

Common Core Principles

and competences for
social care and health
workers working with
adults at the end of life



Common core principles and competences for social care and health workers working with people at the end of life
2nd edition

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Introduction



People nearing the end of their life often need specialist care and support that is provided by experts working in the field. Increasingly though, people working in social care and health who are not specialists in this area find themselves working with people who are dying. This document, while relevant for everyone, is aimed at those non specialist workers.¹ It sets out the principles for working with adults at the end of their life, and describes the underpinning competences, knowledge and values they should have. Used alongside occupation-specific guidance, these ‘common core principles’ form a framework to guide managers and workers, helping to define the additional knowledge and competences needed when supporting someone who is dying.



1. The majority of these workers will be from health and social care organisations, but many other people may be included, such as faith leaders, community workers, or people working in housing or education.

The principles

1. Care and support is planned and delivered in a person-centred way, with the person's priorities, including spiritual, emotional and cultural needs, guiding all decisions and actions.
2. Communication is straightforward, appropriate and timely, and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers². Communication reflects an understanding of, and respect for, the person's cultural and spiritual needs.
3. End of life care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the person, rather than being service-led. Workers maintain ongoing communication so that care and support is properly co-ordinated and responsive to changing circumstances and priorities.
4. Good, clear and straightforward information is provided to the person and their carers.
5. Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of people at the end of life, and their carers. Forward planning, including advance care planning, facilitates well-coordinated, planned and organised care and support.
6. The needs and rights of carers are recognised and acted upon. Carers are offered support both while caring, and during bereavement. Employers recognise the ways in which workers are affected while caring for someone who is dying, and provide appropriate guidance and support.
7. Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of life. Workers are encouraged to take responsibility for their own learning.



The competences, underpinning values and knowledge

Communication	Assessment and care planning	Advance care planning	Symptom management, maintaining comfort and wellbeing	Occupation-specific requirements [not described in this document]
Underpinning values and knowledge				

2. 'Carer' is used throughout to refer to family and friends who provide social care support, as distinct from social care, health or community workers or volunteers.

Using this document



In addition to guiding workforce development practitioners, this document is a framework for people engaged in managing, commissioning and delivering end of life care and support. Using it will help to equip workers, particularly those whose main role is not necessarily working with people at the end of life, to be competent and feel confident in working in this area.

It can be used in a number of ways:

- By leaders and strategic managers as they develop new services and transform approaches to care and support for people at the end of life. It can be used to help in thinking about new roles, as well as ensuring that learning and development requirements are incorporated into plans for transforming or developing services.
- As a checklist for commissioners when developing, purchasing and monitoring end of life care and support.
- As a checklist for people purchasing their own care and support, to help ensure that care and health workers have the skills, knowledge and values that will ensure that the care and support received is in accord with the principles.
- Workforce development leads can use it to ensure practitioners have the necessary knowledge, support and supervision to work confidently and competently with people at the end of life.
- Supervisors and managers can use it to inform supervision, checking the competences against personal development plans, and making sure supervisees are properly supported.
- Practitioners can use it to help them think about their continuing professional development (CPD) needs, as well as using it as a learning tool in itself.



The common core principles

Principle 1

Care and support is planned and delivered in a person-centred way with the person's priorities, including spiritual, emotional and cultural needs, guiding all decisions and actions.

The person is the focal point of all assessment, care planning and delivery; their wishes, beliefs and priorities are paramount in all decision making. Practice is based upon a person-centred, social model of health and disability, and is informed by the principles of respect, dignity, choice and independence. These values mean a shift from professionals knowing best to workers supporting and empowering people to be in control of their own needs and wishes, including the right to change their mind about what they want.

The significance of cultural diversity, including the impact of any faith, beliefs, religion, and of lifestyle, acknowledging the person's right to make their own decisions, is recognised. The importance of spirituality and meeting people's spiritual needs³ is understood, including the impact of diagnosis and prognosis on the person.

People are encouraged and supported to make decisions based on their experience of their needs, utilizing appropriate professional support and guidance.

People are supported in identifying and managing risk proportionately and realistically, and have an understanding of the notion of informed consent, best interest and advance decision to refuse treatment.



3. Spiritual needs are not defined here as they vary in nature from person to person. However, it is noted that spiritual needs are not the sole preserve of those with a religious faith or adherence, but will be important to many others, too.

Principle 2

Communication is straightforward, appropriate and timely and is delivered sensitively, taking account of the circumstances, needs and abilities of the person and their carers. Communication reflects an understanding of, and respect for, the person's cultural and spiritual needs.

Communication is appropriate to the circumstances and needs of the person, recognising the range of factors, such as dementia, learning disability, illness or emotional state, which have an impact on communication.

Workers are knowledgeable about how religious or cultural customs and beliefs, or their absence, may impact upon ways of communicating.

Listening skills are used to recognise cues from people and their carers, and open questions are used to them all to express themselves freely if they wish to.

Workers recognise the changing ability and desires of the person, their family and friends to communicate, and adapt their own communication style accordingly.

Where children and young people are among the family and friends, workers are aware of the significance of child development to communication and to ways of coping with loss and bereavement.

Communication and relationship skills are used to enable, encourage and support people to express their preferences, concerns and needs alongside their strengths and abilities.

Good communication is used to ensure that end of life care plans, including advance care plans (ACPs), are clearly understood and shared by everyone involved in their planning and delivery, including the person and their carers.



Principle 3

End of life care is provided through integrated working, with practitioners collaborating to ensure seamless care and support at the point of delivery. Needs are met in ways that are appropriate to the person, rather than being service-led. Workers maintain ongoing communication so that care and support is properly co-ordinated and responsive to changing circumstances and priorities.

Workers have a good understanding of, and respect for, the services provided by their colleagues in other disciplines, and work in partnership with them to meet the needs of the person, their family and friends.

Care and support are delivered in a co-ordinated way and information is shared in a timely and appropriate manner, recognising the range of communication needs and requirements of people, their families and friends, including children and young people.

People are seen within the context of their own communities, being supported to continue to participate in and contribute to them as they wish.

Networks and partnerships are used to identify resources, information and support systems that will benefit people, their families and friends.



Principle 4

Good, clear and straightforward information is provided to people and their carers.

People and their carers are aware of the range of options and resources available to them, how they may be accessed, and any potential risks or benefits. They are able to use this information to enable them to contribute to the development and delivery of care to support their chosen end of life pathway, and in developing, where appropriate, advance care plans.

People and carers have a named person whom they can contact if they require clarification or advice about any aspect of their care and support.

Information about any relevant illness, its prognosis and any other related factors is shared clearly, sensitively and appropriately. Where a worker is unable to answer questions, (either immediately or by seeking further information themselves) the person is clearly signposted to someone who can.

Workers have awareness and understanding of the significance of legal frameworks around end of life care and advance care planning, and are able to share this information with others as appropriate to their role.



Principle 5

Regular reviews and effective communication ensure that care and support is responsive to the needs and changing circumstances of people, and their carers. Forward planning, including advance care planning, facilitates well-coordinated, organised and delivered care and support.

Care is organised around the needs and circumstances of the person, and is delivered in a co-ordinated manner across services. It is delivered in a way that demonstrates respect for the person, their family and friends, maintaining their dignity at all times. Workers are sensitive to circumstances and their changing nature, and care is delivered accordingly.

Workers support families and friends to take on caring responsibilities where that is desired, but recognise and accept that they may choose not to undertake this role. The rights of carers to be assessed have been strengthened with the introduction of the Care Act in April 2015. Within the Care Act, there is a new single duty for local authorities to undertake a carer's assessment based on whether a carer may appear to have needs for support, either currently or in the future. Carers will be entitled to services and support where their needs meet the national eligibility criteria.

Where conflict arises between the person, their family and friends about the chosen end of life pathway, or advance care plan, the worker is able to work sensitively, and as appropriate to their role, with all parties, to work towards a resolution. This may involve contacting mediation or advocacy services in highly complex situations.

The concerns, fear and anxieties of people, their families and friends are recognised and responded to.



Principle 6

The needs and rights of carers are recognised and acted upon. Carers are offered support both while caring and during bereavement. Employers recognise the ways in which workers are affected while caring for someone who is dying, and provide appropriate guidance and support.

Workers are aware of the impact that age, culture, religion or belief, ability and other factors may have on a person's response to grief, loss and bereavement, and recognise that the importance of spiritual support will vary from person to person. It may also differ between the person and their family or friends.

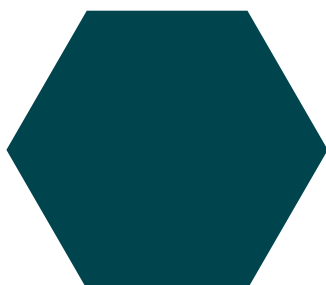
Workers are aware of the impact the person's death and dying will have on those closest to them, and are able to offer appropriate advice, information and support. The worker is able to make referrals to other networks or organisations to ensure that those affected receive the information, care and support they need, when they need it, including after the person's death.

Workers recognise the support needs of those who have chosen to take on a caring role, and take steps to ensure these are met, including undertaking or facilitating carers assessments.

Workers recognise that the responses of children and young people affected by the death of someone close to them may be different from those of adults, and find ways to ensure that their needs are met.

Workers are able to give support to, and receive support from, colleagues, and are able to make links to more structured support where needed.

Employers recognise the potential emotional impact of dying and death upon workers, and have appropriate systems and resources in place to provide support.



Principle 7

Employers provide appropriate learning and development opportunities for workers to ensure that they are properly equipped to work with people at the end of life. Workers are encouraged to take responsibility for their own learning.

Employers are aware of the ways in which adults learn, and the cultures in which they learn best, and ensure that workers are supported in developing their skills and confidence when working with people who are dying and their families and friends. They recognise the link between a well-trained workforce, an open approach to organisational learning, and excellence in the care and support they provide.

Workers recognise that effective work with people depends upon well-developed knowledge and skills and appropriate attitudes. Good use is made of supervision and other learning and development opportunities to reflect on practice and identify end of life care learning needs. They recognise the limitations of their own practice, seeking support when appropriate.

Workers recognise the importance of all members of the workforce, providing help, support and guidance to each other.

Skills for Care has developed end of life care qualifications in conjunction with a wide range of employers to equip workers to not only recognise end of life situations but to manage them more effectively. They are aimed at all learners in social care and health with an interest in end of life care and also build on these common core competences and principles for end of life care.

To find out more about the end of life care qualifications, visit the Skills for Care website www.skillsforcare.org.uk/endoflifecare.



Competences, underpinning values and knowledge



1. Competences

1.1 Communication skills

Communication is at the heart of every aspect of end of life care. It is important that all workers feel able to talk to people about the things that matter to them, and are knowledgeable about who else to involve if they are unable to deal with any concerns or questions from people or their carers.

Competences

- a. Communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.
- b. Develop and maintain communication with people about difficult and complex matters or situations related to end of life care.
- c. Present information in a range of formats, including written and verbal, as appropriate to the circumstances.
- d. Listen to people, their families and friends about their concerns related to the end of life and provide information and support.
- e. Work with people, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of death, dying and bereavement, and recognising that their priorities and ability to communicate may vary over time.
- f. Work with colleagues to share information appropriately, taking account of issues of confidentiality, to ensure that people receive the best possible care. Ensure that information is clear, and non-jargonistic, so that it can be fully understood by others.

1.2 Assessment and care planning

Assessment is the process of identifying the strengths, needs, wants, and aspirations of people. In end of life care, assessment and care planning (sometimes called support planning) is likely to include medical therapeutic interventions alongside meeting the person's other needs (such as social aspirations, spiritual or religious needs, and interests).

Some assessment is formal, using tools or forms, but much assessment takes place informally, during conversations. It is important that information gathered in this way is still included in care plans, and shared appropriately.

All care planning should be person-centred, with the person always at the heart of any care or support.

Listening to people and their carers, and encouraging them to participate in discussions and decision-making helps to ensure that plans meet their needs as they see them.

Care plans relate to the present and the future, and should be regularly reviewed to meet changing needs, circumstances or priorities. They are not the same as 'advance care plans' (ACPs) which are discussed in 1.4, and are plans made by the person to be acted upon at a later stage to guide care if they have lost capacity. If a person no longer has capacity to make decisions about their care, the ACP may be used by those closest to them to guide decisions about care, including treatment. If a person lacks the capacity to make decisions, the processes required by the Mental Capacity Act (2005) should be followed to ensure that the person's best interests are pursued.

In some situations, where a carer provides a high proportion of the person's care, a carers' assessment should be undertaken; this is the responsibility of the local authority.

Assessment and care planning are ongoing processes, incorporated in a cyclical process that includes the delivery of the plan (see symptom management, maintaining comfort and wellbeing).



The cycle of care and support: assessing needs and providing care and support

Competences

- a. Work in a person-centred way, listening to and taking account of the wishes of the person and their carers. Recognise people as experts in their own lives.
- b. Understand the range of assessment tools and ways of gathering information including conversation, and know their advantages and disadvantages.
- c. Assess pain and other symptoms in ways appropriate to your role, including using assessment tools, pain history, appropriate physical examination and relevant investigation. Know when to refer concerns to specialist colleagues.
- d. Undertake/contribute to multi-disciplinary assessment and information sharing, including speaking to colleagues as part of the assessment process, and ensuring that where information is already available, the person is not asked to provide the same information repeatedly.
- e. Ensure that all assessments are holistic, including:
 - background information about the person's life
 - personal strengths, aspirations and priorities
 - religious or other belief, cultural and lifestyle factors
 - current physical health and prognosis, including underlying health or other conditions
 - social, occupational, psychological, emotional and spiritual wellbeing
 - risk and risk management.
- f. Ensure that the needs of carers, including children and young people, are taken into account and that carer support and, where appropriate, assessment are offered.
- g. In partnership with others, review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly shared

1.3 Symptom management, maintaining comfort and wellbeing

At the end of their life, people often need specialist care and support to manage the symptoms of illness. However, keeping people comfortable, and ensuring that their needs, and the needs of their carers, are attended to, encompasses far more than this. Every worker has a part to play, and working together can have a significant impact, making sure that specialist input is provided when needed, but that people's daily lives are also comfortable and managed in ways they have chosen.

Competences

- a. Be aware that symptoms have many causes, including the illness itself, its treatment, any concurrent disorders, depression or anxiety, or other psychological or practical issues. Understand that different causes may require different approaches to treatment, care or support.
- b. Recognise the importance of holistic understanding of the person's perception of their symptoms and how these impact upon their life.

- c. Be aware of the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support.
- d. In partnership with others, including the person and their carers, develop an end of life care plan which balances disease-specific treatment with care and support that meets the needs and wishes of the person.
- e. Know when a person requires specialist support and ensure that appropriate practitioners are informed.
- f. Ensure that any plan is regularly reviewed and updated to meet changing needs, wishes and priorities, including managing pain and other symptoms.

1.4. Advance care planning

An advance care plan (often called ACP) is a very specific kind of plan. It is drawn up with the person and their carers if that is appropriate, for use only if the person is no longer able to speak for themselves. In the plan the person may talk about the kinds of treatment, if any, they wish to be given, or they may talk about how they want to be treated as they die, for example following their religious or cultural beliefs. The plan can be amended by the person at any time they wish. The plan may be recorded in any format that the person wishes; for example, it could be a video.

If a situation arises where the person cannot say what they want, what they have said in the plan is used to make decisions on their behalf. It is therefore important that anyone who may find themselves in that position is aware of the plan and what it says. For example, some people make it very clear that they do not wish to be admitted to hospital at the end of their life, and want to be able to die at home.

Competences

- a. Demonstrate awareness and understanding of advance care planning, and the times at which it would be appropriate.
- b. Demonstrate awareness and understanding of the legal status and implications of the advance care planning process in accordance with the provisions of the Mental Capacity Act 2005.
- c. Show understanding of informed consent, and demonstrate the ability to give sufficient information in an appropriate manner.
- d. Use effective, sensitive communication skills when having advance care planning discussions as part of ongoing assessment and intervention.
- e. Work sensitively with families and friends to support them as the person decides upon their preferences and wishes during the advance care planning process.
- f. Where appropriate, ensure that the wishes of the person, as described in an advance care planning statement, are shared (with permission) with other workers.
- g. When appropriate, know what the advance care planning statement contains, and how this will impact upon a person's care and support.

2. Underpinning values

- a. Person-centred practice that recognises the circumstances, concerns, goals, beliefs and cultures of the person, their family and friends, and acknowledges the significance of spiritual, emotional and religious support.
- b. Practice that keeps the person at the centre of multi-agency integrated care and support.
- c. Practice that is sensitive to the support needs of family and friends, including children and young people, both as part of end of life care, and following bereavement.
- d. Awareness of the importance of contributing to the ongoing improvement of care and support, participating as appropriate in evaluation and development, and of involving the people receiving care and support in that process.
- e. Taking responsibility for one's own learning and continuing professional development, and contributing to the learning of others.

3. Knowledge

- a. Your own professional role and boundaries.
- b. The roles of other practitioners you are working with.
- c. Professional codes of practice or conduct, including the range of common core principles, and their impact on practice.
- d. Relevant legislation and guidance, for example the Mental Capacity Act (2005) and the Mental Health Act (2007) as they relate to end of life care.
- e. The impact of your own beliefs on your practice.
- f. Approaches to risk assessment, risk management and risk taking.
- g. Approaches to and theories of change, loss and bereavement.
- h. Social models of care, and person-centred approaches.



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