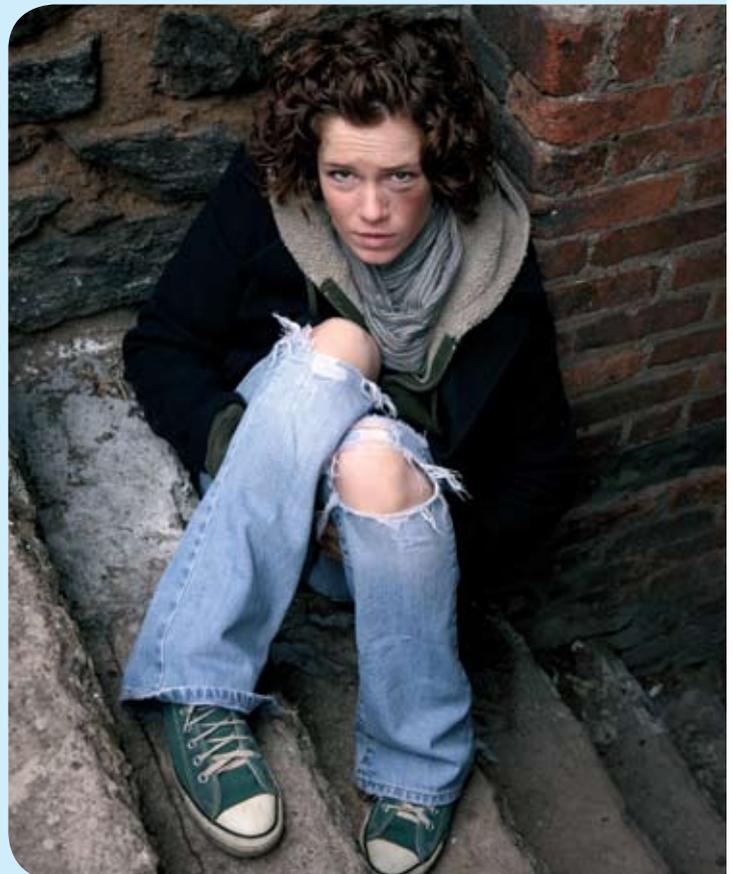
During treatment Mary was often unable to completely self manage and the local authority facilitated a transfer from the self-catering women's hostel where she was staying to a self-contained ensuite flat within the multi-agency Dawn Centre, a 44-bed hostel and YMCA drop-in centre which also accommodates the Homeless Healthcare health suite.

During this time her application for a bungalow reached the top of the housing list but rather than moving her out quickly as was usual practice, the local authority liaised closely with Mary and partner agencies and ensured her treatment was complete and that she would be able to manage before she moved on. Social services arranged for a package of care to be delivered daily and members of all four agencies (that is, GP service, hospice, local authority, social services) worked

collaboratively to ensure that a high standard of care was consistently delivered and all her needs were holistically met.

When her condition deteriorated and she needed admission to the oncology unit, a multi-agency case conference was arranged with both Mary and the above agencies present. She chose not to return to her bungalow with an increased package of care or to the local hospice but instead chose to move to a nursing home.

Following an accompanied visit by a member of the Healthcare Inclusion team she selected a bed in a local nursing home experienced in delivering palliative care and where she eventually died. On one of the team's routine visits she said how happy she was there.



A photograph showing a person with long dark hair, wearing a dark jacket, sleeping in a shelter. They are lying on a dark surface, possibly a cot or bench, with their head resting against a dark wall. The lighting is dim, suggesting an indoor or nighttime setting.

## Step 6 Care after death

“Over 90% of deaths in St Mungo’s projects are perceived as ‘sudden’, although not necessarily unexpected. The average age of death among residents in our projects is 46.” Peter Kennedy, St Mungo’s

Good end of life care doesn’t stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to

family wishes. The support provided to staff, friends and relatives will help them cope with their loss and is essential to achieving a ‘good death’.



### Ask yourself

- Do mechanisms exist to support non-family members such as staff, residents and friends who may also be affected by a death?
- Is there a clear plan to communicate the death to any family members who have not been involved until now?
- Are systems in place for advising on or offering bereavement support to staff, friends and relatives?

### Your role

- Respect individuals' faiths and beliefs and take steps to meet their requirements
- Be aware of verification and certification of death policies
- Provide appropriate information to relatives and carers about what to do after a death
- Offer information about bereavement support services if required
- Provide a comfortable environment in which staff and, where appropriate, residents can discuss or share their feelings
- Provide staff, residents and relatives with the opportunity for remembering and celebrating an individual's life in their own way.

### Top tips

- Residents can be remembered through photos and collages. Sometimes it is really helpful for families to see the photographs around the hostel after someone has died – especially if they haven't been in touch with them
- Recognise that a resident's death may be more significant to some than to others and they may require additional support – as may hostel staff
- Train volunteers to support dying people and their families and friends and offer support to bereaved people
- Hostel staff should be prepared for relatives expressing anger if they have not been contacted. They may also be deeply regretful if they were estranged from the individual before their death
- Use review and feedback to support continuing improvement.



### Case study

St Mungo's aims to support those affected by a resident's death in a range of ways, says the charity's Palliative Care Co-ordinator, Peter Kennedy.

Deaths in projects are not uncommon and are often sudden. As a result, a death can leave residents and staff deeply upset and sometimes traumatised.

There are many ways in which St Mungo's projects commemorate someone's death. Many set up a book of condolence. Some arrange for a tree to be planted or for a bench to be erected. Others hold annual remembrance services.

What staff do in the immediate aftermath of a death is vital, says Peter. This includes how they inform clients, especially significant others, of a death, as well as trying to include them in funerals or remembrance services. "This is really important for lessening the impact and allowing clients to express themselves. And it brings everyone together."

It is also a time of high risk. Clients tend not to have strong social support networks, particularly outside the project. The death of someone close can send them into a downward spiral which has a knock-on effect on other residents. Peter suggests it may be sensible to start making bereavement risk assessments in advance.

The effects of a death can also create high levels of stress for staff who must try and continue with 'business as usual' despite their clients' distress, which they may be sharing.

It is important to have systems in place within the organisation that help to open up dialogue with staff on how they can support each other and then support their clients.

Supporting relatives can also be challenging. In many cases the individual will have had little or no contact with family members, so the first news they may get after a long interval is that their relative is dead. This can be stressful for staff, particularly if they are caught between carrying out the wishes of a client and trying to deal openly and fairly with relatives following a death.

Peter admits there is still some way to go. "But more one-to-one, team support and bereavement training is being made available for staff and they now feel much more assured that they have done everything they could."



- Identify how well your organisation is prepared for managing the needs of someone reaching the end of their life
- The ideal time to talk to people about end of life issues is when they are still well. It may be helpful to sign up to an organisation like the Dying Matters coalition to get access to free leaflets and guidance that can help open up discussions earlier
- What policies and referral pathways are in place now and how can they be improved? (see Appendix 3 for an example of a palliative care pathway developed by St Mungo's)
- Share this information with all staff who may be involved in the delivery of end of life care
- Complete the key contacts sheet and keep in a visible place. This will allow you to have available local information about relevant services including bereavement services
- Consider if it would be useful for a dedicated person to do a course in bereavement counselling
- Look after yourself and each other: build in time to talk about difficult situations
- Find out if there is any available training in your area
- Check the available resources which are on the [National End of Life Care Programme website](#)
- Check National End of Life Care Programme support sheets relevant to this publication.



## Are you prepared as an organisation?

### Case study

Joanne is 30 years old. She began drinking heavily at age 14 and for many years has been using substances such as crack cocaine and heroin. She was diagnosed with advanced liver disease 12 months ago. In a recent hospital admission the medical team told her that if she did not stop drinking her life expectancy would be less than six months.

She is currently being considered for funding for her third detox/rehab programme in two years due to the seriousness of her condition. In her previous two programmes she completed detox but did not reach the rehab stage. She is aware of how unwell she is and continues to live with the belief that she will die within months if she does not get into a detox/rehab programme.

Many staff at the hostel where Joanne lives were insistent she had to stop drinking immediately to improve her chances of living longer. But it is important to allow clients to remain in control of the choices they face when dealing with end of life issues, however difficult staff find them.

In Joanne's case this meant accepting the possibility that, for whatever reasons, she may not be able to undertake or complete a detox/rehab programme, knowing that it will shorten her life. It was also important to let her know that staff would back her request for another chance at detox/rehab and that whatever the outcome they would provide support. This allowed her to retain control of her life but not feel abandoned, regardless of the choices she made.

Joanne is currently awaiting the outcome of an application for funding for a detox/rehab programme. Her engagement with substance use agencies is erratic and her motivation poor. She still has periods of feeling unwell with admissions to hospital. But she continues to receive psychological and emotional support from staff and has been introduced to the community specialist palliative care team.



*Photo courtesy of St Mungo's homeless charity*

For further details on the case studies in this document go to [www.endoflifecareforadults.nhs.uk/case-studies](http://www.endoflifecareforadults.nhs.uk/case-studies)

*End of life care strategy: promoting high quality care for all adults at the end of life*, Department of Health, 2008

*People not paupers: who cares when someone dies homeless?*, UNLEASH (Church Action on Homelessness in London), 1998

*Healthcare for single homeless people*, Department of Health, March 2010

*Dying for a home*, Dr Christine Hugh-Jones, The Willow Walker (magazine working with homeless people in Cambridge, now known as FLACK), Autumn 2009

*Personal health budgets: understanding the implications for staff*, Department of Health, 2009

NHS Choices (patient information)

*End of life care in advanced kidney disease: a framework for implementation*, National End of Life Care Programme/NHS Kidney Care, 2009 (See National End of Life Care Programme website for further examples of condition specific publications)

*Common core competences and principles for health and social care workers working with adults at the end of life*, National End of Life Care Programme/Department of Health/Skills for Care/Skills for Health, 2009

*Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own*, Department of Health, 2008

Preferred priorities for care (PPC), National End of Life Care Programme, 2007

*Advance care planning: a guide for health and social care staff*, National End of Life Care Programme/University of Nottingham, 2008

*Advance decisions to refuse treatment: a guide for health and social care professionals*, National End of Life Care Programme/National Council for Palliative Care, 2008

*Mental Capacity Act 2005 code of practice*, Department for Constitutional Affairs, 2007 (See also Appendix 2: Support sheet Mental Capacity Act)

*Best interests at the end of life: practical guidance for best interests decision making and care planning at end of life*, Hutchinson/Foster (Central Lancashire PCT/East Lancashire PCT), 2008

*Planning for your future care: a guide*, National End of Life Care Programme/National Council for Palliative Care/University of Nottingham, 2009

Making a will (Directgov guidance on wills including links to Citizens Advice Bureau guide to making a will and Age Concern fact sheet)

*Our health, our care, our say: a new direction for community services*, Department of Health, 2006

*Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability*, Mencap, 2008

*End of life care strategy: quality markers and measures for end of life care*, Department of Health, 2009

*Transforming community services: ambition, action, achievement transforming end of life care*, Department of Health, 2009

Macmillan out-of-hours toolkit learn zone. See [www.macmillan.org.uk/learnzone](http://www.macmillan.org.uk/learnzone)

Gold Standards Framework

The Liverpool Care Pathway for the Dying Patient

*Can you see me?* (DVD), The National Council for Palliative Care, 2010

### **Useful websites and organisations that have contributed to this publication:**

Crisis [www.crisis.org.uk](http://www.crisis.org.uk)

Dying Matters coalition [www.dyingmatters.org](http://www.dyingmatters.org)

Homeless Link [www.homeless.org.uk](http://www.homeless.org.uk)

Marie Curie Cancer Care [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

National Council for Palliative Care [www.ncpc.org.uk](http://www.ncpc.org.uk)

National End of Life Care Programme [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

National Veterans Foundation [www.nvf.org](http://www.nvf.org)

Salvation Army [www.salvationarmy.org.uk](http://www.salvationarmy.org.uk)

Shelter [www.shelter.org.uk](http://www.shelter.org.uk)

St Mungo's [www.mungos.org](http://www.mungos.org)

Thames Reach [www.thamesreach.org.uk](http://www.thamesreach.org.uk)

## Quality markers for end of life care

*(End of life care strategy: quality markers and measures for end of life care, Department of Health, 2009)*

1. Have an action plan for the delivery of high quality end of life care, which encompasses clients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

## Support sheet Mental Capacity Act

(Compiled from the *Mental Capacity Act 2005 code of practice* by Julie Foster, End of Life Care Lead, Cumbria and Lancashire End of Life Care Network)

The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

### The five statutory principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

How should people be helped to make their own decisions?

**To help someone make a decision for themselves, check the following points:**

### Providing relevant information

- Does the person have all the relevant information they need to make a particular decision?
- If they have a choice, have they been given information on all the alternatives?

### Communicating in an appropriate way

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

## Assessing capacity

### **Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity.**

- Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.)
- If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

### **Assessing ability to make a decision**

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

### **Assessing capacity to make more complex or serious decisions**

- Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

## St Mungo's palliative care service pathway

