

Draft for Consultation (October 2016)

# End of Life Care Core Skills Education and Training Framework

This framework was commissioned and funded by Health Education England and developed in collaboration with Skills for Health and Skills for Care.



## Acknowledgements

To be completed... e.g. to include a list of all organisations represented on the steering group...

DRAFT

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# Foreword

To be completed...

## Introduction

### Background

Health Education England commissioned Skills for Health and Skills for Care to expand on the *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life (2014)* into this Core Skills Education and Training Framework for End of Life Care. This framework has been developed to align with the current Dementia, Mental health and Learning Disabilities Frameworks all of which will sit under the overarching framework for person centred care. In particular, it aims to promote community development and asset-based approaches to education and training.

Development of this framework sits as part of Health Education England's overall strategic approach to end of life care which includes coordinated and shared work by:

- Health Education England Local Offices;
- NHS Employers identifying best practice on end of life care through showcasing impactful employer strategies;
- The National Council for Palliative Care exploring the conditions necessary for a successful community development/asset based approach to education and training, and approaches to CPD training of staff;
- The National Council for Palliative Care exploring the conditions necessary for a successful community development/ asset based approach in education and training.

Health Education England is also an active member of all the national end of life care work streams.

### End of Life Care

For the purpose of this framework, those approaching 'end of life' refers to adults who likely to die within the next 12 months (approximately). This includes:

- Those whose death is expected within days or hours, including acute conditions caused by sudden catastrophic events
- Those with advanced, progressive or incurable conditions
- Those at risk of dying from an acute crisis associated with an existing condition

Adapted from '[Treatment and care towards the end of life: good practice in decision making](#)', (General Medical Council, 2013').

'End of life care' refers to care that...

'...helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'

Source: '[Ten questions to ask if you are scrutinising end of life care for adults](#)' (National Council for Palliative Care, 2006)

For the purpose of this framework, 'end of life care' includes the care and support provided by professionals, as well as that provided by friends, family and other members of the community.

A general awareness of end of life care underpins all other subjects within this Framework. Everyone will receive end of life care; most people will support a loved one through end of life care. All people working in health and care are likely to care for someone at end of life and others choose a career in providing this care. Providing end of life care can be rewarding but it is important to understand the different roles and the support available, otherwise it can be emotionally, psychologically and physically tiring.

As someone receiving care or supporting a loved one, knowing what to expect from the professionals around you can reduce anxiety and improve your experience. As a health or social care worker, understanding the context of end of life care will support you delivering person-centred in the best way possible.

The effort and drive to improve the quality of end of life care has led to refreshed and updated government strategy and policy across all four nations, as well as numerous publications in the form of research, resources, plans, guidance, standards and recommendations. Examples of these documents can be found in the Appendix 1 and 2, as well as within each subject area.

The current English strategy *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*, presents six ambitions and what is needed to realise these ambitions. These ambitions underpin much of this Framework and are the driving force for current innovation and initiatives in end of life care.

- 1) Each person is seen as individual
- 2) Each person gets fair access to care
- 3) Maximising comfort and wellbeing
- 4) Care is coordinated
- 5) All staff are prepared to care
- 6) Each community is prepared to help

## Underpinning values

The following values underpin all the subjects in this framework:

- 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

(Ref: *Skills for Care & Skill for Health 2014, Common Core Principles and competencies for social care and health workers working with adults at the end of life*)

[The Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England](#) sets the standard of conduct expected of all adult social care workers and healthcare support workers in England.

It helps workers provide high quality, safe and compassionate care and support and outlines the behaviours and attitudes that people who use care and support should rightly expect.

The '6Cs', which underpin the new [Leading Change, Adding Value](#) framework, were developed as a way of articulating the values which need to underpin the culture and practise of organisations delivering care and support. These are immediately identifiable as values which also underpin quality social care provision.

## Scope of the framework

The framework will be applicable to health and social care employers, employees, patients, carers, the community, public and also to educational organisations which train students who will subsequently be employed in the health and social care workforce.

The framework aims to describe **core** knowledge and skills i.e. that which is common and transferable across different types of service provision. Specialist or organisation specific skills and knowledge are outside the scope of the framework. Additional learning outcomes may be locally determined to meet education and training needs in specific settings for example according to local context, risk assessment or policy.

The core knowledge and skills described in the framework are therefore defined at 3 tiers:

**Tier 1** those that require general end of life care awareness, focusing on a community development, asset based approach to care

This tier outlines the knowledge and skills that will support people accessing end of life care, as well as their family, friends and carers, to ensure they are making the most of the support on offer and are able to plan effectively for their own current and future care needs. This tier is also relevant to those working in health and social care who have infrequent contact with individuals approaching the end of life.

A community development, asset based approach to care encourages individuals to look beyond traditional care provision and also consider what is important to them and how the people within their community and social networks could support them to achieve these goals.

For example:

- Individuals accessing end of life care services
- Families, carers and friends of those accessing end of life care services
- Ancillary health and social care workers – receptionists, gardeners, cleaners, administrators
- General public
- Religious leaders

**Tier 2** those in roles that will have some regular contact with people receiving end of life care

For example:

- Healthcare assistants/Care workers
- General Practitioners
- Doctors (not specialising in end of life care)
- Occupational Therapists
- Nurses
- Social Workers

- Leaders of certain community groups

Tier 3 those in roles which frequently involve providing end of life care

For example:

- Healthcare assistants/Care workers in end of life care services
- Doctors specialising in end of life care
- Occupational Therapists working in end of life care services
- Nurses working in end of life care services
- Social Workers working in end of life care services

## Development of the framework

Development of the framework was guided by a steering group comprising representatives of key stakeholders, including health, social care and education sector organisations. A reference group was also established to include a wider range of organisations and individuals that wished to be kept up-to-date on development of the framework and to provide comments or feedback as part of the consultation process. As part of the consultation process employers, employees, patients, carers, the community, public were specifically included through an open online consultation which ran [to be completed]

The first phase of the project focussed on desk research to identify and review existing resources, leading to production of a literature review at the end of June 2016. Subsequent development of the framework was based on the findings of the literature review, consultation with the steering group and the findings of an online consultation [to be completed]. Key references which informed the development of the framework are presented in Appendix 4. In particular, the framework builds upon recent previous activity to develop standards, principles and competence frameworks for end of life care including:

- Skills for Care & Skills for Health (2014): Common core principles and competences for social care and health workers working with adults at the end of life
- Leadership Alliance for the Care of Dying People (2014): One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life
- National Palliative and End of Life Care Partnership (2015): Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020
- National Voice and National Council for Palliative Care (2015): Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations
- HE Kent, Surrey and Sussex: End of Life Care Competency Framework
- Health Education England Yorkshire and the Humber End of Life Care Learning Outcomes for Unregistered Support Workers, Pre-qualifying students, Registered Professionals in Health and Social Care providing general and specialist palliative care, HEE (V. Taylor, 2016)
- HE East Midlands Education Standards.

NB. This framework also builds upon and will supersede the previous guide:

Skills for Care, Skills for Health & National End of Life Care Programme (2012): *Developing end of life care practice: A guide to workforce development to support social care and health workers to apply the common core principles and competences for end of life care.*

## How to use the framework

### Structure of the framework

The framework is presented in 15 subjects - each subject comprises:

- an introduction
- suggested target audience
- key learning outcomes
- links to relevant guidance and/or legislation
- links to relevant national standards, frameworks and qualifications.

Appendices include

- sources of further guidance
- glossary of terms

The subjects are numbered (1 to 15) for ease of reference. This does not indicate a prescribed process or subject hierarchy; relevant subjects can be selected from the framework as required.

Within each subject, the learning outcomes are presented for relevant tiers. The learning outcomes are intended to provide a clear focus on what a learner should know, understand or be able to do following completion of any learning activity.

The framework is incremental i.e. tiers 2 and 3 assume that learners possess the skills and knowledge at preceding levels (to minimise unnecessary repetition).



## Summary of framework subjects and the relevant target audience

Subject	Target audience		
	Tier 1	Tier 2	Tier 3
Subject 1: Person-centred end of life care	●	●	●
Subject 2: Communication in end of life care	●	●	●
Subject 3: Equality, diversity and inclusion in end of life care	●	●	●
Subject 4: Community skills development in end of life care	●	●	●
Subject 5: Support for the individual in relation to feelings associated with approaching the end of life	●	●	●
Subject 6: Promoting health and wellbeing for individuals at the end of life	●	●	●
Subject 7: Assessment and care planning for individuals, their family and carers	●	●	●
Subject 8: Symptom management in end of life care	●	●	●
Subject 9: Working in partnership with other professionals	●	●	●
Subject 10: Support for family and carers	●	●	●
Subject 11: Maintain own health and wellbeing when caring for someone at the end of life	●	●	●
Subject 12: Caring for a deceased individual	●	●	●
Subject 13: Law, ethics and safeguarding	●	●	●
Subject 14: Leading end of life care services and organisations		●	●
Subject 15: Improving quality in end of life care through policy, evidence and reflective practice	●	●	●

### Key

● = Target audience for each subject

## How the framework can support you

The framework will be applicable to health and social care employers, employees, patients, the community, public and also to educational organisations which train students who will frequently be employed in the health and social care workforce. Use of the framework will support organisations to:

- standardise the interpretation of end of life care education and training
- guide the focus and aims of end of life care education and training delivery
- ensure the educational relevance of end of life care training
- improve the quality and consistency of education and training provision.

The framework also supports the assessment of competence, training needs analysis and provision of minimum standards of performance within performance management systems (e.g. as part of supervision or appraisal).

## Learning outcomes

The learning outcomes in the framework aim to describe what the learner will know, understand or be able to do as a result of their learning. This approach is derived from Bloom's Taxonomy<sup>1</sup> i.e.

- Knowledge: Remember previously learned information
- Comprehension: Demonstrate understanding
- Application: Apply knowledge to actual situations
- Analysis: Break down objects or ideas into simpler parts and find evidence to support generalisations
- Synthesis: Compile component ideas into a new whole or propose alternative solutions
- Evaluation: Make and defend judgements based on internal evidence or external criteria.

The majority of learning outcomes at tiers 1 and 2 describe knowledge, comprehension/understanding and application, although there are some learning outcomes (particularly at tier 3) which may include analysis, synthesis and evaluation.

The learning outcomes for each subject should together indicate the minimum content for the design and delivery of teaching and learning for each tier in that subject. However, it is important to reiterate that this is a core skills and knowledge framework i.e. the scope of the framework is that which is common and applicable to all settings. Additional content may also be required for some roles and contexts.

The learning outcomes are written as broad statements e.g. 'The Learner will: be aware of / know / understand / be able to...' This provides scope for the framework to be applicable across a wide range of contexts and settings.

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<sup>1</sup> Bloom B (1956), *Taxonomy of educational objectives*

## Training and assessment

The framework does not prescribe a training/teaching method however a focus on experiential, work based, reflective learning has been shown to effectively delivery results.. This will be developed according to the particular context or setting. Similarly, the framework does not seek to prescribe assessment methods.

For application in a specific context, relevant learning objectives or assessment criteria may be developed to measure achievement of the learning outcomes. In a given context, more specific verbs may be applied to each learning outcome e.g. 'The learner will: explain / describe / demonstrate / discuss / identify / etc...'

For example, in different organisations or contexts learning outcomes may be assessed by a range of methods e.g. e-assessment, group discussion, observation of performance, products of work, testimony from witnesses, project/case study work etc. The learning outcomes in the framework are intended to be adaptable to this variety of assessment methods.

## Who is this framework for?

The framework provides a focus on the skills, knowledge and behaviours expected for the delivery of end of life care services. This should be of particular value to:

### Individuals and teams

The framework sets out clear expectations for learners and in particular, the core learning outcomes that specific tiers of the workforce should be able to demonstrate. This supports individuals and teams to:

- be clear about the requirements of their roles and to recognise their own transferable skills
- conduct formal or informal training needs analysis, comparing current skills and knowledge with required skills and knowledge
- plan future education and training requirements to enable continuing professional development and career progression.

### The public including those accessing end of life care, their family and carers

The framework outlines what members of the public would benefit from knowing and being able to do in respect of end of life care. It places a particular emphasis on the importance of members of the public understanding their own role in end of life care, how they can support those approaching the end of life, and how they can access support from their community, as well as from health and social care professionals.

### Subject matter experts / trainers

The framework helps those who design education and training opportunities to focus on the key outcomes that learners need to achieve, which in turn will guide the content to be included and the use of appropriate teaching strategies.

The specific learning outcomes also support the effective evaluation of education and training. Approaches to evaluation can include:

- evaluating whether learners have achieved the required learning outcomes immediately following a learning intervention (e.g. through assessment of knowledge and/or competence)

- evaluating whether the learning is being applied in the workplace (e.g. through longer-term evaluation of impact on practice, possibly as part of supervision or appraisal processes)
- evaluating the impact on quality of care (e.g. measuring patient outcomes and/or levels of satisfaction from individuals and their families). Such evaluation will require data collection to measure what changes.

### **Assessors of occupational standards**

References to relevant national occupational standards and national skills frameworks indicate how the framework relates to national standards. For example, a learner working towards the requirements of a national occupational standard could use the framework as a guide to the skills and knowledge they would need to demonstrate in achieving the national occupational standard in the specific context of *end of life care*.

### **Managers in organisations / commissioners of training**

The framework enables managers and commissioners to be clear about the specific outcomes required from staff development interventions. Use of the framework within an organisation enables managers to demonstrate that core end of life care training has been planned and delivered in accordance with a nationally recognised framework. Similarly, commissioners can use the framework to provide education and training providers with a quality assurance specification for end of life care core skills education and training.

### **Education providers**

Universities, colleges and private training providers can use the framework to underpin the design of education and training curricula, ensuring that the required core learning outcomes are integrated appropriately and/or mapped to overall achievement of curriculum aims. This will help ensure that those learners undertaking health and care programmes are given the opportunity to acquire end of life care core knowledge and skills which are relevant to the requirements of employing organisations.

### **Regional and national implementation**

A further aspiration in providing this framework is that organisations will be able to review their current arrangements for defining and delivering end of life care education and training and through the adoption of the framework align their approaches. Such alignment should then have benefits in ensuring consistent approaches, which, through the use of learning outcomes, should be more educationally focused and valued. This has the potential to promote organisational and system wide efficiencies by encouraging the adoption of education and training which meets recognised standards and in doing so help to prevent unnecessary duplication of education and training delivery.

The framework also supports the increasing integration between health and social care services and their respective workforces. In particular, a core skills framework can help to develop synergies such as improved communication, collaborative working and potentially providing opportunities for joint education and training.

# Subject 1: Person-centred end of life care

## Introduction

‘Each person is seen as an individual... I am asked what matters most to me’ (Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, 2015).

This ambition is reflected in all recent best practice end of life care publications. People approaching the end of life should be seen as individuals, treated as a person not an illness, retain as much control as possible, be supported to be independent as possible and have their strengths, abilities and values acknowledged, (Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations, 2015).

Person-centred care is based on principles of respect, dignity, choice and independence. The individual receiving care should be at the centre of every conversation, action and decision. Their specific needs, wants and individual circumstances should guide all care and support offered by professionals. The individual is the expert in their own life and should be empowered and supported to retain control.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) be able to engage in conversation with an individual nearing the end of life, and understand and respect what is important to them
- b) understand that individuals are experts in their own lives
- c) understand that the individual's wishes may differ from your own and be willing to support these wishes
- d) understand that person-centred care includes all elements of an individual's life that are important to them, not just their symptoms
- e) understand the significance of cultural diversity
- f) understand who is important to the individual and who they see as 'leading' their care
- g) understand the part you play in the individual's end of life care and know where to seek support
- h) understand importance of the caring network from which the individual, their family and carers may benefit

## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) understand how to make the individual the focal point of their own care and support, and that the individual's wishes, beliefs and priorities are paramount
- b) be able to empower individuals to gain control of their needs and wishes and retain independence and dignity
- c) be able to assess the needs, concerns and priorities of individuals, their family and carers in a person-centred way
- d) be able to encourage and support individuals to make decisions based on their own experience, utilising professional support and guidance
- e) be able to support individuals to identify and manage risk
- f) be able to work with others to develop an end of life care plan that balances disease-specific treatment with care and support needs and wishes of the individual

## **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

### **The learner will:**

- a) be able to support individuals, their family and carers meet their needs within the available resources
- b) be able to recognise and suggest ways to overcome potential barriers individuals may face in accessing end of life care
- c) understand and seek to manage, through advocacy or other methods, the potential service or organisational constraints and challenges a person-centred approach may present

## **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 to 6](#)
- **Getting it right every time: Fundamentals of nursing care at the end of life 2016**
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**

- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - Priority 1 to 5
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

## **Legislation**

Care Act 2014

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principle 1

### **Care Certificate Standards**

- Standards 3 to 7, 9 and 10

### **National Occupational Standards**

- [SCDHSC0385 Support individuals at the end of life](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

### **The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- Function B3

# Subject 2: Communication in end of life care

## Introduction

Not knowing what to say is common in end of life care, and starting conversations about this sensitive subject can be difficult. But communication is at the heart of every aspect of end of life care.

People approaching the end of life need to have the opportunity to talk about what matters to them. They will need time for open and honest discussions about the options available to them and plan for practical matters, as well as time to explore their feelings, their relationships and their spiritual needs. Families and carers will need support and information, as well as answers to hard questions. Professionals will need to share information with each other effectively and in the best interest of the individuals and others.

Communication needs to be open, sensitive and appropriate to the person and their situation.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) know how to be a good listener
- b) know how to start a conversation and feel able to talk about death and dying
- c) understand the importance of discussing dying, death and bereavement, and expressing wishes and preferences associated with this
- d) know how to communicate own worries and concerns and assert own wishes about dying and the care provided. Be able to engage in activities to support this
- e) be able to express own and others' wishes and preferences regarding end of life care and future care needs to others e.g. family and friends, carers, doctors and nurses



## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) be able to communicate sensitively with individuals, their family and carers, on a range of matters relating to end of life care, in a non-judgemental, empathetic, genuine, collaborative and supportive manner that is appropriate to them and the situation
- b) be able to use active listening skills and open questions to recognise cues from individuals, their family and carers and support individuals, their family and carers to express themselves
- a) be able to effectively communicate in an accessible way with individuals, their family and carers who have additional care and support needs, such as learning disabilities or cognitive impairment
- c) know when to seek advice about difficult and complex matters or situations
- d) be able to use communication and relationship skills to encourage and support individuals express their preferences, concerns and needs, alongside their own strengths and abilities
- e) understand how religious or cultural customs may impact on communication
- f) understand the changes in the ability and desire of individuals, their family and carers to communicate, and be able to adapt own communication methods accordingly
- g) understand why silence is an important part of communication in end of life care, and feel confident in managing silence
- h) be able to use communication skills to ensure end of life care plans, and advance care plans, are understood and shared
- i) be able signpost individuals, their family and carers to sources of information
- j) be able to share information about the illness and its prognosis in a way that is accessible and uses appropriate language
- k) be able to manage conflict where it arises between the individual, their family and carers regarding end of life care or advance care planning choices, work sensitively with all parties towards a resolution and access mediation and advocacy services where appropriate

## **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

### **The learner will:**

- a) understand the barriers to communication at end of life and have strategies in place to overcome these barriers
- b) be able to develop and maintain communication with individuals, their family and carers about difficult and complex matters or situations related to end of life care

- c) be able to provide appropriate information to the individual, their family and carers, about the individual's illness and available support. This could include information about an individual's prognosis, changes in condition, and that end of life may be imminent, and provide support to make informed decisions based on that information
- d) understand that sensitive communication includes the need to respect wishes of those who do not want to have open discussions about their condition or end of life
- e) be able to communicate appropriately across the age spectrum with people facing bereavement

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - Ambitions 1,2, 4 and 5
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **Getting it right every time: Fundamentals of nursing care at the end of life 2016**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - Priorities 1 to 4
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

### Legislation

Care Act 2014

Data Protection Act 1998

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## Indicative mapping to relevant national standards or frameworks

### Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life

- Principles 2 to 5 and 7

### Care Certificate Standards

- Standards 3 and 5 to 7

### National Occupational Standards

- [SCDHSC0021Support effective communication](#)
- [SCDHSC0031Promote effective communication.](#)
- [SCDHSC0233Develop effective relationships with individuals](#)
- [SCDHSC0385 Support individuals at the end of life](#)

### Regulated Qualifications Framework components (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

## Additional resources to support Tier 1

[Dying Matters](#) website resources

[Macmillan](#) website resources

[e-ELCA](#) (End of Life Care for All)

# Subject 3: Equality, diversity and inclusion in end of life care

## Introduction

The needs of individuals are as diverse in approaching death as they are throughout life. Care and support should be delivered in such a way that enables understanding and appreciation of, as well as effective response to, the diverse range of experiences, beliefs and needs of individuals, their family and carers.

Beliefs, culture, disability, religion, spirituality and sexuality can be important to many experiencing end of life care and may affect an individual's experience and the support they need. Appropriate support should be made available. It should not be assumed that individuals, their family and carers share the same spiritual beliefs and needs, or that these beliefs and needs remain stable through end of life, dying or grieving.

Services continue to strive to improve the quality of end of life care, but not everyone receives the quality of care they deserve from every professional they encounter and there are still significant differences in the way individuals, family and carers experience end of life care. In a recent survey of family and carers, the care their loved ones received in care homes, hospices and at home was rated as significantly better than care received by loved ones in hospitals (*National Survey of Bereaved People (VOICES): England, 2015*). Addressing equality, diversity and inclusion in end of life care therefore also means ensuring 'each person gets fair access to care' (*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020, 2015*).

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) understand how bereavement and the grieving process may affect people differently
- b) know how to talk about own beliefs and values and recognise that they may differ from those of others
- c) be able to listen to and support individuals who hold different beliefs and values, or have had different life experiences

## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) understand the significance of diversity, including the impact of faith, values, beliefs, religion, lifestyle on the care provided and choices made
- b) understand the importance of spirituality and be able to assess and meet the spiritual needs of individuals, their family and carers
- c) be able to communicate in a way that is appropriate to the needs and circumstances of the individual, their family and carers
- d) understand how religious or cultural customs and social norms may impact on care and support preferences
- e) be able to challenge poor, unethical or discriminatory practice
- f) understand referral criteria for specialist services

## **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

### **The learner will:**

- a) be able to distinguish between spirituality and religion
- b) be able to assess and support an individual to meet their needs
- c) understand the factors that can affect an individual's views of death and dying including social, cultural, religious and spiritual considerations
- d) be able to find and access specialist services for diverse client groups
- e) understand how an individual's awareness of spirituality may change as they approach death
- f) be able to recognise where grieving and bereavement is complex and know who to refer to

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 and 2](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 3 to 5](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

### Legislation

Care Act 2014

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## Indicative mapping to relevant national standards or frameworks

### Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life

- [Principles 1 and 2](#)

### Care Certificate Standards

- [Standards 4 and 5](#)

### National Occupational Standards

- [SCDHSC0234 Uphold the rights of individuals.](#)
- [SCDHSC3111 Promote the rights and diversity of individuals.](#)
- [SCDHSC0385 Support individuals at the end of life](#)

### Regulated Qualifications Framework components (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

**The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- Function B2, B4

**Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

# Subject 4: Community skills development in end of life care

## Introduction

The 6<sup>th</sup> ambition within ‘*Ambitions for Palliative and End of Life Care: A national framework for local action 2015:2020*’ is that ‘each community is prepared to help’. The provision of care and support at the end of life can, and should, extend beyond health and care professionals, and even beyond the central roles played by carers, friends and family. It should encompass the support and skills available within the community as a whole, and how these can benefit individuals approaching the end of life, their family and carers. Death and dying are complex social events for which professional care is just one element (*Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six, 2016*).

Our communities are filled with people with diverse skills, qualities and experiences, but many communities, and the individuals that make up those communities, may not recognise how these skills can be harnessed to support individuals receiving end of life care and their carers.

Understanding what is important to the individual, their family and carers, is a starting point to considering what community assets are already available to provide support, and then build on them. A neighbour who enjoys long walks could be a real asset to an individual who’s becoming too frail to walk their dog, or to a carer who no longer has the time. This neighbour provides a useful, practical service to an individual, their family or carer, which inadvertently benefits their wellbeing by reducing stress, guilt or worry.

[‘Skills around the person: Implementing asset based approaches in adult social care and end of life care, 2014’](#) demonstrates creative and practical approaches to developing and harnessing community skills, as well as an illustration with a range of different skills, qualities and experiences that could be present within communities.

Health and care professionals and organisations play a key role in working with and supporting communities to recognise and develop their community skills capacity for those approaching the end of life, their family their carers. This might be in the form of supporting local community groups to extend their reach; providing training to community leaders; opening the doors of the hospice or care home to the public to break-down barriers; marketing the idea of end of life discussions at local events or in public spaces; encouraging engagement in discussions through social media; or working with local authorities to develop compassionate cities or communities.

The aim should be that these projects become self-sustaining and peer-led over time. Building compassionate and resilient communities will require resource investment, whether it’s from health and care providers, Clinical Commissioning Groups, Local Authorities or other sources. But this approach can ‘enhance and enlarge’ services ‘in ways that are beyond the impact of professional services alone’, and evidence suggests community development approaches improve a range of outcomes including mental and physical wellbeing, self-efficacy, and reduced use of formal health services (*Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six, 2016*).

[‘Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six, 2016’](#) provides health and care professionals with a ideas and recommendations, along with case studies, about how to develop compassionate and resilient communities to better support people approaching the end of life, their family and carers.



## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 knowledge and skills for those for those in roles that frequently provide care for people who are nearing the end of life

## Key learning outcomes

### Tier 1

#### The learner will:

- a) understand that supporting someone at the end of life, their family and carers goes beyond health and social care intervention
- b) understand the huge potential the community has to offer in providing end of life care support, e.g. how the community can enable individuals to stay in, or return to, their own home, and the various support services the community has to offer
- c) understand that different personal skills, qualities and experiences could be valuable to individuals, their family and carers, in meeting their social, intellectual, spiritual, emotional, psychological or physical needs
- d) be able to engage in local community support schemes that offer services to individuals, their family and carers – either to offer or access support
- e) understand what is meant by a 'caring network' (family, friends and others around an individual), and the value a caring network can bring
- f) be able to develop the practical skills of enhancing networks: saying yes to offers of help and learning how to ask
- g) be able to develop the practical skills of caring e.g. how to lift and move an individual in a safe way

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) understand the concept and principles of a community development, asset-based approach to end of life care
- b) understand that the support needs of individuals, their family and carers are wide ranging and extend far beyond the care, support and treatment provided by health and care professionals

- c) understand how local community schemes could benefit individuals, their family and carers
- d) be able to support individuals, their family and carers to access local community groups and services, and to understand the benefits accessing such groups could bring
- e) be able to support individuals, their family and carers to consider their network of support (referred to as a 'caring network') s which may be beyond immediate family and friends
- f) be able to develop the practical skills of individuals, their family and carers to enhance networks: saying yes to offers of help and learning how to ask
- g) understand the importance of multi-disciplinary teams involving and including community development workers
- h) understand the value of everyone being involved in supporting community development, not just clinical teams
- i) be able to map community assets to the Public Health England asset database

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) be able to understand, engage with, influence and strengthen the community
- b) be able to promote and support effective relationships between communities, public bodies, voluntary organisations and other agencies that facilitate wellbeing for individuals, groups and communities
- c) be able to facilitate learning opportunities for community development
- d) be able to cascade information and skills in relation to community development to colleagues, individuals, family and carers
- e) be able to identify and overcome barriers to community skills development
- f) be able to promote the benefits of developing community skills and engaging with the local community amongst colleagues and senior managers/board members

## **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambition 6](#)

- **Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six**
- **Skills around the person: Implementing asset based approach in adult social care and end of life care**

## **Legislation**

Care Act 2014

Equality Act 2010

## **Indicative mapping to relevant national standards or frameworks**

- **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**
  - Principles 1, 3 and 6

### **Care Certificate Standards**

- Standard 7

### **National Occupational Standards**

[JETSCD00 Community Development](#)

[SCDHSC3101 Support the development of community networks and partnerships](#)

[SCDHSC3102 Work with community networks and partnerships](#)

[SFHPHS16 Involve communities as active partners in all aspects of improving health and wellbeing](#)

[SFHPHS17 Empower communities to improve their own health and wellbeing](#)

### **The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- Function A2, B2

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

[NHS Choices](#) End of Life Care Guide

# Subject 5: Support for the individual in relation to feelings associated with approaching the end of life

## Introduction

Many people approaching the end of life find it difficult to talk about death and dying, and expressing the feelings associated with this. It might be because they are scared, it might be because they don't want to burden others, or perhaps they just can't find the 'right' words.

Whatever the reason, being able to offer someone the opportunity to express and explore feelings associated with approaching the end of life may well be one of the most significant ways you can support them.

Having the confidence and communication skills is just one element of providing this vital support. An empathy with and understanding of the different emotions the individual is going through will also help.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### **The learner will:**

- a) be able to say goodbye to those considered important
- b) know how to offer support to someone who is dying
- c) understand the importance of promoting and maintaining the dignity of someone approaching the end of life
- d) be able to express own feelings
- e) be able to discuss and listen to others feelings and recognise and accept these may be different to your own
- f) know where to direct an individual, family or carer for more support

## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) understand the process and different expressions of loss and grief including; loss, bereavement, grief and mourning
- b) understand the factors that could affect an individual's view of dying, including physical, emotional, psychological, spiritual, cultural and religious needs
- c) be able to deliver care and support in a way that promotes respect, dignity, choice and independence
- d) be able to use open questions to support individuals to express themselves freely
- e) understand the importance of spiritual support, and that the spiritual support needs may vary between individuals, their family and carers
- f) understand the benefits that networking and engaging with the community can provide individuals
- g) be able to demonstrate an awareness of the impact of dying
- h) be able to use networks and partnerships to identify resources, information and support for individuals
- i) be able to provide individuals with information on a range of options and resources available, how they might be accessed, and the potential risks and benefits
- j) understand the need to be sensitive to the individual's changing circumstances, and adapt care and support accordingly

## **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

### **The learner will:**

- a) understand the types of loss an individual at end of life might experience
- b) be able to support individuals who are grieving, and with thoughts associated with death and dying
- c) understand internal and external coping strategies of individuals when facing death and dying
- d) be able to assess when individuals need to be alone
- e) understand the psychological effects of the dying phase/last days of life for an individual and the key theories and models relating to loss and grief
- f) understand the importance of relationships as a person nears the end of life, and be able to support a dying person to maintain these relationships
- g) understand why someone with a life limiting illness may become depressed, and identify possible signs of depression

- h) be able to undertake initial risk assessment of mental health and emotional needs and, if required, recognise complex grief, and refer to psychological services where appropriate
- i) be able to advocate on behalf of the individual to ensure their voice is heard in family conflicts, or understand how to access advocacy services for individuals

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - Ambitions 1, 2, 3 and 5
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **Getting it right every time: Fundamentals of nursing care at the end of life 2016**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - Priority 2
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

### Legislation

Care Act 2014

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## Indicative mapping to relevant national standards or frameworks

### Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life

- Principles 1 to 5

### Care Certificate Standards

- Standards 4 to 7, and 9

## **National Occupational Standards**

- [SCDHSC0226Support individuals who are distressed](#)
- [SCDHSC0350Support the spiritual well-being of individuals](#)
- [SCDHSC0385 Support individuals at the end of life](#)

## **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

[NHS Choices](#) End of Life Care Guide

e-Learning for Healthcare: [e-ELCA](#) (End of Life Care for All)

# Subject 6: Promoting health and wellbeing for individuals at the end of life

## Introduction

Individuals approaching the end of life will likely experience a range of symptoms. Health and care professionals play a crucial, and often specialised, role in assessing these symptoms and supporting individuals to manage them to enhance their quality of life, health and wellbeing.

However, promoting health and wellbeing goes far beyond professional input and everyone can be involved. How someone experiences the end of life could be improved just by being supported to sit up, having extra pillows, being made warmer/cooler or having someone to spend time with.

Inadequate nutrition and hydration could be both a cause and consequence of ill health. Supporting an individual to eat and drink, and addressing any reasons why they may not be able to do so, or want to do so, is a key part of promoting an individual's health and wellbeing.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### **The learner will:**

- a) know how to make someone comfortable at the end of life
- b) be able to respond to the individual's wishes regarding nutrition and hydration
- c) be able to support the individual to tell you what would benefit their health and wellbeing

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### **The learner will:**

- a) understand that people should be seen within the context of their own community and be supported to participate and contribute to this as they wish
- b) be able to recognise and respond to individuals' concerns, fears and anxiety



- c) be able to provide emotional, physical and psychological support to individuals to maintain comfort and well-being
- d) understand the impact of social, environmental and economic issues on health and wellbeing for individuals, their family and carers
- e) be able to support an individual to eat and drink as long as they wish and are able to, and take appropriate action to rectify problems individuals may have with eating and drinking

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) understand why support for an individual's health and well-being may not always be related to their life-limiting condition
- b) be able to support individuals to make decisions about their treatment considering the potential benefits, burden and risks
- c) understand guidance, risks and benefits, and ethical considerations associated individual's nutrition and hydration related needs, including that related to clinically assisted nutrition and hydration
- d) be able to understand, listen to, and respond appropriately to, individual's nutrition and hydration needs

## **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1, 3, 4 and 5](#)
- **Getting it right every time: Fundamentals of nursing care at the end of life 2016**
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **General Medication Council 'Good Medical Practice' 2013**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 3 and 5](#)

- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

## **Legislation**

Care Act 2014

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principles 3 to 5

### **Care Certificate Standards**

- Standard 5, 7 and 8

### **National Occupational Standards**

- [SCDHSC3112 Support individuals to manage their own health and social well-being](#)
- [SCDHSC0385 Support individuals at the end of life](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

# Subject 7: Assessment and care planning for individuals, their family and carers

## Introduction

Assessment and care planning is an on-going process during an individual's end of life care and places the individual at the centre of care, as well as including those closest to them. Assessments and care plans should look beyond the medical and care interventions an individual may require, and take account of their background, strengths, aspirations, and priorities, as well as spiritual, emotional, social, intellectual and well-being needs. Care plans reflect this ensuring the individual is able to work towards their goals and receive care that is designed around their specific needs.

The Government's paper '*Our commitment to you for end of life care: The government response to the review of choice in end of life care*' (2016), acknowledges the importance of having a 'personalised care plan, based on what matters to you and your needs and preferences, including any advance decisions and your views about where you want to be cared for and where you want to die, and to review and revise this plan throughout the duration of your illness.'

Advance Care Plans enable individuals to make decisions and guide the care they receive if they lose the capacity to make informed decisions at a later stage. They enable the individual to remain in control of their care and at the centre of all decisions.

The Care Act 2014 introduced a duty for all local authorities to provide Carer's Assessments and offer support, where a carer meets national eligibility criteria – so it isn't only the person receiving end of life care that is entitled to a person-centred assessment and care plan.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- g) understand the importance of including individual's wishes, beliefs and priorities in all assessment, planning and decision making
- h) understand that the individual has a right to change their mind regarding the sort of care they want
- i) be able to encourage and support individuals to make decisions based on their own experience, utilising professional support and guidance

- j) understand the importance of choice, and the options available in, planning for end of life care and future care needs e.g. where care will take place, decisions to refuse some treatments, funeral planning, organ donation, mental capacity, lasting power of attorney
- k) understand how to plan for end of life care and future care needs, and how to access specialist support services

## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) understand the importance of making assessments and care plans **'holistic'**
- b) understand and use (as appropriate to role) a range of assessment tools and know their advantages and disadvantages
- c) be able to assess the variety of needs individuals, their family and carers may present
- d) understand why assessments need to be reviewed in partnership with others and take account of the changing needs and wishes of individuals
- e) understand how an individual's faith, belief, religion and lifestyle may affect assessment and care planning
- f) know the importance of taking account and acting on of the observations and judgements of family and carers when planning care
- g) understand how to plan and deliver care and support in a person-centred way
- h) understand why a care and support plan should be regularly reviewed and updated to meet the changing needs, wishes and priorities of the individual
- i) be able to carry out person-centred, holistic end of life care assessments using appropriate tools
- j) be able to carry out assessments in a private and dignified manner
- k) be able to use communication aids where appropriate to support assessments
- l) understand when and why an advance care plan would be appropriate
- m) be able to explain and provide information on advance decision planning for individuals, their family and carers and check individual's understanding
- n) be able to appropriately share (with permission) wishes and preferences in an individual's advance care plan
- o) understand the contents of individuals' advance care plans and the impact this has on care and support offered
- p) understand the rationale for involving individuals, their family and carers in advance care planning

- q) be able to use effective, sensitive communication skills when having advance care planning discussions as part of ongoing assessment and intervention

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) understand the pathophysiology of common disorders, diseases, conditions and symptoms experienced at the end of life
- b) be able to involve families in the agreement and review of risk management strategies where appropriate
- c) know of a range of assessment tools that could be used to assess individual's symptoms, including those with cognitive impairment, their advantages and disadvantages
- d) be able to provide family with clear rationales for decisions made and make assessments openly
- e) understand the variety of needs that should be considered when planning end of life care with individuals, their family and carers
- f) be able to involve the individual, and where appropriate their family and carers, in care planning, and respect when an individual does not wish to be involved
- g) understand how to work in the best interests of an individual unable to participate in decision making
- h) where appropriate, be able to ensure that the wishes of the individuals, as described in an advance care planning statement, are shared (with permission) with others
- i) understand the importance of sharing and discussing the advance care plan with others (where appropriate)
- j) be able to support and record decisions about advance care planning

### **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

#### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 to 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**

- **Mental Capacity Act 2005 Code of Practice (2007)**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 1 to 5](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

## **Legislation**

Care Act 2014

Equality Act 2010 Data Protection Act 1998

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

Mental Capacity Act 2005

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- [Principles 1 to 5 and 7](#)

### **Care Certificate Standards**

- [Standards 1, 5, 7, 9 and 14](#)

### **National Occupational Standards**

- [SCDHSC0025 Contribute to implementation of care or support plan activities](#)
- [SCDHSC0328 Contribute to the planning process with individuals](#)
- [SCDHSC0329 Support individuals to plan, monitor and review the delivery of services](#)
- [SCDHSC0414 Assess individual preferences and needs](#)
- [SCDHSC0416 Lead the planning process with individuals](#)
- [SCDHSC0385 Support individuals at the end of life](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

[NHS Choices](#) End of Life Care Guide

e-Learning for Healthcare: [e-ELCA](#) (End of Life Care for All)

# Subject 8: Symptom management in end of life care

## Introduction

Individuals receiving end of life care may experience numerous symptoms associated with the approach of death; with their illness or condition; and with treatment they are receiving. Being aware of the different types of symptoms that might occur, will support individuals, their family and carers to understand the dying process and enable them to be involved in care provision (if they wish to be). Understanding what is to be expected will also ensure that individuals, family and carers know when to alert professionals to deterioration and/or ask for extra support.

Health and care professionals need to be able to understand the various different causes of symptoms; the various different ways to relieve symptoms; and how the root cause may affect the treatment options provided. Professionals also need to consider treatment options in a holistic manner, taking account of the individuals' personal circumstances, wishes and preferences, and cultural beliefs.

Ensuring professionals work together and specialist input is received where necessary will have a significant impact of symptom management, but the overriding influence must be the individual's wishes and preferences.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) be able and willing to listen to an individual describing their symptoms and know how to direct them for more help
- b) know who to contact if symptoms or pain are not being managed well
- c) know how to support an individual to access medicines, especially at weekends and holidays

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) understand that the individual is the focal point for all care, and their wishes, beliefs and priorities are paramount when managing their symptoms



- b) understand common symptoms associated with the approach of end of life
- c) understand the types of symptoms and pain, including emotional pain, commonly experienced by individuals approaching the end of life
- d) understand the importance of a holistic understanding and assessment of the individual's perception of their symptoms
- e) understand that an individual's culture, faith, beliefs, religion and lifestyle may affect their decisions regarding symptom and pain management
- f) be able to make individuals aware of the range of options for symptom and pain management available to them and any potential risks and benefits
- g) understand that symptom and pain management should be organised around the needs of the individual, and delivered in a co-ordinated manner
- h) understand that symptoms have many causes and that different causes may require different approaches to treatment, care and support
- i) know of the range of therapeutic options available to individuals, including community support and practical help
- j) be aware of different symptom assessment tools and how these can be used across teams
- k) be able to support the individual retain dignity during symptom and pain management
- l) be able to support family and carers to continue or take on caring responsibilities where they want to
- m) understand when to refer concerns about an individual's symptoms to specialist colleagues
- n) understand local and national policy relating to medicines management
- o)

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) understand physiological processes associated with end of life common symptoms and when death is approaching
- b) be aware of current evidence to inform holistic assessment and management of symptoms associated with end of life
- c) understand the importance of, and know how to, provide regular symptom relief, and measure its effectiveness
- d) understand the reasons for planning activities after symptom relief and management has taken effect

- e) be able to use evidence-informed strategies to promote effective symptom management and holistic care to individuals according to their needs
- f) be able to evaluate the significance of an individual's own perception of their symptoms
- g) understand and respond to an individual's culture and beliefs in relation to symptom management
- h) be able to work in partnership with others, including the individual, their family and carers, to develop an end of life care plan which balances disease-specific treatment with care and support that meets the individual's needs and wishes
- i) understand the importance of using evidence-based symptom assessment skills and tools
- j) know about the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support, and how to support such interventions in a role appropriate way
- k) understand the World Health Organisation's analgesic ladder and apply appropriately in accordance with local and national guidelines
- l) understand how different factors can alleviate or exacerbate pain and discomfort
- m) understand implications of co morbidities and how to manage them
- n) understand methods of medication administration where appropriate, and administer in line with patients changing status and own responsibilities

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1, 3, 4 and 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 3 and 5](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**
- **The Handling of Medicines in Social Care (Royal Pharmaceutical Society of Great Britain)**

## **Legislation**

Care Act 2014

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principles 1, 4, 5 and 7

### **Care Certificate Standards**

- Standards 1, 4, 5 and 7

### **National Occupational Standards**

- [SCDHSC0385 Support individuals at the end of life](#)
- SCDHSC3122 Support individuals to use medication in social care settings

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

[NHS Choices](#) End of Life Care Guide

# Subject 9: Working in partnership with other professionals

## Introduction

To deliver the best care possible, health and social care professionals must deliver care and support in a coordinated way. They should understand the fundamental roles other professionals in a multi-disciplinary team play, within their own organisation and across different organisation, in delivering quality end of life care. Importantly, professionals should work collaboratively and communicate effectively between one another to ensure everyone understands and can respond to the needs and wishes of the individual in an agreed way that is appropriate to the individual.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) know which professionals are involved in a persons end of life care and know who to contact with any questions or with any issues
- b) be able to work in partnership and communicate with all those involved in supporting the person

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) understand and collaborate with the services provided by other professionals
- b) be able to work in partnership with colleagues in other disciplines to meet the needs of the individuals, their family and carers
- c) be able to deliver care and support in a co-ordinated way, and organised around the individual's needs
- d) be able to share information in a timely and appropriate manner, taking into account issues of confidentiality
- e) understand referral criteria and processes for referral to specialist services to meet the needs of individuals, their family and carers

- f) understand the potential emotional impact of death and dying upon colleagues and provide support

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) be able to promote effective team work to co-ordinate and communicate care for the individual and their carers
- b) be able to integrate and explore the views of the wider multi-professional team when making a holistic assessment of individual and carer needs
- c) be able to provide accurate and timely handovers to multi-professional teams and other services, particularly regarding the persons wishes
- d) be able to undertake/contribute to multi-disciplinary assessment and information sharing, where appropriate, 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) be able to manage challenging conversations with other professionals, demonstrating a commitment to partnership working to facilitate care
- f) be able to provide education and support to team members

### **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

#### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 and 3 to 6,](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priority 5](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

## **Legislation**

Care Act 2014

Data Protection Act 1998

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principles 3 and 5

### **Care Certificate Standards**

- Standards 1, 3, 5 and 6

### **National Occupational Standards**

- [SCDHSC0385 Support individuals at the end of life](#)
- [SCDHSC0433 Develop joint working arrangements for health and social care services](#)
- [SCDHSC3100 Participate in inter-disciplinary team working to support individuals.](#)
- [SCDHSC0399 Maintain effective working relationships with staff in other agencies](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

### **The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- Function B2

# Subject 10: Support for family and carers

## Introduction

The people important to the individual approaching the end of life should be at the centre of their support (*Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations, 2015*); involved in discussions about, and the delivery of, care; and have the opportunity to provide feedback (*Our Commitment to you for end of life care: The government response to the review of choice in end of life care, 2016*). Not only will family and carers need to support to do this, but they'll also be experiencing a host of feelings including loss and grief, and will need support to manage and explore these feelings.

Families and carers, just like the individual, should be treated with respect, dignity, compassion and empathy; their experiences dealt with sensitively; and they should be provided with appropriate emotional support, as well as practical support and information.

For health and social care professionals, it's important that the support offered doesn't stop upon an individual's death. Instead, families and carers may need time to explore their thoughts and feelings, and guidance on what to do next. It might be that this support is more appropriately offered by another service or organisation or the community itself, so ensure the family and carers are sensitively put in touch with others services, and have information about where to go and what to do next.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) understand what support, services and resources are available, and know how to access them
- b) know how to access spiritual support
- c) know how to access advocacy support
- d) be able to recognise and understand the changes that occur in the dying process
- e) be able to access a Carer's Assessment and resultant support
- f) understand how to access support for family conflicts
- g) understand how to access financial and practical advice
- h) understand how to plan for a funeral and how to access support for this
- i) know how to offer support to someone who is bereaved and grieving

## **Tier 2**

*Tier 1 learning outcomes plus the following:*

### **The learner will:**

- a) be able to use open questions to support family and carers to express themselves freely
- b) understand the importance of spiritual support, and that the spiritual support needs may vary between individuals, their family and carers
- c) understand the importance of assessing the specific support needs of family and carers and ensuring that these needs, including those of children and young people, are taken into account and that carer support and, where appropriate, assessment is offered
- d) understand the duty of local authorities to undertake carer's assessments
- e) understand the need to be sensitive to the family and carers changing circumstances and needs, and adapt care and support accordingly
- f) be able to use networks and partnerships to identify resources, information and support for family and carers in their community, and make referrals where appropriate
- g) be able to sensitively support families and carers when individuals are making advance care planning decisions
- h) understand the impact of dying, death and bereavement
- i) understand the different factors that may affect family and carers response to grief, loss and bereavement
- j) be able to offer guidance and/or training to family and carers on practical aspects of care

## **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

### **The learner will:**

- a) understand the importance of recognising the expertise of family and important others and support them to continue performing tasks should they wish to do so
- b) be able to take account of the observations and judgements of family and carers and integrate them when making a holistic assessments of the individual's needs and responding to crisis situations
- c) be able to undertake appropriate bereavement risk assessment and, if required, refer appropriately way
- d) be able to retain open communication channels between family, carers and professionals, including with those families who do not wish to talk about death
- e) be able to support those important to the individual to maintain their relationships



- f) be able to explain to families their role in best interest decision making
- g) understand how conflicts may arise between individuals and family and carers and be able to navigate these complex relationships
- h) understand the stages of bereavement, the factors that may affect the intensity and duration of someone's grief, and be able to support someone through this process
- i) be able to evaluate models and theories of loss and grief
- j) be able to provide additional support around practical issues to family and carers where death has been unexpected, e.g. post mortems, coroners, death certification procedures

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambition 1 and 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **Mental Capacity Act 2005 Code of Practice (2007)**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 2 to 4](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

### Legislation

Care Act 2014

Equality Act 2010

Human Rights Act 1998

Mental Capacity Act 2005

## Indicative mapping to relevant national standards or frameworks

**Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principles 2 to 7

### **Care Certificate Standards**

- Standards 5 and 6

### **National Occupational Standards**

- [SCDHSC0387 Work in partnership with carers to support individuals](#)
- [SCDHSC0426 Empower families, carers and others to support individuals](#)
- [SCDHSC0427 Assess the needs of carers and families](#)
- [SCDHSC0384 Support individuals through bereavement](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

### **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

[NHS Choices](#) End of Life Care Guide

# Subject 11: Maintain own health and wellbeing when caring for someone at the end of life

## Introduction

Providing care for someone approaching the end of life can be physically, emotionally and psychologically exhausting. For families and loved ones, lives may be put 'on-hold' during this period. Recognising the need to care for yourself, as well as the person approaching the end of life could make all the difference to how you're able to cope and manage your own feelings.

There is a variety of support available to families and loved ones, as well as for health and social care professionals working in end of life care. It's important that people know how to access this and have the confidence to ask for support.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) understand the importance of caring for yourself and others providing caring roles, and be able to maintain own health and well-being whilst caring for a loved one
- b) know what caring network is available to the person and yourself and how to access this and ask for help
- c) understand the potential emotional impact of death and dying on oneself and those involved in caring for the person at end of life
- d) know how to access support to help oneself and others involved in caring for the person at end of life

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) understand the importance of making good use of the support available, including supervision
- b) be able to reflect on practice and identify learning and support needs

- c) understand the potential impact the death of someone may have on own feelings
- d) be able to access support and guidance from colleagues, as well as offer it
- e) be able to access support for developing own skills and confidence in working with individuals at the end of life, their family and carers
- f) understand how own experiences of loss and bereavement may affect the care provided to individuals
- g) be able to access support for own learning and development

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) understand the factors that can affect own view of death and dying and how these can impact on practice, ability to listen and respond appropriately
- b) understand own behaviours and attitude and the effect it may have on others

## **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambition 5](#)
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priority 4](#)

### **Legislation**

Care Act 2014

Human Rights Act 1998

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- [Principle 7](#)

## Care Certificate Standards

- [Standard 2](#)

## National Occupational Standards

- [SCDHSC0033Develop your practice through reflection and learning](#)

## Regulated Qualifications Framework components (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

## Additional resources to support Tier 1

[Dying Matters](#) website resources

[Macmillan](#) website resources

# Subject 12: Caring for a deceased individual

## Introduction

Care for an individual does not cease when they die. Their dignity should be upheld and their bodies treated in a respectful way, taking account of any wishes and preferences expressed before death and including any cultural needs.

In addition to continuing to treat the individual with respect and dignity, professionals have additional responsibilities including; contacting the relevant people (including family and carers), recording appropriate information, and transferring the person's body. These all need to be carried out within agreed ways of working.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) understand how to register a death and inform local services/central departments e.g. banks, DVLA, passport office

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) be able to carry out care after death in a way that promotes dignity and respects the individual's wishes, culture and religious practices, as well as follow agreed ways of working
- b) understand processes and procedures following death
- c) understand which organisations should be contacted when transferring a deceased individual
- d) understand the precautions needed, including use of protective clothing, when undertaking the care and transfer of deceased individuals, including those with specific high risk diseases and conditions
- e) understand how the physical changes after death may affect laying out or moving someone, and act accordingly

- f) be able to follow agreed ways of working to ensure a deceased person is correctly identified
- g) understand what details need to be recorded when caring for and transferring a deceased person
- h) understand the importance of recording property and valuables that are to remain with the deceased
- i) be able to record details of the care and transfer of a deceased person in line with agreed ways of working

### **Tier 3**

*Tier 1 and 2 learning outcomes*

## **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 and 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priority 1](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**
  -

### **Legislation**

Care Act 2014

Data Protection Act 1998

Equality Act 2010

## **Indicative mapping to relevant national standards or frameworks**

**Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

### **Care Certificate Standards**

- [Standard 4, 5, 7 and 15](#)

## **National Occupational Standards**

- [SCDHSC0385 Support individuals at the end of life](#)
- [SCDHSC0239 Contribute to the care of a deceased person](#)

## **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

## **Additional resources to support Tier 1**

[Dying Matters](#) website resources

[Macmillan](#) website resources

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# Subject 13: Law, ethics and safeguarding

## Introduction

Anyone working in end of life care needs to be aware of the legislation surrounding this area of work, particularly in relation to how care is delivered, or decisions are made, when an individual loses their capacity to make informed decisions for themselves.

A key theme that arose from '*What's important to me: A review of choice in end of life care, 2015*' was that individuals want 'involvement in, and control over, decision about [their] care'.

Supporting an individual in a person-centred way, to make these decisions can sometimes raise ethical and safeguarding concerns, particularly when the decision is likely to have a negative consequence on the individual's health or wellbeing. It's therefore important for those involved in end of life care to understand the individual's rights in relation to making these decisions, their own role in supporting such decisions, and how these are influenced by legislation and policy.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) know who to contact regarding legal, ethical or safeguarding issues

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) understand the concepts of **informed consent**, **best interest** and **advance decision to refuse treatment**
- b) understand the legal status and implications of advance care planning process in accordance with the provision of the Mental Capacity Act 2005
- c) understand own role in safeguarding individuals

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) understand and be able to implement local and national end of life care policy and legislation
- b) understand the circumstances in which life-prolonging treatment can be stopped or withheld
- c) be able to care for a dying and a deceased person in line with legal requirements and agreed ways of working
- d) understand the legal requirements and agreed ways to working that protect the rights of individuals at the end of life, and how these apply to own role
- e) understand the ethical and legal issues that may arise from advance care planning
- f) understand the potential conflicts and legal issues that may arise in relation to dying, death or end of life care and understand ways to address such conflicts
- g) be able to support others to recognise when mental capacity has reduced to the extent that others will determine care and treatment for the person at the end of life
- h) understand the process of obtaining a second opinion, where there is a continuing difference of opinion about the treatment or care of a dying person, accessing support to facilitate communication, and when a court ruling would be sought.
- i) understand legal and ethical aspects of decision-making to inform discussions within the multi-professional team, and with individuals, families and carers
- j) know the legal requirements, legal and ethical issues, and agreed ways of working that underpin care for a deceased person

### **Relevant guidance and/or legislation**

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

#### **Guidance**

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambition 1, 2, 4 and 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **General Medication Council 'Good Medical Practice' 2013**
- **Mental Capacity Act 2005 Code of Practice (2007)**

- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

## **Legislation**

Care Act 2014

Data Protection Act 1998

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

Mental Capacity Act 2005

Safeguarding Vulnerable Groups Act 2006

## **Indicative mapping to relevant national standards or frameworks**

### **Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life**

- Principle 1

### **Care Certificate Standards**

- Standards 10 and 11

### **National Occupational Standards**

- [SCDHSC0385 Support individuals at the end of life](#)
- [SCDHSC0024 Support the safeguarding of individuals](#)
- [SCDHSC0035 Promote the safeguarding of individuals](#)
- [SCDHSC0045 Lead practice that promotes the safeguarding of individuals](#)
- [SCDHSC0335 Contribute to the support of individuals who have experienced harm or](#)
- [SCDHSC0395 Contribute to addressing situations where there is risk of danger, harm and abuse](#)
- [SCDHSC0430 Lead practice to reduce and prevent the risk of danger, harm and abuse](#)
- [SCDHSC0234 Uphold the rights of individuals.](#)

### **Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

# Subject 14: Leading end of life care services and organisations

## Introduction

The role of leaders within end of life care cannot be underestimated, and whilst many Leaders may not deliver direct care, they play a pivotal role in ensuring that individuals accessing their services receive the best quality, person-centred, care possible. This leadership may relate to health and care organisations but leadership may also come from the patient, family, or members of the community.

The Care Quality Commission's report 'State of health care and adult social care in England 2014/15' describes the close relationship between the quality of leadership within a care setting and the quality care of provided. 94% of services rated as good or outstanding for leadership were also rated good or outstanding overall.

Effective leadership in end of life care ensures that the workforce deliver personalised care where the individual is at the centre of all discussions and decisions. This includes care being provided in line with best practice, taking into account local and national policy and frameworks; vulnerable individuals being safeguarded; workers being supported in what is often an emotionally and physically challenging role and being able to develop themselves; and multi-agency, integrated, working being promoted for the benefits of individuals.

## Target audience

Tier 2 those in roles that will have some regular contact with people receiving end of life care

Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 2

#### The learner will:

- a) understand how adults learn and the cultures in which they learn best
- b) be able to provide support for workers to develop their skills and confidence when working with individuals, family and carers
- c) understand the relationship between a well-trained workforce, an open approach to learning, and excellent care and support provision
- d) be able to provide effective supervision regarding end of life care
- e) understand own role and the limits of own knowledge and competence, and know where to seek support
- f) be able to facilitate workers to offer support and guidance to each other

### **Tier 3**

*Tier 1 and 2 learning outcomes plus the following:*

#### **The learner will:**

- a) be aware of, and implement, local and national policies shaping the delivery of end of life care and how these influence service delivery
- b) be aware of evidence-based research, innovations and developments in end of life care and consider how service delivery should be adapted
- c) be able to support staff and others to comply with legislation, policies and procedures to deliver safe end of life care
- d) be able to build a skilled and competent end of life care workforce through assessing learning and development needs and evaluating programmes and systems to meet these needs
- e) be able to anticipate and prepare for the future by scanning for ideas, best practice and emerging trends that will have an impact on outcomes for people at the end of life
- f) understand the importance of collecting quality assurance information including from individuals, their family and carers, and act on feedback received
- g) be able to implement strategies to empower and support staff involved in the delivery of end of life care to ensure positive outcomes for individuals and others
- h) be able to critically reflect on methods for measuring the end of life care service against national indicators of quality
- i) be able to analyse the features of effective partnership working within your work setting
- j) understand how legislation and regulation influence partnership working, including how information is shared
- k) understand how integrated service provision that crosses traditional boundaries achieve better outcomes for individuals
- l) understand the importance of demonstrating leadership in delivering compassionate person-centred care
- m) be able to promote team practices that champion diversity, equality and inclusion
- n) be able to analyse how reflective practice approaches can improve the quality of end of life care services
- o) be able to support others to reflect on practice in end of life care, and use outcomes of this to improve service delivery
- p) be able to support others manage own feelings when working in end of life care, including making relevant resources accessible

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambitions 1 to 5](#)
- **Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations**
- **One Chance to Get it Right: Improving people's experience of care in the last few days and hours of life**
  - [Priorities 1 to 5](#)
- **Our Commitment to you for end of life care: The government response to the review of choice in end of life care**

### Legislation

Care Act 2014

Data Protection Act 1998

Equality Act 2010

Health and Social Care Act 2008 (Regulated Activities) Regulations 2014

Human Rights Act 1998

## Indicative mapping to relevant national standards or frameworks

### Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life

- [Principle 7](#)

### Care Certificate Standards

- [Standards 10 and 11](#)

### Leadership Qualities Framework

### National Occupational Standards

- [SCDLMCSB2 Lead and manage provision of care services that promotes the well being of people](#)

### Regulated Qualifications Framework components (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

Level 5 Diploma in Leadership and Management in Adult Care

Level 4 Certificate in Principles of Leadership and Management in Adult Care

**The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- [Function C1, C2 and C4](#)

# Subject 15: Improving quality in end of life care through policy, evidence and reflective practice

## Introduction

The continuing development and improvement of end of life care requires on-going research and development of evidence-based practice, as well as a reliance on the end of life workforce being aware of, and implementing, this research and practice. This enables services to deliver end of life care in a way that is proven to be effective both in terms of the health and social care interventions offered, but also in meeting the individuals' various needs.

## Target audience

- Tier 1 those that require general end of life care awareness, focusing on a community development, asset based approach to care
- Tier 2 those in roles that will have some regular contact with people receiving end of life care
- Tier 3 those in roles which frequently involve providing end of life care

## Key learning outcomes

### Tier 1

#### The learner will:

- a) be able to participate in reviews, research and surveys, including service satisfaction surveys
- b) understand what is meant by 'informed consent'
- c) know where to obtain information about policy and evidence based practice

### Tier 2

*Tier 1 learning outcomes plus the following:*

#### The learner will:

- a) be aware of current guidance and evidence to inform assessment and decision making
- b) be aware of local and national end of life policy and where to find additional information about this
- c) be able to reflect on practice and learn from experiences
- d) be able to judge the value of information e.g. according to its source or evidence base

### Tier 3

*Tier 2 learning outcomes plus the following:*

#### The learner will:



- a) understand principles of evaluating quality of end of life care through audit and collection of data, including internal sources of evidence e.g. patient and service user experience surveys
- b) be able to analyse the impact of local and national drivers on current approaches to end of life care
- c) be able to evaluate how a pathway or policy in end of life care can support individuals and others
- d) be able to analyse local end of life care policy and strategy
- e) be able to use evidence to inform all areas of care
- f) understand principles and underpinning rationale of initiatives to facilitate better end of life care
- g) understand how evidence can be used to develop and improve the care provided for the individual, their family and carers, and improve service delivery
- h) be able to evaluate own care service delivery involving individuals, their family and carers
- i) understand how to critically review evidence to determine relevance to own decision-making
- j) be able to critically reflect on how the outcomes of national and international research can inform your workplace practices and service delivery
- k) be able to monitor and evaluate the outcomes of community skills projects
- l) understand the options available to further develop research skills such as advanced practice, clinical academia and research roles

## Relevant guidance and/or legislation

Sources of further guidance and information are presented in Appendix 1. Examples of key relevant guidance or legislation for this subject are as follows:

### Guidance

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020:**
  - [Ambition 5](#)
- **Mental Capacity Act 2005 Code of Practice (2007)**

### Legislation

Care Act 2014

Equality Act 2010

Mental Capacity Act 2005

## Indicative mapping to relevant national standards or frameworks

### National Occupational Standards

- [SCDHSC0442 Evaluate the effectiveness of health, social or other care services.](#)

**Regulated Qualifications Framework components** (due for review in January 2018)

Level 2 Award Awareness of End of Life Care

Level 3 Award Awareness of End of Life Care

Level 3 Certificate in Working in End of Life Care

Level 5 Certificate in leading and managing services to support end of life care and significant life events

**The Public Health Skills and Knowledge Framework (PHSKF) August 2016**

- Function A1

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# Appendix 1: Sources of further guidance and information

The following are sources of further guidance and information. Click on the links below to access the relevant web sites:

- [Citizens Advice](#)
- [Dying Matters](#)
- [Find Me Help](#)
- [Health Education England \(HEE\)](#)
- [Macmillan](#)
- [Marie Curie](#)
- [National Council for Palliative Care \(NCPC\)](#)
- [NICE](#)
- [NHS Choices](#) *End of Life Care Guide*
- [NHS Leadership Academy](#)
- [Public Health England](#)
- [Royal College of General Practitioners](#)
- [Royal College of Nursing](#)
- [Social Care Institute for Excellence \(SCIE\)](#)
- [Skills for Care](#)
- [Skills for Health](#)

## Appendix 2: Related standards and frameworks

### National Occupational Standards (NOS)

National Occupational Standards (NOS) are statements of the standards of performance for individuals when carrying out functions in the workplace, together with specifications of the underpinning knowledge and understanding. NOS are developed for employers by employers through the relevant Sector Skills Council or Standards Setting Organisation.

All national occupational standards are available from the [NOS Directory](#)

Competence search tools are also available from the [Skills for Health Tools web site](#).

### Care Certificate Standards

Following the Francis Inquiry, Camilla Cavendish was asked by the Secretary of State to review and make recommendations on the recruitment, learning and development, management and support of healthcare assistants and social care support workers. The resulting [report](#), published in July 2013, found that the preparation of healthcare assistants and social care support workers for their roles within care settings was inconsistent, and one of the recommendations was the development of the Care Certificate.

Skills for Health, Skills for Care and Health Education England worked together to develop and pilot the draft Care Certificate documents.

The Care Certificate was formally launched in April 2015, replacing both the National Minimum Training Standards and the Common Induction Standards. Further information about the Care Certificate is available from [Skills for Health](#) and [Skills for Care](#).

### Regulated Qualifications Framework components

The Office of Qualifications and Examinations Regulation ([Ofqual](#)) regulates qualifications, examinations and assessments in England.

The Regulated Qualifications Framework components listed in the framework are due for review in January 2018 and may be superseded at that time.

## Appendix 3: Glossary of terms

To be completed...	###
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## Appendix 4: Reference list

The following are key references which informed the development of this framework.

To be completed...

### Sub heading

Author/Organisation (date) Title: [hyperlink](#)

