

The route to success  
in end of life care –  
achieving quality for  
social work



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**How to live well is an ancient question which most of us consider from time to time, even if only in our more reflective moments. But how to die well is a question that most of us are much less inclined to face, despite – or perhaps because of – the inevitability of death.**

We have the good fortune to live in a society in which people are living longer, healthier lives. The number of over-85s is expected to double over the next 20 years. But, as society ages, the end of life will be accompanied by lengthier periods of frailty and illness, and levels of dementia will continue to rise.

Social workers have an important role in helping people to die well and with dignity. They have the practical and emotional understanding to raise the issue honestly and talk about it with delicacy and tact. They support vulnerable people at critical times in their lives, so it is logical that they should do so at this time, the most critical of all.

Most people, if asked early enough, say they would prefer to die at home. Yet the truth is that more than 53% of people end up dying in hospital, and this figure rises to 70% for the most socially deprived older people. Death in hospital is more likely still for those with conditions such as heart failure, dementia and liver and respiratory diseases, but even then specialist palliative care is all too frequently unavailable.

End of life care should be an everyday part of practice, not just for palliative care social workers but for every social worker working with adults. We would urge social workers never to shy away from the subject, wherever it is relevant. It is here that social workers' advocacy skills come into their own, helping people to find a path through an unknown, frightening terrain where they would otherwise feel utterly disoriented.

They will need to be able to listen intently, broach difficult issues sensitively and act swiftly if people's wishes and hopes are to be realised. Prompt decisions will be required about benefits entitlements, adaptations to the home, and access to other professional and community resources.

The end of life is often unplanned, giving little time for individuals and their carers to come to terms with death. By solving problems and responding with empathy to the prospect of loss, good social workers can make this last stage of the journey much easier to bear.

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## About this guide

**This guide aims to provide practical support for social workers and managers in their work with people and families at the end of life. It is part of a series of good practice guides produced by the National End of Life Care Programme relating to provision of high quality end of life care in particular settings or by specific professional groups.**

The guide builds on previous work in developing and implementing the Programme's Social Care Framework and draws on the expertise of a wide range of individuals from across the field of social work – including frontline staff, managers, educationists, service users and carers.

The guide offers a structure to guide social work practice with people and their carers and families at each step of the end of life care pathway. It describes:

- Key issues at each step along the end of life care pathway and actions that individual social workers and managers can take to help achieve high quality care
- Top tips – practical suggestions to ensure social workers are able to fulfil their key role in end of life care
- Reflective questions for social workers and managers to consider as they carry out their role
- Case studies (anonymised but drawn from recent practice), which demonstrate social workers attending to the needs and wishes of users and carers at the end of life in all the complex realities of everyday practice; and good practice examples that illustrate how social workers are contributing to high quality care at the end of life.



## Section 1



### Introduction

Social work has a long history of supporting people who are dying or bereaved, and hospices provide the most established models of social workers working in multidisciplinary teams. Yet as social work in the UK has shifted towards the management of risk and a focus on outcomes over process, anecdotal reports suggest that therapeutic interventions with dying and bereaved people have come to be seen as a luxury that mainstream social work cannot afford.

Specialist palliative care social workers remain, but shrinking numbers and redefined roles and functions have led to feelings that their specialism is under threat (Ref. 1) despite evidence from service users of the value placed on their interventions (2). These factors have combined to produce a situation where social work support has all too often been missing from the end of life care package (3).

It was this absence of social work and social care support in end of life care which led the National End of Life Care Programme to establish its social care workstream in 2009. The Department of Health had launched the End of Life Care Strategy in 2008 (4) and the contribution of social care to high quality care at the end of life was acknowledged to be vital.

With the launch and rollout of the National End of Life Care Programme's Social Care Framework (1) in 2010, much has already been achieved in raising awareness and confidence and in developing the skills amongst the social care workforce to – jointly with health – support people at the end of life.

However, evidence has emerged that social work frequently lacks confidence in its capacity to engage with end of life care and struggles to envisage how it can accommodate end of life care in mainstream practice amidst heavy workloads and economic constraints (5). Yet when given even small amounts of specialist training and with the support of their managers, social workers involved in test site projects have shown that they have an important contribution to make to end of life care *as an embedded part of their everyday practice* (6).

Just as importantly, social workers involved in the projects reported beneficial effects on the whole of their practice as well as immense job satisfaction. They developed the confidence and knowledge which enabled them to use their core skills to support service users and their families in articulating and achieving their personal choices for care at the end of life.



## Section 1

### Social work's core values and skills for end of life care

Social workers are well-placed to maintain and develop further their practice with people at the end of life. Their professional role is based on a clear framework of values and ethical standards, a thorough understanding of diversity and social inequality, a commitment to upholding the rights of the individual and to promoting justice and a repertoire of knowledge and skills that are of direct relevance to good end of life care.

Importantly, social workers generally work with individuals and groups who are materially disadvantaged, marginalised and excluded from mainstream society. These are the people whose mortality rates are highest and who are most likely to experience a premature and untimely death, yet who are often unable to obtain the support that they need and want. Social workers' specialist skill and experience of advocacy work enables them to facilitate disadvantaged people's access to the resources and services that can mean a better end of life experience.

Ensuring that people's rights to resources and services are respected is also of crucial importance in the context of end of life care. People's material circumstances might change, as a result of a period of hospitalisation or because of a move to a nursing home, for example.

A thorough knowledge of people's rights and entitlements can enable a social worker to make a significant difference to a family facing a death. In culturally and ethnically diverse

contexts social workers understand the importance of resources that are sensitive to culture, which is of increased importance at the end of life.

Understanding the *individual in context* is central to social work. In addition to their skills in advocacy and assessment, the social worker also brings experience of how to support the people surrounding that individual. Indeed, working with 'families' in the broadest sense – i.e. anyone the individual regards as being part of their family, is key to social work at end of life. It necessitates an understanding of the vulnerability of carers and the wider family at this time but also of their knowledge and experience, which can inform person-centred practice. At times when there are divergent or conflicting perspectives on the needs of the dying person, social workers can exercise their skills in mediation and negotiation.

Social workers' values and skills underpin their professional practice. They are, therefore, committed to work in partnership with service-users and their families, ensuring that their needs and wishes are listened to, understood and responded to appropriately. Approaching their work in a systemic and holistic way requires clarity of purpose and an understanding of the individual in the context of their life-course and their sources of support.

Social workers are well-placed to ensure a seamless transition from long term care to end of life care, when there might be a change in the intensity and nature of services or a change of location. Social workers are educated and experienced in working with loss and grief, helping individuals to adjust to changed circumstances, changed abilities and increased reliance on others for help.

At the same time, the social work role is strongly focused on upholding people's rights to self-determination and autonomy, also of increasing importance when individuals are vulnerable as a result of their declining health. Importantly, social workers have a unique ability to navigate between the individual's 'inner and outer world' – from practical support to difficult conversations about very personal matters.

A thorough knowledge of the context and organisation of practice within end of life services is crucially important to social work. Social workers are able to draw on their experience of working in partnership with colleagues in health services, to be able confidently to identify their role and the range of skills they bring to the team. They can also bring a wider perspective to the dialogue with other professions in terms of their ability to focus on the needs of the whole family.



## Section 1



### The current challenge

The importance of end of life care for social work practice is established in its inclusion in the new Professional Capabilities Framework (PCF) (7). Social work in adult services is facing new challenges arising from demographic change. Annual numbers of deaths in the UK are expected to rise by 17% from 2012 to 2030, and some estimates have suggested that without changes in practice, fewer than 1 in 10 will die at home (8).

People are living longer but with increasing levels of frailty, disability and chronic health problems. In the UK now, most people will die in old age from cardio-vascular or respiratory disease; steadily increasing numbers have dementia, a

condition leading eventually to death (9); people with life limiting illness are living longer; a significant proportion of the prison population has end of life care needs; homelessness is associated with a range of health problems leading to early death; learning disabled adults are taking on caring responsibilities for older or sick family members; older spouse carers may be involved in palliative care provision; parents and grandparents caring for young children die of cancer and other terminal conditions.

In a myriad of ways, social workers find themselves working with individuals, carers and families where good end of life care and support is central to their intervention.

## Section 2

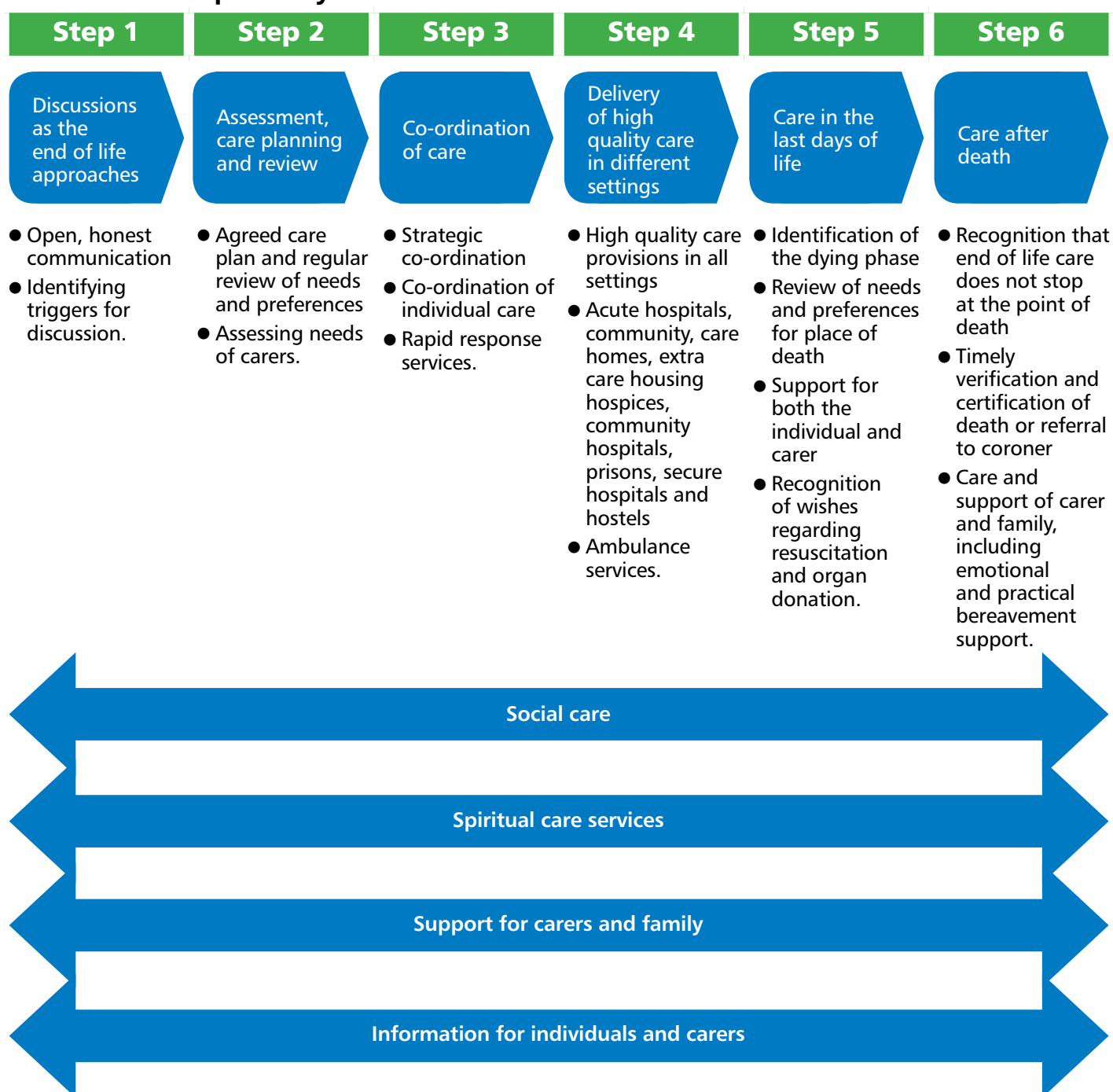
### Social work across the end of life care pathway

This section of 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.

At each step of the pathway, the guide:

- Sets out the key issues that apply to social work
- Offers top tips and reflective questions that social workers may find it useful to reflect upon as they consider how best to support the individual and family
- Describes case studies and good practice examples
- Makes suggestions for social work managers.

### End of life care pathway





## Section 2



The Social Care Framework (1) makes the point that, ‘the pathway through end of life care offers a helpful structure for planning services. However, in reality, it is not a tidy linear progression. People move back and forth, go through ‘steps’ in a different order, or miss out some stages altogether’.

Similarly, social workers may become involved with the person for a variety of reasons and at various points in the care pathway, but it is important to recognise that this person may be nearing the end of life and the implications this has for care planning and service provision. The case studies under each step have been selected because they may have particular relevance for that step, but the tendency is that once social workers become involved, they usually stay in touch to the end.

Social workers have a particular focus on maintaining quality of life in its broadest sense and on recognising and validating the individual’s own definition of quality. People have aspirations and legitimate goals even at end of life and these should be respected.

While there are objective ‘standards’ for quality in relation to settings – for example on space and light, access to support etc – the individual’s experience of quality will also depend on subjective measures which may be influenced by a wide range of factors including culture, sexuality and spirituality.

The social worker looks at all of these elements. Crucially, the person remains a person – as well as a ‘patient’ – to the end. Some core tasks, which reflect social work’s core values and principles, are applicable across the end of life care pathway:

- A focus on the wider holistic needs of the individual to ensure quality of life right until the end
- Recognising and validating ‘quality’ as the individual perceives it
- Working with a whole family approach
- Assessing the needs of carers and the family and ensuring that these are also addressed
- Working with other health and social care professionals, including effective communication and information-sharing
- Fulfilling statutory duties at end of life, particularly in relation to safeguarding, property protection and mental capacity, and dealing with broader risk issues such as potential suicide
- Paying attention to practical needs, including referral to services that may help with financial assessments and benefits entitlements
- Understanding and valuing community networks as a source of support for individuals and their families.

## Section 2



Social workers may find it helpful to keep some core questions in mind whenever they come into contact with the person and their family:

- Who knows what? In particular, what does the person/carer/family know, or want to know, about their diagnosis and any prognosis?
- What is the recent history and why have I been called in at this point?
- What matters to this person – in the broadest sense – and what does ‘high quality care’ mean to them?
- Who is important to this person and how would they like them to be communicated with?
- What is my role in keeping the focus on the person right to the end?
- How is this impacting on carers and family and are their needs being assessed and addressed?
- How can I positively navigate any differing agendas within the person’s family and personal network?

For social work managers, there are also some common issues which will need to be considered, including:

- Training and education for all social workers to ensure they understand their role in supporting people in end of life care as well as the roles that other professionals play; and are fully aware of issues around mental capacity, advance decisions and Safeguarding of Vulnerable Adults (SOVA). Accessing training provided through specialist palliative care services such as hospices and palliative care teams, is often highly beneficial for social workers in mainstream settings. Useful e-learning modules are also available for social work at end of life.
- Establishing systems and procedures that encourage joint working and information sharing, both between health and social care and with others involved in care; this includes ensuring that information recording and sharing systems are flexible enough to accommodate the often complex needs of people and carers at end of life.
- Considering the team as a whole – this includes developing mechanisms for allocating cases so that the right social worker is selected, setting measures and outcomes as a team and considering hybrid posts to ensure that integrated health and social care provision can be accessed through one person.
- Ensuring there is adequate support for social workers who are working with people, carers and families at the end of life. This includes use of supervision to address the social worker’s own emotional and development needs, ensuring that staff have manageable caseloads and ensuring that managers themselves have the skills and capacity to support their staff in dealing with the difficult emotions that can arise when working in end of life care.
- Being a ‘champion’ and voice for good quality end of life care, promoting what is available and positioning themselves on boards and groups to influence decision-making; this includes promoting person-centred commissioning.

## Section 2

### Case study:

#### A social worker's role in offering care and support across the end of life care pathway

Agnes, aged 70 years, had been admitted to hospital with abdominal pain, which turned out to be inoperable cancer. A referral was received by the hospital social work team and it was identified that she would require a community care assessment prior to returning home with a package of home care.

The social worker met Agnes on a ward visit and explored her recent history. This early discussion helped her get to know Agnes as a person. It also helped Agnes feel assured that she had someone other than the busy ward staff with whom she could discuss any issues that were worrying her.

Agnes was very sociable with a good sense of humour; she prided herself in her charity work and was an active member of her church community. But she was shocked and scared at what the doctors had told her. The social worker provided her with emotional support and gave her the opportunity and space to discuss her feelings in relation to her diagnosis and her faith.

Above anything else, Agnes wished to leave hospital and return to her own home. The palliative care team had agreed to monitor her in the community and become involved when the time was appropriate, but her pain was not under control in the hospital and the team instead recommended she be transferred to a hospice to enable her pain to be effectively managed prior to a return home.

Agnes was upset and fearful on hearing this as she considered the hospice as a place where she would go to spend her last days. The nurse and social worker reiterated that the plan was still for her to return home, however, her pain needed to be under control first. Understanding this, Agnes consented to being transferred to a hospice for pain management.

The social worker remained in close contact with Agnes, her family and the hospice. She and Agnes agreed on a package of home care to support her with activities of daily living, Telecare (assistive technology), and a key safe.

Whilst Agnes' pain management significantly improved at the hospice, she still experienced a significant amount of pain when lying down and became very fearful of lying down in a bed. She slept in a riser recliner chair at the hospice, and due to a decline in her mobility she remained in the chair for most of the day; she was adamant that she would not sleep in a bed.

The specialised riser recliner chair helped avoid skin breakdown problems, but Agnes did not have such a chair



in situ at home. The family were unable to privately fund the purchase and the OT department could not provide a riser recliner chair for home use so the social worker began to seek a way to acquire such a chair.

Through discussions with the continuing healthcare team, she learned of an individual funding request panel for specialised equipment; she submitted an application, which was agreed within the same day and the chair was quickly purchased and delivered to Agnes' home. The social worker co-ordinated the various services involved and organised Agnes' return home.

Agnes died a week or so later. Her family were pleased that she had the opportunity to return home to spend her last days there with them. The social worker posted a condolence card to the family stating that it was a pleasure to meet Agnes and the family and that she was pleased we were able to fulfil Agnes' hopes and wishes in her final days. The family replied to thank her for the support she had provided.

The social worker reported that she had found it very rewarding to work with Agnes. She had been able to establish, develop and maintain a relationship with her and her family as she carried out her social work role, providing emotional support as well as practical support. The value of multi-agency working, information sharing and communication was vital to coordinating services and enabling Agnes to fulfil her wish of a return home.



## Step 1

# Discussions as the end of life approaches

Discussions  
as the  
end of life  
approaches

Assessment,  
care  
planning  
and review

Co-ordination  
of care

Delivery  
of high  
quality care  
in different  
settings

Care in the  
last days of  
life

Care after  
death

**Early discussions about needs and preferences can help the individual, their carers and family to prepare for end of life and help ensure that individuals can achieve a dignified death, ideally in the place of their choosing.**

However, identifying when someone is approaching the end of life is often complex. End of life care is usually thought to apply when a person is in the last six to twelve months of life, although the time period for end of life care varies widely from person to person. This may be complicated by confidentiality considerations, which may mean that the social worker may not know the full picture or the specifics about an individual's condition or circumstances.

For some, the period from diagnosis to death may be short; for others, for example those with long term conditions such as dementia, the final phase of life may extend over several years, making it particularly important to initiate discussions when the person still has capacity to engage in them. A social worker may already be involved, either providing short-term, sometimes crisis, intervention or in the monitoring of longer-term support. Indeed, the social worker could be the first professional to identify that an individual may be approaching the end of life.

A key challenge is knowing how and when to begin a discussion about preferences for end of life care and when to refer to other professionals. Sometimes the indication may have come from another social care worker, such as a home carer.

The social worker has the skills both to pick up on the cues and clues that it is time to talk about end of life care arrangements and to create the right environment for open, sensitive discussions with the person and (where appropriate) their family. Ideally, s/he will be able to prepare for that conversation by obtaining information from others involved in their care and s/he will need to draw on their knowledge to quickly establish the fullest picture of the individual, their carers, family and friends, and the particular circumstances.

Social workers sometimes find it difficult to initiate such discussions. A wide range of factors – lack of confidence and time, uncertainty about how much the individual or



family knows about the prognosis/trajectory, concerns about conflicting agendas and complex family dynamics, or about whether there will be support and back-up from managers and others once the 'conversation' has been initiated – can leave social workers nervous about tackling the subject. However, evidence shows that with the right support and training, social workers develop the confidence to utilise their skills and have a particularly valuable contribution to make at this stage.

## Step 1

# Discussions as the end of life approaches

## Top tips for social workers

- Be clear when meeting the individual why the referral has been made and what your role is in supporting them
- Ensure the individual and carer/family has the opportunity and 'permission' to talk about end of life when they are ready. This will involve being open – in 'listening mode' - and drawing on core skills to establish an environment that is conducive to discussion
- Establish the individuals' needs, aspirations and concerns at this point in time and, as far as possible, for the future
- Make referrals where appropriate to other professionals who have a role in providing end of life care, especially when the person is newly identified as needing end of life care
- Ensure that carers and family members, including children, are engaged in discussions as appropriate.

### Ask yourself

- Would I be surprised if this person died in the next 12 months? And is s/he already on an end of life care register?
- What do this individual and family know about the diagnosis and/or prognosis?
- Is this person ready to talk about their end of life care needs and preferences? Am I the right the person for them to talk to and, if not, who could I involve?
- Who else is involved in this person's life – personally, socially and professionally – with whom I may need to liaise?
- Are there any dependants, vulnerable third parties or pets to consider?
- What else do I need to find out about this person to get a full picture of their needs and preferences?

## Top tips for managers

- Ensure social workers recognise that there is a role for social care in end of life care planning as part of the support plan process
- Ensure social workers are aware of tools such as preferred priorities for care (PPC), Liverpool Care Pathway (LCP) and Gold Standard Framework (GSF) and Advance Care Planning (ACP)
- Establish robust mechanisms to collect information at the point of referral
- Establish team allocation processes that can identify the most appropriate person to take on the case
- Identify and address any training needs, such as communication skills, which would help social workers feel more comfortable having end of life discussions; this includes e-learning and local training available through hospices
- Ensure that social workers have access to specialist palliative care social work support and resources and encourage them to be proactive in referring to other professionals, including specialist palliative care social workers, as necessary
- Ensure individual supervision allows social workers to explore available options for end of life care.

### Ask yourself

- Is this social worker sufficiently confident to deal with complex end of life care issues for the person and their family? Should they contact other professionals who may need to be involved in order to enhance the care provided?
- Does this social worker feel comfortable participating in discussions with people about approaching death?
- Is this part of the individual's staff development and performance plan?

## Step 1

## Discussions as the end of life approaches

### Case study:

#### Supporting people and vulnerable dependants to prepare for end of life

Gwen, aged 78, contacted Judy, a social worker on the community care management team, about her daughter Megan. Judy had placed Megan, who has a learning disability, in a supported living flat a few years previously.

Megan had remained in daily contact with her mother and was emotionally and practically quite dependent. Gwen had a chronic respiratory tract condition which was increasingly debilitating and wanted Megan to be prepared for such time as she had to manage without her mother's support and ultimately, her death.

Judy soon realised, however, that Gwen also needed support for herself - practically, emotionally (she continued to have unresolved issues arising from her husband's death a few years previously) and in making her own preparations for death. Whilst Gwen clearly realised that she was in her 'dying phase', Judy had to fight to get the services Gwen needed to support her in daily living in order that her energies could be conserved for what to her was important business – such as returning to her place of birth in order to say goodbye.

Without a terminal diagnosis and still presenting as relatively independent, Gwen was refused home care services. However, she continued to 'set her affairs in order', including arranging her own place in a nursing home when she could no longer manage at home.

Judy worked with Megan to help her understand that her mum was getting sicker and would not be around forever. Megan needed reassurance that she would not be left to manage on her own and encouragement of her developing independence. Judy also worked with the support staff on the network to assist them in helping Megan understand the implications of her mother's death for her and her future life.



Freed from practical responsibilities, Gwen was able to spend the time with Judy talking about her feelings of loss – the loss of her husband, which she had never got used to and was looking forward, as she believed, to being reunited with him in heaven; the loss of her health and the freedom and independence that goes with it; the loss of her parenting role. Judy also helped Gwen and Megan to plan the funeral with a local minister.

Finally, Gwen was at peace and ready to die, and Megan, although initially very distressed when she realised that her mother would soon die, found solace in this active engagement with her mother's death and was able to be with her when she died. Megan took part in the funeral service, which Judy also attended, and 'received' the mourners after, supported by her cousins.

**Adapted and abridged from Holloway, M. (2007) *Negotiating Death in Contemporary Health and Social Care*, Bristol: Policy Press, p.166 and 175-6. Reprinted with permission.**



## Step 1

## Discussions as the end of life approaches

### Good practice example:

#### Initiating early conversations: palliative care social workers sharing their expertise

Social worker members of the Practice Development Facilitators Team at LOROS (Leicestershire and Rutland Organisation for the Relief of Suffering) have been working with colleagues to improve the end of life care pathway for both service users and home care provider agencies.

The Practice Development Facilitators were involved in the delivery of provider-based teaching with 11 agency carers, who were subsequently shadowed in practice during their visits to service users' homes. The teaching has included familiarising providers with tools such as GSF and LCP, helping care staff recognise and identify the dying process whilst promoting a co-ordinated approach care at end of life.

Shadowing focused on recognising the dying process at an earlier stage than previously identified or acknowledged by care staff, whilst promoting open and honest communication and helping staff identify cues for discussion.

As a result, care agency staff noted an increase in their skill and confidence levels and reported increased awareness of how to recognise 'end of life' at an earlier stage. Carers also reported feeling more confident about referring and liaising with others involved in the delivery of end of life care.

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### Good practice example:

#### Using social work skills to build links into the community and access informal support

Specialist Palliative Care Social Workers from Birmingham St Mary's Hospice have used their core social work theories, skills and techniques to build links into the wider community, particularly with the different ethnic and spiritual/religious minorities.

Based on systems and bio-psycho-social models of illness and other theories, the 'Compassionate Communities' programme has enabled the social workers to partner with members of the local communities to offer holistic support to people and their families at the end of life.

Having established in their earlier qualitative research that death, dying and loss is a taboo subject in most communities, the social workers advocated for debate on this issue. The aim was to encourage individuals, families and communities to start viewing death, dying and loss as a natural part of life, thus empowering them to proactively engage in these difficult conversations so as to access services.

With support from Macmillan they have run local level workshops around cancer, death, dying and loss. At these open sessions, Social Workers have used their core skills in

communication to facilitate group discussions that help tackle taboos about death and dying and raise awareness of the end of life care services available through the hospice and other providers.

A reference group has now been established comprising people from diverse ethnic groups, religious/spiritual/non spiritual communities, diverse sexual orientation groups, and any other minority groups.

The reference group members act as hospice ambassadors supporting social workers to communicate more effectively with people from their communities and can act as cultural brokers when appropriate. This 'anti-oppressive' style of working eases difficult conversations, supports people to make better informed decisions and offers service providers deeper insight into people's needs.

These social workers have used their social pedagogy skills, which are essential in advocacy to change attitudes within all communities including end of life care service providers and commissioners.

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## Step 2

## Assessment, care planning and review



**An early holistic assessment of the person's needs and wishes as they approach end of life is vital to establish their preferences and choices and to identify any areas of unmet need so that this can be addressed through the care plan. Understanding need in the broad holistic sense – psychosocial, spiritual, cultural, sexual, environmental and financial – and then matching resources to this need is central to what social workers do.**

Social workers have a particular role in assessing complex family circumstances including co-dependency between the person and carer and where the person nearing end of life may themselves be a carer of a vulnerable adult or child. Social workers often need to synthesise layers of sometimes conflicting information in their assessment and take account of difficult ethical questions.

Social work assessment is frequently the gateway to other services and it is not a one-off intervention. End of life care needs rarely remain constant: health conditions deteriorate

(or even improve temporarily); family circumstances may change; the person's wishes or priorities may change. Assessment, planning and review are therefore part of a continuous cycle across the end of life care pathway. Moreover, usual timelines may not apply at end of life: the individual or carer's needs may need to be reviewed continually rather than once every six or twelve months.

The social worker may contribute his/her assessment to joint professional review and it is important to minimise any duplication and unnecessary intrusion for the individual and family. It is also vital that social workers, who may be involved earlier in the care pathway than other health professionals, are alert to end of life care preferences in drawing up care plans.

The principle of working in partnership with the individual is as important in end of life care planning as any other circumstance and can be a valuable way of giving the person back a sense of control at a time when they may feel powerless. For this reason it is vital that the person is supported in expressing their wishes and making their own plans at a point when they are able to meaningfully participate.

### Top tips for managers

- Ensure that social workers are aware of their obligations regarding mental capacity assessments and safeguarding
- Ensure social workers are trained and knowledgeable about the legal requirements for recording advance decisions including decisions to refuse treatment
- Be pro-active and avoid 'crisis' by promoting the role of social work amongst health and social care colleagues and requesting timely referrals
- Ensure there is adequate time for a full assessment and review 'visit' to be undertaken
- Ensure that prompts to consider end of life care are included in all assessments/review documentation.

### Ask yourself

- Are social workers aware of the need to identify cultural needs and preferences early on?
- Are your social workers aware of other assessments that may be underway, and encouraged to make joint assessments with other professionals to minimise disruption and duplication?
- Are our information recording and sharing systems and protocols sufficiently flexible to suit complex circumstances?
- Is information and advice clear at the point of entry to the system to aid those who do not need local authority support?
- Is Fair Access to Care Services (FACS) criteria being applied appropriately?
- Who within the social work team is best placed to input into advance care planning for an individual?

## Step 2

## Assessment, care planning and review



### Top tips for social workers

- Keep in mind the 'whole person' in their family and community context, recognising and validating diversity; culture, sexuality, faith and identity can be powerful determinants of what constitutes good end of life care for that person
- Support the individual and family to do what is important to them, including identifying and respecting their current capability to support themselves but also being mindful of how this might change over time
- Ensure that the needs of other family members, including vulnerable third parties, are also addressed and be aware that these may change
- Enable people to access practical help and resources by informing them of what is available, matching resources to need and advocating on their behalf where necessary; this can be particularly difficult for people to do for themselves at end of life
- Signpost or refer to other care, support and advice services including financial assessment where appropriate
- Familiarise yourself with the end stages of common progressive diseases e.g. multiple sclerosis using the Gold Standard Framework
- Be aware of statutory requirements and duties including in relation to vulnerable third parties, the Mental Capacity Act, safeguarding and deprivation of liberty and the particular issues they pose at end of life. This includes consideration of parental responsibility and legal aspects of planning for the future of any dependants.

### Ask yourself

- Is there a Preferred Priorities for Care or other advance decision/plan already in place? Would the person like to draw one up?
- Am I thinking of this individual as a whole person, who still has a life to lead until they die? What is important to this person and what are they concerned about?
- What do the individual and family want to do for themselves? What resources can they access through their own personal and social network and how might this change over time?
- Does a contingency plan need to be drawn up with regards to any dependants or vulnerable third parties?
- Has a carers assessment been considered?
- How does my assessment fit into the multidisciplinary wider picture? Who else is already assessing this person and how can we minimise duplication and intrusion? Who else might need to be involved in the assessment?



## Step 2

## Assessment, care planning and review

### Case study:

#### Assessing and meeting complex needs at the end of life

Steve was a 34 year old man with recurrent malignant melanoma. He was estranged from his partner and had limited contact with his children, aged eight and three. He moved back to live with his parents, in a small upstairs flat. His treatment was complicated by heroin/methadone dependence. As his pain increased and he became more ill his mother took to 'scoring' his drugs for him as she feared for his safety.

Steve's mother broke down while accompanying him at an outpatient appointment. The hospital social worker attached to the multidisciplinary team caring for Steve was asked to see her. Together with Steve's clinical nurse specialist the social worker negotiated for Steve to be admitted as an inpatient so that members of the multi-professional team could optimise medication for his pain, taking account of complications associated with his drug dependence.

The social worker worked with occupational therapists, physiotherapists and clinical nurse specialists to carry out a holistic assessment and facilitated open discussion between Steve and his parents so that they could develop an advance care plan. She co-ordinated planning for his return home, including arranging home care and involving an occupational therapy colleague to provide specialist equipment needed for his personal hygiene within the limitations of his parents' home.

She also helped the family to claim all their entitlements and provided Steve's mother with advice and resources so that she could help her son talk to his children about his illness and prepare them for his death.

As a result, Steve was able to return home for the final weeks of his life, with his pain adequately controlled without recourse to illegal drugs. His parents were adequately supported in caring for him. The social worker identified a local bereavement service for children and families so that Steve was reassured that his family would be given the support they needed after his death.

### Case study:

#### Assessing and addressing financial needs

Burcin's finances were plunged into chaos following her diagnosis of advanced cancer. Her husband, Mehmet, was the sole earner and was self-employed, and when he had to take time off work to support her through intensive chemotherapy, they quickly fell behind in their rent and council tax. At the height of Burcin's treatment, she and Mehmet were facing eviction notices and court summonses for unpaid council tax, which added considerably to their stress.

A social worker was brought in by the Macmillan team to support the couple. He quickly grasped the situation and negotiated a halt to the eviction proceedings. He also began negotiating with the council tax and benefits agencies to resolve the council tax arrears and get appropriate benefits for Burcin, but this proved much more problematic. Both agencies had complex procedures and were unwilling to be flexible in response to Burcin's acute illness, insisting, for example, that she come in to

sign claims forms in person despite the fact that she was hospitalised to receive treatment.

Working together, the social worker and Macmillan nurse compiled a dossier explaining in detail Burcin's current circumstances and why it was impossible for her to comply with regular procedures; eventually, the agencies relented and Burcin was able to apply for benefits and resolve the council tax arrears.

The social worker also arranged access to a range of other benefits and grants to help Burcin during her illness, including winter warmth payments to enable her to heat her flat during the day and a grant for a bed she could sleep in near to her living room fire, as cold was a particular problem for her. The social worker was also able to inform Mehmet of his own entitlements to benefits now that his caring role prevented him from working.

As a result of the support and action by the social worker, the couple were able to re-establish their financial stability and focus on helping Burcin cope with the effects of her cancer treatment.

## Step 2

## Assessment, care planning and review

### Case study:

#### Assessment and care planning to enable those with complex needs to be cared for at home

Grace, aged 95, lived alone in her own occupied house. She was not known to the local social care team, having been supported by a private care package twice daily for meal preparation and housework.

When Grace was admitted to hospital after a fall at home it was discovered that she had a metastatic brain tumour, secondary to a malignant melanoma. Whilst on the ward she needed constant supervision needed to maintain her safety as she did not listen to instructions at times and was at high risk of falls; she needed two carers at least four times during the night for toileting.

Due to the high level of support required, a multi-disciplinary team meeting was convened. The team advised that Grace could not manage at home even with a care package and recommended a period of short-term nursing care. However, supported by an Independent Mental

Capacity Advocate (IMCA), Grace expressed a wish to return home to see if she could manage.

Following assessment from a social worker from the Integrated Discharge Team she was discharged from hospital with a care package organised to provide two carers four times daily. Within a few days this broke down when she became immobile and the Admission Prevention team became involved to organise a nursing home bed rather than return her to hospital.

The case was referred to the locality multi-disciplinary team and a Rapid Access Social Worker went out to assess her. As Grace had experienced a rapid deterioration she met the continuing healthcare criteria and the social worker ensured that her application was fast tracked; it was approved in due course.

As a result of these interventions, Grace was able to move out of hospital and, later, to avoid readmission, in accordance with her needs and wishes. She eventually died in the nursing home.

### Good practice example:

#### Assessing and responding to the needs of carers

The social worker at St Wilfrid's Hospice in Eastbourne leads a monthly Carers Support Group to meet the need for both emotional and practical support and information for adult carers of people with a palliative condition.

The group is facilitated by a social worker experienced in group work and a nurse who works across the Hospice at Home and Day Therapy services. This collaborative approach enables carers to access a range of knowledge and skills in one setting. The social worker emphasises the values of user-involvement and self-management, and brings skills in family systems and group interaction and knowledge of community resources available to carers.

The style of the group is informal, with safe boundaries that encourage the carers to discuss 'difficult' topics, including how to face the knowledge of an uncertain prognosis, the changing nature of the carer's relationship with the person they are caring for, and how it feels when the person they care for puts on a brave face for others

while behaving negatively towards them.

Carers have reported their appreciation of the opportunity to meet others who share the same concerns and worries as they do and to talk openly about how they feel with their peers in an informal and confidential setting. They also value the protected time to reflect and talk about their own needs and feelings and have a break from their caring responsibilities.

The sessions also enable them to hear occasional speakers from hospice and community based professionals and agencies and talk to staff individually if they have specific concerns about their situation. Staff are now considering developing short term, group support for carers after bereavement.

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## Step 3

## Co-ordination of care

Discussions  
as the  
end of life  
approaches

Assessment,  
care  
planning  
and review

Co-ordination  
of care

Delivery  
of high  
quality care  
in different  
settings

Care in the  
last days of  
life

Care after  
death



**Once a care plan has been agreed, careful co-ordination is needed to ensure that the individual and family receive an integrated package of care that is tailored to their needs. Effective co-ordination benefits organisations as well as individuals and families: it can help prevent crises and avoidable admissions and is crucial in facilitating the person's return home after a period of hospital or respite care, as well as minimising duplication in services and identifying gaps.**

However, with multiple staff and organisations and complex systems (including funding arrangements) involved in end of life care, co-ordinating this care can be a challenging task. The social worker may have a key worker role or may have responsibility for co-ordinating a particular component of the care package such as domiciliary care.

In some cases, individuals and/or families will want to co-ordinate care themselves. Here, the social worker can provide much-needed support and guidance as they attempt to navigate complex systems and procedures and inform them of services and support they may be entitled to. S/he can also step into a more active role should circumstances change and the individual or family no longer feel able to pro-actively co-ordinate their own care.

Social workers may be part of an interdisciplinary team (IDT), multidisciplinary team (MDT) or other team involved in supporting an individual and family. This team may be virtual or based physically in a setting. In either case, the social worker may have a particular focus on ensuring that the care package is meeting wider needs, including those of the family, and supports quality of life.

Often the social worker is key to ensuring that the person's voice is heard. They will need to be clear on how their role relates to those of other members of the team and also to support effective communication and information-sharing within the team, particularly when the team is virtual.

Professionals can all too easily appear to 'take over' in end of life care, resulting in disempowerment of the dying person and their family. Social work's development of person-centred models has much to offer in ensuring that the individual and family remain at the centre of care and are given the information and support they need to make choices about the care they receive.



## Step 3

## Co-ordination of care

### Top tips for social workers

- Keep the focus on the individual and their family, especially as increasingly complex services become involved
- Help the individual and family navigate the system themselves as far as they are able and they wish to do this; this may include use of personal budgets
- Ensure that the person and their family have the information they need to remain in control of their own care pathway, including who to contact when experiencing problems
- Establish a directory of contacts/resources in each locality which can be used for signposting
- Build strong relationships with other services in both health and social care so that they understand the role and contribution of social care and make use of joint working and visits
- Ensure that new service providers are properly briefed and introduce them where possible to the individual and their family
- Contribute to the team by communicating regularly and sharing information
- Check that care providers feel equipped and supported to continue providing the right level of care
- Manage risk at an acceptable level to avoid crisis.

### Ask yourself

- Am I the key worker for this person? If not, who is and who do I need to liaise with?
- Is there an advance care plan (ACP) or Preferred Priorities for Care (PPC) in place?
- Have the person's needs changed and how stable is their current situation?
- Are there any unmet needs that have not yet been identified? If so, can these be addressed and what is my role in this?
- Are systems in place for services to respond rapidly if circumstances change – including out of hours? Do individuals and families know how to access these?
- Who else do I need share information with about the individual and family's needs and circumstances? Is the individual on an end of life care register?

### Top tips for managers

- Ensure social workers liaise with other professionals and share information within the team surrounding the person
- Ensure social workers understand how to make use of the opportunities presented by discharge policies and agreements to effect timely discharges
- Maximise opportunities for joint working by promoting case conferences, inter-professional planning meetings and joint visits between professionals
- Ensure there are good channels of communication between the different disciplines and seek to develop streamlined shared information systems; electronic palliative care co-ordination systems (EPaCCS) can be a helpful mechanism for enabling professionals to share information
- Ensure social workers are aware of what services are available in their area
- Negotiate clear agreement pathways for funding decisions and ensure clear processes for continuing healthcare applications
- Establish in conjunction with commissioners a preferred providers list to enable prompt access to care when needed.

### Ask yourself

- What are the local information recording and sharing systems (including EPaCCS) and can social workers access and make use of these?
- Are there robust referral pathways, in place and understood by social workers and other professionals?
- Should a social worker be attending the GP Gold Standards Framework meetings for information-sharing?

## Step 3

## Co-ordination of care



### Case study:

#### **Liaising with other specialties and services to meet the needs of individuals and their carers**

John, aged 28, lived with his sister, Mary, in a two bedroom social housing flat. He had a learning disability and was known to the Community Nurse Specialist, but was not currently receiving services from the adult services of his local authority. As he became increasingly ill with a neurological condition, his symptoms became difficult to control and he and his sister were finding it increasingly difficult to manage at home.

John came in to the hospice for symptom management and was nursed in a single room with an unusually high level of support from family members, in particular, Mary. Through offering a listening ear to Mary, the social worker at the hospice learned a lot about this complex family, where some members had needed to find ways of coping with their history.

The social worker gradually learnt that Mary herself had long-standing mental health issues and was currently under the care of the acute mental health team with a fast-track agreement for consultation with the duty psychiatrist if her own consultant was not available.

For Mary, being there for John to the end was her goal. She met with the social worker quite a few times, sometimes by arrangement and sometimes informally. One day Mary sought the social worker out and was clearly in distress, talking of how she felt she was going into “meltdown”. Through further exploration, the social worker was able to identify that a short-term increase in Mary’s medication might see her through and simple support of this process was all that was needed.

The social worker spoke with the mental health co-ordinator who arranged for the psychiatrist to ring back at a set time. Mary took the call and was ensured privacy to have the needed consultation. An increase in medication was agreed with a follow-up call arranged for several days later; this enabled her to cope during her brother’s final days and to play her desired role in caring for him.

The social worker had played a crucial role through successfully identifying the needs of the family, and engaging and developing a relationship which enabled the key relative to use a support route which was already in place, retaining her privacy and dignity.

Following John’s death the social worker and mental health team identified that as part of Mary’s ongoing care she would welcome some specific bereavement support from the mental health social worker, who visited Mary at home over the following months.

## Step 3

## Co-ordination of care

### Good practice example:

#### Co-ordinating care provided by care agencies at end of life

Adult social care social workers in Cumbria responsible for co-ordinating domiciliary care for people nearing the end of life have established close and supportive relationships with preferred care agencies to ensure they are able to provide appropriate high quality care at this stage.

Social workers have worked with their county council's preferred providers to enhance their understanding of the particular needs of people and families as they near end of life and to build the confidence of staff and managers in meeting these needs. This included highlighting the importance of:

- **Responsiveness** – wherever the person is in the palliative stage of illness or on the end of life pathway, time is precious and rapid response is essential
- **Consistency in staffing** – with up to four visits a day, often with two carers per visit, it is important to minimise the number of different people involved
- **Sensitivity** – end of life is frequently deeply stressful for individuals and families; sensitivity to people's feelings and respect for the home environment are vital
- **Flexibility** – people's needs can change and vary as they approach end of life and carers may from time to time need to spend more time with a person than anticipated or to be able to step in to relieve carers at short notice
- **Information-sharing** – domiciliary care staff are encouraged to look out for and report back to social workers any unmet needs or emerging concerns; this required social workers to reassure staff about confidentiality arrangements.

Crucially, social workers have been careful to ensure that, as people's needs change and additional costs are incurred, they are reflected in reliable contracting arrangements that can accommodate, for example, an additional 15 minutes spent helping someone on a particularly bad day. This means that care agencies respond to need, confident that they will be paid in full for any additional support their staff provide.

Social workers have needed to invest a great deal of time in educating the care agencies and staff in these areas but the effect has been transformational, with considerable benefits for all involved. Information flow between



social workers and domiciliary care staff has improved significantly, meaning that needs are identified and met sooner and care is more effectively co-ordinated.

Care agencies and staff report greatly enhanced confidence and job satisfaction as they find they are able to meet complex needs of individuals. As a result, people and their families benefit from a more integrated service from sensitive, responsive and competent domiciliary care staff.

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## Step 4

## Delivery of high quality care



**As death approaches, individuals may move between different settings for elements of their care; the right residential setting may also change over time. At this point on the pathway, there are three priorities:**

- Ensuring that the transition between different settings is managed so that the individual's quality of life is maintained
- Ensuring that change is minimised where possible
- Ensuring that care is high quality wherever the individual happens to be.

Social workers may also be involved in transferring a person from one setting to another, including as discharge facilitator. Communication can sometimes fail at these times, especially when discharge takes place outside normal working hours.

There may also be complexities around access to equipment and around transport services, for example when moving equipment or drugs. Here, the social worker is often well placed to liaise between settings to ensure a smooth transition. S/he will also often be a constant amid the upheaval of the move and associated changes in care personnel.

Sometimes, even when a care setting is not ideally suited to the individual's needs and preferences, small changes can make a significant difference to how they feel about it. Social workers will often need to be creative in helping adapt and modify the environment to make it more conducive to the things which make for quality of life for this person, e.g. the presence of pets, helping to facilitate new friendships or being able to listen to music of their choice.

At other times, the setting or care available may not be up to the required standard. Here the social worker will play a key role in driving up quality, including identifying and reporting gaps and poor practice and working with care staff to support better practice.

Whatever the setting and circumstance, the social worker will need to retain the focus on quality in its broadest sense and ensure that the wider needs of the individual and family are being met.

## Top tips for managers

- Ensure that communications systems are in place to keep all those involved in care up to date with developments
- Ensure social workers liaise as required and carry out effective discharge planning to the person's preferred place of care
- Ensure social workers are aware of how to rapidly access equipment, assistive technology and housing adaptations.

## Ask yourself

- Are social workers aware of how to make use of patient transport services, via both the GP and hospital provision, at the end of life?
- Is there a key person within the social work team who takes responsibility for supporting colleagues who are dealing with end of life care issues?
- Is supervision utilised to ensure staff support and maximise learning around end of life care?

## Step 4

## Delivery of high quality care

### Top tips for social workers

- Keep the focus on delivering the individual's care/support plan and meeting wider needs and preferences, e.g. beyond immediate pressing health and social care needs, as they move between settings
- Support the person to stay in the place of their choice and help minimise the changes in care settings
- Be a system navigator on behalf of the individual and family where required, and act as a conduit for information between services, settings and teams
- Monitor care as people move around, paying attention to the environment and culture of care - this will include identifying and reporting substandard settings or care in accordance with professional requirements, such as Safeguarding of Vulnerable Adults (SOVA), but also supporting the development of improved practice
- Liaise closely with direct providers and other professionals to ensure smooth transition between settings and act as a constant point for the individual and family throughout any transfers
- Promote communication and collaboration between services and settings, including ambulance services, out of hours services and the GP
- Be creative when considering how to adapt an environment - small changes can make a huge difference
- When equipment or adaptation is needed, press for prompt access in order to help prevent unnecessary admissions
- Consider the impact of a change in setting on carers and families, for example on travel arrangements, care of pets etc. and offer advice where appropriate. This may include significant emotional impact, for example where a family has been caring for the individual in their own home
- Where the social worker is discharge facilitator, be clear about the person's priorities and liaise/facilitate communication between the discharging and receiving organisation
- Use regular telephone contact to pick up concerns early and avoid crises, to enable the person to remain in their preferred place of care wherever possible
- Specialist social workers should be prepared to share their expertise to enhance the quality of care provided by all professionals, e.g. through consultation, education and training.



### Ask yourself

- Do I know what 'good' looks like for this person? Could their quality of life be improved?
- How appropriate is this setting for him/her? How could this setting be enhanced to support quality of life? If this is not possible, where does this person need to be and how can I ensure they get there?
- When a person is being moved to a new setting, what does the receiving provider need to know in order to maintain his/her quality of life?
- Have ambulance and other transport services been informed of the individual's end of life care status and any advance decisions?
- Can I be a resource to other members of the team involved in this person's care?

## Step 4

## Delivery of high quality care

### Case study:

#### Joint working with other professionals to adapt the home environment

Adaeze had been admitted to hospital following a fracture in her arm as a result of secondary bone cancer. Adaeze knew she was terminally ill and wished to be discharged home to continue her care there, but she lived alone and her flat was not suitable to accommodate the wheelchair she now relied upon to move around.

A social worker from the adult social care short-term urgent care team was responsible for facilitating discharge. She was able to liaise with hospital staff to arrange a safe discharge home which included providing basic equipment and care support, but a longer-term solution was needed to enable Adaeze to be cared for at home until her death.

The social worker promptly referred her to an occupational therapy (OT) colleague within the team for assessment and support. As this was a co-worker referral for someone nearing end of life, the referral was given priority status. The OT was able to quickly assess Adaeze's environment and needs and recommend a series of adaptations, including replacing the bath with a walk in shower, widening doorways to accommodate the wheelchair and installing a ramp. The OT also applied for a disabled facilities grant from the district council to cover the costs.

The social worker and OT continued to work jointly to ensure that any changing needs were assessed and addressed. As a result, Adaeze was able to stay in her usual place of residence in accordance with her preferences.

### Case study:

#### Implementing a care package to enable a person to die in their local care home

Jim lived in a dilapidated caravan and had been reluctant to engage with services. He had lived all his life in his village and didn't want to move from it. He had become estranged from his family and although he had several good friends on the caravan site, was largely reclusive and suspicious of new people.

When he was diagnosed with very advanced oesophageal cancer, it was felt that there were no treatment options for him – other than pain relief and supportive care. The problem was whether he could stay in his caravan, and if not where he would be able to receive care up to his death.

The social worker, from the adult social care older adults team, initially worked with Jim to try to find a solution that would enable him to stay in the caravan, and gradually gained his trust. The caravan had no electricity and relied for heating and cooking on a primus stove in the living room. There was running cold water, but the tap wasn't working properly and the roof in his bedroom had begun to leak.

Eventually it was clear that Jim was becoming much more poorly and needed 24 hour nursing care. There was a residential care home in the village but Jim's needs were becoming increasingly complex and health-oriented, and there were no nursing homes within 25 miles of his village. Jim became extremely distressed at the prospect of being moved far away.

However, the social worker worked with the district nurse team, continuing healthcare (CHC) and the local residential care home to provide a package of care around him so that he was able to die in the home. The social worker and district nurse worked with the care home management staff to support them as they cared for Jim, and CHC agreed to fund additional care to support the staff. District nurses and GPs visited very regularly to help him manage his symptoms and control pain and the care home staff were able to call on them whenever an issue arose.

As a result, Jim was able to die in the village where he'd been born and lived the whole of his life, cared for by people he'd known all his life. His friends from the caravan park were able to come and see him, and through them and the social worker he was reunited with his estranged daughter, whom he'd not seen for 20 years.

Jim's case raised several issues for adult social care regarding providing specialist care in a very rural setting, and highlighted the importance of locality working in these circumstances. This care was made possible by the system of patch-based locality working, as well as by the social worker's existing links to the GP and very strong collaborative working relationships with the district nurses and nursing home.

The reflection/debrief offered to the residential home staff raised questions for them about how difficult it had been to care for someone with palliative care needs, and prompted the managers to access the six-step palliative care training for residential homes run by the palliative care team.



## Step 4

## Delivery of high quality care



### Good practice example:

#### Helping people and families prepare for end of life

Members of the social work team attached to Princess Alice Hospice were keen to extend the support they could offer to people and their families in preparing for end of life. However, they found that people were often reluctant to make use of the hospice's day or inpatient services because they were afraid that this would cause distress to their families, especially their children or grandchildren.

The social workers convened a focus group session for people nearing end of life and their families to discuss their concerns. This led to a plan to organise a family day to introduce the hospice's services and help 'normalise' end of life care for families.

The event offered a range of creative activities and active games, complementary therapy sessions for carers as well as hospitality. The team were able to engage staff and volunteers from across all areas of the hospice's activities so that families were able to meet doctors, nurses, therapists, members of the chaplaincy team, chefs,

housekeepers, secretaries and fundraisers in a relaxed setting.

People and their families were able to experience the hospice as a place for living well rather than a place where people come to die. As a result, they felt more confident about using the hospice's services. They also appreciated the chance to spend time with other people in similar situations and several families remained in touch afterwards. For staff and volunteers the day provided a valuable source of team building.

The family day has since become an annual event. Other peer support groups have also been established including monthly sessions for women with secondary breast cancer and for bereaved families.

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## Step 5

## Care in the last days of life

Discussions  
as the  
end of life  
approaches

Assessment,  
care  
planning  
and review

Co-ordination  
of care

Delivery  
of high  
quality care  
in different  
settings

Care in the  
last days of  
life

Care after  
death

**A point comes when an individual enters the dying phase. For some this may appear to happen suddenly and without warning but for others it will be a more gradual process. Supporting the person to die well, with their dignity and choice respected, can make a huge difference to all involved and may reduce future bereavement support needs. This includes being able to live well and achieve desired goals, even in the very final stages of life.**

Sound assessment and care planning earlier on the care pathway can help in preparing for the last days, but needs may fluctuate unpredictably at this point: the person's health may deteriorate and rally repeatedly; preferences for care, such as Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) or preferred place of death, may also change rapidly.

It is particularly important that social workers liaise closely with health colleagues at this stage. Sometimes, for example if a person is in a specialist palliative care setting, the social worker may be called in for the first time at this stage, and will need to be able to rapidly assess and support both the individual and family.

The goals of care may change at this final stage, with a greater focus on comfort and peace. It is not always appropriate to rapidly escalate clinical intervention in response to deterioration in health. Rather, it may be appropriate to adjust the care package in the very final phase to avoid unwarranted interruption and intrusion at this stage, when time is precious.

Needs may also increase for the carers and family in the last days of life and the social worker is responsible for helping maintain their wellbeing. Families may need even more emotional support than the dying person at this final stage. Support may also include helping them manage practicalities such as getting children to school, most of which will not be covered by continuing healthcare arrangements.

Crises sometimes arise in the final stages because informal care and support from family members is suddenly withdrawn, perhaps because they are no longer able to cope or have become ill themselves. This can restrict choices and result in emergency decisions being taken, which do not



accord with the individual's preferences about where they wish to be cared for.

Yet with the right care, including 24/7 support or respite care, people may be able to avoid crises and make different choices; social workers often have an important contribution to make by arranging rapid access to this support.

Whatever the circumstances, the very final days of life are often a highly emotionally charged time for the dying person, their family and care providers. Social workers can play a crucial role in 'holding the space' around the individual and family and keeping the focus on maintaining quality of life right until the end.

## Step 5

## Care in the last days of life

### Top tips for social workers

- Avoid making assumptions about needs and wishes, including those expressed in formal care plans; check whether the individual's preferences have changed
- Needs may need to be reviewed frequently, sometimes more than daily, and information rapidly shared among those involved in providing care
- 'Be there and listen' – assess the wellbeing of individuals and their family and then ensure the right support is rapidly put in place
- Maintain the focus on the individual's quality of life in its widest sense, ensuring they and their family continue to have choices about care – this may also mean recognising that the goals of care may have changed and guarding against unnecessary intrusions and interventions that may address clinical needs at the expense of comfort and dignity
- Anticipate needs and issues wherever possible and prepare the individual and family for the dying phase – this includes informing and signposting the family so that they understand what to expect and what to do when the person dies, particularly if professional carers are unlikely to be in attendance
- Consider practicalities such as domestic arrangements and pet care, which may be important to the individual but are often overlooked
- Provide the individual and family with good written information, such as the Liverpool Care Pathway leaflet about dying (10)
- Anticipate and make provision for care after death, including considering the needs and safeguarding issues for vulnerable adults or children
- Where a person does not have friends or family around, ensure s/he has company during the dying phase if desired.



### Ask yourself

- Is this person on the electronic palliative care co-ordination system or register? Are they on the Liverpool Care Pathway?
- What are the person's wishes and preferences about their death? Have these changed since the most recent review?
- Is there a Preferred Priorities for Care (PPC) in place and what can I do to help achieve it?
- Are the individual and family still in control as much as they want to be and are they able to make informed choices about care in the final days?
- Are carers and family equipped and supported to cope? Has there been any change in the support available from carers and family that could result in a crisis?
- If hospital admission is being considered, is this the right intervention for the individual at this time? Would choices change if the right kind of support was available?
- Have the family been advised what to do in the event of deterioration? And what to do after death? Have carers/families been informed and helped to prepare for the final days?
- Who else needs to know that this person is in the last days of life – including personal and social contacts as well as professionals and services involved?
- Are there any requirements/preferences about how the body is cared for or what happens after death (e.g. donation of body to science) and have these been recorded as required?



## Step 5

## Care in the last days of life

### Top tips for managers

- Review funding arrangements regularly to ensure that they remain fit for purpose and enable rapid access to equipment and services in the final days of life
- Ensure your social workers are knowledgeable and trained with regards to cultural aspects in relation to body care
- Ensure your social workers are confident in how to ensure the individual's wishes take precedence over family concerns or pressures
- Ensure your social workers can rapidly access support for themselves, to help them support others at this highly charged time
- Ensure there are arrangements for social workers to share information with other professionals
- Develop clear protocols with Health colleagues to minimise changes to care (for example in formal carers) when funding responsibility shifts from social care to health
- Ensure that your social workers are facilitated in being able to be as responsive as possible to the changing needs of individual/family members
- Ensure that supervising managers are equipped to support the involved social worker.

### Ask yourself

- What feedback processes are in place to enable social workers to learn from what went well?
- Are their opportunities, preferably within the MDT, for lessons to be learned when final arrangements have not gone well?
- Do social workers and/or managers have authorisation to access and agree immediate changes to care needs at this final stage?
- What additional kinds of support will be required by the social worker to enable them to engage and manage effectively through this stage
- How is the social worker coping emotionally with managing the rapid deterioration of the person's health?
- Do I have the skills and capacity to support social workers in dealing with any difficult emotions that may surface for them as a result of their involvement in end of life care?

### Case study:

#### Creating a care package to enable a terminally ill person to spend time at home before dying

Andrew, 58, was a hospice resident as he entered the terminal phase of a rapidly deteriorating disease. He wished to return home to celebrate his birthday, sort out his affairs and say goodbye to family and friends. A single man, his elderly parents lived nearby and he was a popular neighbour.

Confidence in the care plan was key as high levels of support were required. A care plan was agreed by the social worker, district nurses, general practitioner and care agency, with a strong focus on multi-disciplinary working across health, social care and the domiciliary care agency.

Thanks to the provision of a seamless care package, Andrew was able to spend a week at home with his neighbours and family spending time with him, including



his brother, who lived abroad. He returned to the hospice to end his days, appreciative of the opportunity to put his affairs in order.

## Step 5

## Care in the last days of life

### Case study:

#### Crisis intervention in the final days of life

Paul, aged 75, was admitted to a surgical ward in a busy acute hospital for exploratory surgery, only to find that he had widespread disease. His condition deteriorated very quickly and it became clear that he was likely to die within days.

The busy ward team were unable to provide adequate palliative care; Paul became withdrawn and his family were angry and distressed that he had not been correctly diagnosed earlier and vented their frustration upon the medical and nursing staff on the ward.

Witnessing the escalating crisis, the social worker from the hospital's specialist palliative care team quickly intervened to help resolve it. Building on her existing working relationships, she was able to bypass the hospital's normal bed management system to get Paul transferred to a single room where he could be cared for in a more peaceful environment.

She then worked with the palliative care consultant and ward nurses to ensure Paul's symptoms were managed and that he was as comfortable as possible. Once the immediate care crisis had been resolved, she then spent time with Paul and family members individually and helped them to work through their anger and to talk to one another.



Family members felt that they had been listened to and that Paul himself was now being cared for as well as possible. This allowed the family to put aside their anger and to make the most of the remaining few days of his life.

### Case study:

#### Supporting people to make their own life choices as death approaches

Jackie was a 40 year old widow who had breast cancer. Her husband had died in an accident five years previously following which her two young children had been referred for therapeutic intervention because of disruptive behaviour at school.

Now in their teens, Jackie was fiercely protective of them and made every effort to keep social workers and other support services away. At times, this resulted in her failing to take advantage of treatments and support for herself – she attended the day hospice only once and often was out when home visits had been arranged.

As death neared, all the stops were pulled out for Jackie to enable her to live her life to the end as she

wanted. Against normal practice, when she was eventually admitted for hospice care her children were accommodated with her. Against all medical advice she took her children on a last trip to London and their place in the hospice was held open for them to return to.

For the most part Jackie remained hostile and defensive, although she did begin to trust the social worker who arranged the family accommodation in the hospice. The children also began to seek out other people to talk to about their fears. She died peacefully when her sister, who she had asked to look after her children, arrived and took them out to the cinema.

**Adapted and abridged from Holloway, M. (2007) *Negotiating Death in Contemporary Health and Social Care*, Bristol: Policy Press, p. 174. Reprinted with permission.**

## Step 6

## Care after death



**Good care does not stop at the point of death. Instead, the focus of care shifts to carers and families to help them cope with their loss. It remains important to offer choices and to understand what the carers and family would like to do for themselves.**

It is particularly important that care is sensitive and culturally appropriate – sometimes families may want more time alone with the body, for example. Carers and families also need to understand what needs to be done about drugs, equipment and, indeed, the body. For example, there are special arrangements about disposal of opiates.

The precise role of the social worker immediately after death will be different in each circumstance. Where s/he is the key worker, immediate responsibilities may include reviewing needs of any vulnerable third parties and helping with arrangements for the removal of the body.

It may also include managing withdrawal of support services (including their own support), which must also be handled sensitively: being contacted the morning after a death to arrange retrieval of equipment, for example, can be very painful as can receiving routine letters a few weeks later because the system has not been updated after a death.

If there are no family or friends to manage affairs, the social worker may be required to register the death and arrange the funeral and property protection. Sometimes, there may be concerns about care or about the death itself; here statutory duties to report will apply.

The most common need for social work support, however, arises from the ongoing needs of the bereaved relatives and friends. Sometimes the social worker may become involved for the first time with someone who is struggling with their loss – for example, an older person may become depressed and self-neglect after the death of a long-term partner. Sometimes a person they are already working with experiences a death of a loved one and their grief becomes the focus of intervention.

Social workers may also be involved in supporting vulnerable dependants. Many users of social work services are particularly vulnerable to loss and experience complicated grief. The social worker has an important role in continuing to listen and support when other professionals involved in end of life care have withdrawn.

At the same time, those who had cared for the person up until their death, a home carer, for example, may need support, including validation of their role. The social worker should also acknowledge his/her own feelings and draw on the team for support when needed.

## Top tips for managers

- Be aware when a person dies and ensure the social worker has the support that they need, including emotional support
- Ensure there are feedback mechanisms to identify what worked well and what could have been better; this may include identifying gaps in communication channels that could be addressed for the future.

### Ask yourself

- Do social workers have the knowledge and skills to support the family in coping with what happens after the death?
- If the case is not allocated, or the social worker is on leave, what processes are in place for sign off, to avoid continued correspondence or care bills?
- Does the social worker need to hold the case for a short time after the death to allow for appropriate 'endings'/withdrawal?
- Is there a follow-up process in place for sending condolence wishes?
- If the family invites the social worker to attend the funeral, what is the policy with regards to this and does the individual worker wish to attend?
- Are social workers advising as to the Tell us Once notification of a death service?



### Top tips for social workers

- Be prepared for what can happen after a death in order to be responsive as needs arise
- Provide written information to families such as the 'What to do after a death' leaflet (11)
- Inform families about what they may and may not do at this point in relation to the body and support them in their choices; some people may appreciate the social worker accompanying them to view the body
- Reassess carers/family needs and ensure the necessary support is in place; this may include informing and signposting to other sources of support. Consider safeguarding issues where there are vulnerable dependants
- Ensure consideration is given to all those who may be in need of support at this time; these may include people important to the individual as identified in the initial assessment
- Consider how to support those who may not be in the immediate geographical area; consider engaging with local services to support such people
- When in the role of keyworker, make follow-up contact and signpost to other support and bereavement services as well as yourself
- Ensure timely and sensitive withdrawal of services and equipment, this includes sensitive ending of your own and others' relationships with the carers/family, and ensuring that records and systems are updated following the death, e.g. through the Tell us Once notification of a death service
- Advise on arrangements for disposal of the body where required; this may include registering the death yourself if there are no family or friends to do it
- Report any concerns about care or the circumstances of death in line with statutory duties.



### Ask yourself

- What do carers and family need to know about what to expect after the death?
- What would the carers and family like to happen now?
- What were the individual's preferences about disposal of their body and have these been adhered to? To whom does the body now 'belong'?
- Who else needs to be informed of the death – personal and professional contacts?
- What are my responsibilities as the social worker if the person was without family or close friends?
- Do there appear to have been any concerns about the care or the manner of death?
- Are there any financial considerations in relation to funeral planning that need to be addressed?
- Have I paid attention to 'endings' with the carers/family?
- Do I or my colleagues need any support in dealing with the emotional impact of the death?

## Step 6

## Care after death



### Case study:

#### Providing bereavement support in complex family circumstances

Carol was referred to the community team attached to a hospice by the local social services care management team. The request was for bereavement support as Carol appeared to be struggling with bringing up her teenage granddaughter, Laura, since her husband's death some two years previously. Laura was the child of their daughter, Susan, born when Susan was herself only 16. The family had had no contact with Susan for many years.

Carol's health was poor and she was eventually diagnosed as being in renal failure. She was offered a kidney transplant operation but displayed great anxiety about this operation, being convinced that she would not survive it. Her social worker says that, with hind-sight, he wishes he had listened more to her fears, since the extent of her agitation - for which there was no rational basis - probably indicated some deeper discomfort.

In fact, Carol died of organ failure a day after the operation. In the middle of this crisis, as the social worker was trying to offer emotional and practical support to Laura, who was totally unprepared for this eventuality, Susan arrived on the scene.

Laura had no recollection of her mother, but Susan explained that she had tried many times over the years to see her daughter but had been prevented by her own mother from visiting. Susan took Laura home with her but within a few days she contacted the social worker, desperately wanting to talk about her feelings and informing him that Laura had run away.

The social worker began to work with Susan, who he recognised had experienced a very complicated double bereavement of both her parents (she had only just learned of the death of her father) as well as losing her daughter just when she thought she had regained her. It emerged that Susan had suffered abuse at the hands of her mother.

The social worker then engaged in a therapeutic relationship with Susan over a six month period. Only when she was ready to draw a line under the memories of abuse did she address her grief - for her parents and for the childhood which she wanted, and felt she had a right to. She then began to search for, and eventually to find, Laura.

**Adapted and abridged from Holloway, M. (2007) *Negotiating Death in Contemporary Health and Social Care*, Bristol: Policy Press, p. 171-2. Reprinted with permission.**

### Case study:

#### Supporting the individual and family up to and beyond the death, including care of vulnerable dependents

Paula was 24 years old and four months pregnant with her third child when she was diagnosed with cervical cancer. Her baby was delivered at 33 weeks and Paula continued to have chemotherapy, but when her daughter was three months old she was told that the treatment had not worked and she was terminal.

Paula lived with Dave and their two children as well as Paula's five year old daughter Lucy, of whom she had custody following her split from Lucy's father, Tom.

At the time the palliative care social worker became involved, Paula was reasonably able; she knew her condition was terminal and wanted to make plans for the children. She also wanted to make memory boxes and wanted support for Dave and also some help in telling her older daughter that she was going to die.

The social worker also negotiated with the school and education authority to appeal a decision to deny Lucy a place in the nearest school. She also kept contact with the school and informed them of Paula's condition.

Paula knew she would have to make legal provision for her daughter. At the time, Lucy spent two days a week with her father, Tom, but she did not like his new partner and felt upset when leaving her mother. Paula was shocked to discover that the father had checked his parental rights and had employed a solicitor to help him apply for a residence order for Lucy when Paula died. This added to Paula's stress as she did not want Lucy to be parted from Dave, her home and her younger siblings.

As Paula's health deteriorated, the social worker supported the whole family. She helped Paula to complete letters and items for the boxes for the three children and helped her explain to Lucy that she was going to die. She supported Paula's parents and sisters, who visited regularly, and took Dave away for a coffee when he needed a break. She also helped negotiate with the family some private time for Dave and Paula to be alone together when the end was near.

Paula died at home with her family and friends. The children were at home right up until her last day, until it was decided they should go to a relative and Lucy to her father's. The children did not see her after death, but they did attend her funeral, as did the social worker. The social worker informed the school of Paula's death as no one in the family had felt able to do this.

As Paula's death had come quite quickly at the end, no firm arrangements had been made for Lucy and her



father was determined to have her come to live with him. The social worker was now asked by Dave and his family to help facilitate a meeting between all parties involved including Lucy's father and his own parents. She agreed but also explained that disputed cases of residence are dealt with by the Child and Family Court Advisory and Support Services (CAFCASS).

New residence arrangements were eventually agreed, which still left Lucy with Dave and her siblings for the majority of the time but increased the time she spent with her father, Tom. However, after a year or so Tom decided he wanted to keep Lucy and he refused to return her to Dave. Before the case could be returned to court, however, this new arrangement also broke down, and Tom abandoned Lucy at her maternal grandparents' house.

As a result, Lucy developed significant problems with trust and displayed behavioural problems at school. The social worker from the Family Support Team has continued to provide Lucy and her family with support, much of which has been ongoing bereavement support to help them adjust to their loss. As a result, Lucy's behavioural problems are gradually decreasing.



## Key messages

Social workers have the skills to work with people approaching the end of life and their families and carers; they have a particular contribution to make in maintaining a focus on the dying person in their family, community and cultural context.

Social work support may begin at any stage in the end of life care pathway. Often the social worker is already involved with the person or their family and may be the first professional to recognise that the person is in need of end of life care.

It is important for the managers of social workers to validate and support their social workers in engaging with the end of life care needs of service users; this includes facilitating access to end of life care training, resources and systems.

Specialist palliative care social workers can offer a valuable resource to social workers in other settings through consultation, education and training, as well as receiving referrals as appropriate.





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## Further resources

### Quality standard on end of life care for adults

National Institute for Health and Clinical Excellence, 2011  
[www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp](http://www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp)

### TEST: Supporting people to live and die well

National end of Life Care Programme (NEoLCP), 2012  
[www.endoflifecareforadults.nhs.uk/publications/test](http://www.endoflifecareforadults.nhs.uk/publications/test)

### End of life care resource

Social Care Institute for Excellence  
[www.scie.org.uk/adults/endoflifecare/index.asp](http://www.scie.org.uk/adults/endoflifecare/index.asp)

### Developing end of life care practice

NEoLCP/Skills for Health/Skills for Care, revised 2012  
[www.endoflifecareforadults.nhs.uk/publications/corecompetencesframework](http://www.endoflifecareforadults.nhs.uk/publications/corecompetencesframework)

### e-ELCA e-learning

NEoLCP/Department of Health/e-Learning for Healthcare  
[www.e-lfh.org.uk/projects/e-elca/index.html](http://www.e-lfh.org.uk/projects/e-elca/index.html)

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[www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm](http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm)

### Mental Capacity Act (MCA) resource

Social Care Institute for Excellence  
[www.scie.org.uk/publications/mca/index.asp](http://www.scie.org.uk/publications/mca/index.asp)

### Capacity, care planning and advance care planning in life limiting illness

NEoLCP, 2011  
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### Best interests at the end of life: practical guidance for best interests decision making and care planning at end of life

East Lancashire PCT/Central Lancashire PCT, 2008  
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Mencap, 2008  
[www.mencap.org.uk/page.asp?id=9753](http://www.mencap.org.uk/page.asp?id=9753)

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### Planning for your future care

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NEoLCP, revised 2007  
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### Making a will

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### Can you see me? (DVD)

National Council for Palliative Care, 2010  
<https://www.committedgiving.uk.net/ncpc/publications/Product.aspx?id=339>

### National information standard (ISB 1580) on end of life care co-ordination: core content

Department of Health / NEoLCP  
<http://tinyurl.com/eolc-information-standard>

## Further resources

### Useful websites

#### National End of Life Care Programme

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

#### National End of Life Care Intelligence Network

[www.endoflifecare-intelligence.org.uk](http://www.endoflifecare-intelligence.org.uk)

#### Admiral Nurses

[www.dementiauk.org/what-we-do/admiral-nurses/](http://www.dementiauk.org/what-we-do/admiral-nurses/)

#### Cruse Bereavement Care

[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

#### Gold Standards Framework (GSF)

[www.goldstandardsframework.org.uk](http://www.goldstandardsframework.org.uk)

#### Help the Hospices

[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

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# Glossary

The following glossary sets out definitions for terms used in this route to success publication, gathered from a range of sources. The glossary is a work in progress: usage of these terms varies widely and may change over time. The National End of Life Care Programme welcomes feedback, comments and suggestions on the glossary via its website.

Advance care planning	The process of identifying future individual wishes and care preferences. This may or may not result in recording these discussions in the form of an Advance Care Plan.
Advocacy	Taking action to help people to say what they want, securing their rights, representing their interests and obtaining services they need. May be provided by a person/organisation independent of the services being provided.
BME	Black and minority ethnic.
Care pathway	Specifies treatment and care for a given condition based on nationally agreed guidelines, standards and protocols incorporating best practice and evidence-based guidelines. Care pathways, which map out the care journey an individual can expect, are multi-professional; cross-organisational boundaries; and can act as a prompt for care. They provide a consistent standard of documentation that also provides the basis for ongoing audit.
Carers	The family or friends who take on, in an unpaid capacity, some or all of the responsibility for the care and support of the individual.
Domiciliary care	Care services provided to an individual in their own home by a care worker paid to provide care as part of their employment. Also known as home care.
EPaCCS	Electronic palliative care co-ordination systems, also known as end of life locality registers. These enable key information about an individual and their decisions to be recorded and shared by professionals involved in their care.
End of life care	All elements of support to people approaching the end of their lives. In addition to the highly skilled and focused care and support that may be provided by those working as palliative care specialists, all of the other significant support that is given needs to take on a different focus and perspective to accommodate this stage of life. It encompasses the management of all symptoms including pain, and provides psychological, social, spiritual and practical support.
End of life care for all (e-ELCA)	A e-learning programme providing national, quality assured online training content in end of life care for the social and health care professions.
Fair Access to Care Services (FACs)	A system for deciding how much support people with social care needs can expect, to help them cope and keep them fit and well. It applies to all the local authorities in England and aims to help social care workers make fair and consistent decisions about the level of support needed, and whether the local council should pay for this.
Gold Standard Framework (GSF)	A systematic evidence based approach to optimising the care for people nearing the end of life delivered by generalist providers, which aims to improve the quality, coordination and organisation of care in primary care, care homes and acute hospitals.
Independent Mental Capacity Advocate (IMCA)	A new role created by the Mental Capacity Act 2005. A local council or NHS body has a duty to involve an IMCA when a vulnerable person who lacks mental capacity needs to make a decision about serious medical treatment, or an accommodation move.
Liverpool Care Pathway (LCP)	An integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life. It is recommended as a best practice model, most recently, by the Department of Health in the UK.



Palliative care	An approach that improves the quality of life of people and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Personalisation	Involves putting the outcomes that people want to achieve at the centre of assessment, planning, implementation and reviews. The aim is to promote the individual's wishes about the outcomes they are aiming to achieve, and the solutions that best fit how they want to maximise their independence, promote their dignity and wellbeing. These may include better access to universal services. A second component of personalisation is an emphasis on early intervention and prevention to reduce or delay the need for social care support, and providing information and advice for people who are not eligible for publicly funded social care support.
Preferred Priorities for Care (PPC)	The PPC document is designed to help people prepare for the future. It gives them an opportunity to think about, talk about and write down their preferences and priorities for care at the end of life.
Safeguarding	A range of activity aimed at upholding an adult's fundamental right to be safe. It is of particular importance for people who, because of their situation or circumstances, are unable to keep themselves safe.
Safeguarding of Vulnerable Adults (SOVA)	Term used to refer to procedures put in place to safeguard (see above) adults made vulnerable by physical or mental impairment or health problem or frailty.
Tell us Once	Service provided by local authorities which helps people tell the government just once about a death.
Surprise question	"Would you be surprised if this person were to die within the next year?" The question was originally devised by Prof Joanne Lynn and is part of prognostic indicator guidance within the Gold Standard Framework.

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