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

Health Education England commissioned Skills for Health and Skills for Care to expand the *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life*[1] into this Core Skills Education and Training Framework for End of Life Care.

1. 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 (2nd edition)

Contents

Foreword

Death and dying is an inevitable part of life, and will occur in all settings: at home, in care homes, in hospices, hospitals and other institutions. As health and care staff, we have the opportunity to make a positive difference to the experience of people who are dying, and their families, carers and those important to them. This privilege brings with it the responsibility to equip ourselves properly, in the range of skills, knowledge, attitudes and behaviours that are needed to be able to support, care and treat people at this vulnerable time of their lives - not just at the very end of life, but also throughout the trajectory of their illness and, for their loved ones, after death has occurred.

Service providers, employers and commissioners carry a similar responsibility - to value and appreciate our workforce as a precious resource, and to educate, train and support accordingly. Looking after people who are facing the end of their lives, and those who are close to them, is tough physical and emotional work – it requires not only technically competent skills, but also fine judgement, kindness, compassion and resilience, all of which can take a significant toll over time, if not properly equipped and supported.

The *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* sets out 'All staff are prepared to care' as one of its six ambitions. The underpinning foundations of the Ambitions framework, and the building blocks within the other five ambitions, all have areas that require staff (and volunteer) training and development to turn them into reality. Moreover, there is good evidence that a positive staff experience is associated with improved patient experience and outcomes. So, investment in staff education, training and support simply makes good sense in all sorts of ways.

This framework, commissioned by Health Education England, and developed in collaboration with Skills for Health and Skills for Care, sets out the core skills and knowledge that are required in a clear and logical framework, against which local commissioners, services providers and clinical teams can benchmark their own standards, identify areas which need to be improved and take steps to address these. In the spirit of collaboration, they may also wish to identify areas of particular strengths which can be shared with others across the country. The Knowledge Hub, hosted on the Ambitions for Palliative and End of Life Care website (www.endoflifecareambitions.org.uk) provides a mechanism for sharing good practice.

Prof Bee Wee

National Clinical Director for End of Life Care, NHS England

Introduction

Background

Health Education England commissioned Skills for Health and Skills for Care to expand the *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life*[2] 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, considering the strengths, abilities and potential of communities in supporting end of life care.

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 National and 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;
- Working with Colleges and Professional associations on strengthening under and postgraduate curricula;
- Focusing on the conditions necessary to improve end of life care including experiential and work place based learning;
- Improving access to End of Life Care for All, e-learning programme (e-ELCA)[3]

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, 'end of life' refers to adults who are 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[4]

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2. 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 (2nd edition)

3. e-ELCA aims to enhance the training and education of the health and social care workforce so that well-informed high quality care can be delivered to people at the end of their lives by confident and competent staff and volunteers to support people wherever they happen to be. It has been developed by Health Education England e-Learning for Healthcare in partnership with the Association for Palliative Medicine of Great Britain and Ireland. e-ELCA comprises over 150 sessions of interactive learning, written and reviewed by experts in palliative care, in bite-sized chunks of 20–30 minutes.
For more information on e-ELCA, please visit: http://www.e-lfh.org.uk/programmes/end-of-life-care/

4. General Medical Council (2013), Treatment and care towards the end of life: good practice in decision making

'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[5]

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. End of life care includes palliative care; care that makes the individual as comfortable as possible by managing distressing symptoms through a holistic approach. Everyone will receive end of life care; most people will support a loved one through end of life care. Most people working in health and social 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 care 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.

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020[6] reframes the government's 2008 *National End of Life Care Strategy*[7] placing person-centred care at the forefront and presents six ambitions, based on collective experience and analysis of the many reviews and reports in to this area of care, along with what is needed to realise these ambitions. The 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

More recently, the Government in England published a national commitment to end of life care, *Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care*[8] which outlines the actions Government is taking to ensure that everyone has access to *'high quality, personalised end of life care built around their needs.'* These commitments are referred to throughout this Framework.

5. National Council for Palliative Care (2006), Ten questions to ask if you are scrutinising end of life care for adults.

6. 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.

7. Department of Health (2008), End of Life Care Strategy: Promoting high quality care for all adults at the end of life.

8. Department of Health (2016), Our Commitment to you for end of life care: The Government Response to the Review of Choice in End of Life Care.

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.

Source: Common Core Principles and competencies for social care and health workers working with adults at the end of life[9]

The *Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England*[10] 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 individuals who use care and support should rightly expect.

The '*6Cs*[11]', which underpin the new *Leading Change, Adding Value*[12] 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 health and social care provision, therefore underpinning all work in end of life care.

Scope of the framework

The framework will be applicable to health and social care employers, employees, patients, carers, the community, the 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.

Whilst much of the content of the framework will be applicable to supporting children and young people who are approaching the end of life, it has specifically been designed with adults in mind. This is because both the key documents that drove the framework's development refer to care and support for adults: *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*[13] and the *Common Core Principles and Competences for Social Care and Health Workers Working with Adults at the End of Life*[14].

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9. Skills for Care & Skills for Health (2014), Common Core Principles and competencies for social care and health workers working with adults at the end of life (2nd edition)

10. Skills for Care & Skills for Health (2013), Code of Conduct or Healthcare Support Workers and Adult Social Care Workers in England

11. Care, Compassion, Competence, Communication, Courage, Commitment

12. NHS England (2016), Leading Change, Adding Value

13. 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

14. Skills for Care & Skills for Health (2014), Common Core Principles and competencies for social care and health workers working with adults at the end of life (2nd edition)

The core knowledge and skills described in the framework are 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 individuals 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 limited contact with individuals approaching the end of life.

A community development, asset-based approach to care encourages individuals to look beyond traditional care provision, ask 'what is important to me?' and how this could be achieved alongside care and support from health and social care professionals. This might include: the strengths and abilities of individuals approaching the end of life; the strengths and abilities of their family, friends, loved ones and carers; and the potential of the community to provide care and support.

The tier will be relevant to you if:
- You are a member of the public
- You have been diagnosed with a life limiting condition
- You support someone with a life limiting condition
- You work in the adult health and social care sector but have limited contact with anyone approaching the end of life. For instance, you might deliver care and support in ophthalmology or physiotherapy, or may be in a role that doesn't deliver care and support such as administration or maintenance.

Tier 2 — Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment. However, they do not work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

The tier will be relevant to you if:
- You work in adult health and social care. Most of the individuals you support are not approaching the end of life, but some are. For instance, you might work on an acute ward, in a GP's surgery or in a residential care home.
- You work in adult health and social care and provide supervision and professional support to other professionals. Most of the people they provide care and support for are not approaching the end of life, but some are.
- You do not work in adult health and social care but your professional role means you often provide support for individuals approaching the end of life. You might be a religious leader, work for a community development project or offer art or activity therapy to individuals approaching the end of life.

Tier 3 — Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

The tier will be relevant to you if:
- You work in adult health and social care. Most of the individuals you support are approaching the end of life. For instance, you may work in a hospice or in a palliative care service.
- You work in adult health and social care and provide supervision and professional support to other professionals. Most of the people they provide care and support for are approaching the end of life.
- You work in adult health and social care. Most of the individuals you support are not approaching the end of life, but some are. Your role is to lead the end of life care offer within your team or organisation.

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-dated 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, and the public were included through an open online consultation which ran during October and November 2016.

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 the online consultation. Key references which informed the development of the framework are presented in Appendix 4. In particular, the framework builds upon recent 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 Voices 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
- Health Education 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)
- Health Education 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 14 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
- case study scenario

The subjects are numbered (1 to 14) 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).

Not all subjects will be relevant to all people – however, where a subject is relevant to a person's role, then it should describe the skills and knowledge which are common and transferable between settings.

How the framework can support you

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 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[15] 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.

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 deliver 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.

15. Bloom, B. S. (1956). Taxonomy of Educational Objectives. Vol. 1: Cognitive Domain. New York: McKay

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, and the people who are important to them

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.

From this point forward, where a term appears in **bold** *a definition is provided in Appendix 3. Terms are only made bold the first time they appear.*

Subject 1: Person-centred end of life care

Introduction

'Each person is seen as an individual… I am asked what matters most to me'[16]. This ambition is reflected in all recent best practice in **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 as independent as possible and have their strengths, abilities and values acknowledged[17].

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: Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3: Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

16. 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

17. The 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

Key learning outcomes

Tier 1

The learner will:

a) be able to engage in conversation with an individual nearing the end of life

b) understand and respect that individuals are experts in their own lives

c) understand and be willing to support the diverse needs and wishes of individuals, that may differ from your own

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 who is important to the individual and who they see as 'leading' their care

f) understand the part you play in the individual's end of life care and know where to seek support

g) understand importance of a **caring network** from which the individual and those important to them 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, prioritising individuals' wishes and beliefs to support them to retain independence, choice and dignity

b) be able to empower and support individuals manage their care and support and to make decisions based on their own experience, utilising professional support and guidance

c) be able to assess the needs, concerns and priorities of individuals and those important to them in a person-centred way, and support them to meet these needs

d) be able to support individuals to identify and manage risk

e) be able to work with individuals and **others** to develop a person-centred 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 recognise and suggest ways to overcome potential **barriers** individuals may face in accessing end of life care

b) understand and seek to manage, through advocacy or other methods, the potential service or organisational constraints and challenges a person-centred approach to end of life care 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 2015

- Every moment counts: A new vision for coordinated care for people near the end of life calls for brave conversations

- NICE guideline NG31 Care of dying adults in the last days of life (2015)

- 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
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
    - 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
    - Function B3
- Person-centred approaches: A core skills education and training framework (due for release in 2017)

Additional resources

Dying Matters information and resources including:

- Being with someone when they die;

- Talking about death and dying;

e-ELCA (End of Life Care for All)

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.

Individuals 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. They may also need support to communicate with loved ones, to talk about what matters to each of them and to make sure that the things they want to share do not go unsaid. 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. It is about more than *what* is said. It includes our tone of voice, ability to listen and understand, facial expressions, body posture and much more. It also includes the written word, charts, and diagrams.

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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 1

The learner will:

a) understand the importance of discussing dying, death and **bereavement**, and expressing wishes and preferences associated with this

b) know how to communicate own worries and concerns and assert own wishes about dying and the care provided, and be able to engage in activities to support this

c) be able to talk about death, dying and bereavement and actively listen to others

d) know how to be a good listener in relation to end of life discussions

Tier 2 and 3

Tier 1 learning outcomes plus the following:

The learner will:

a) be able to communicate sensitively with individuals and those important to them on a range of complex 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 support individuals and those important to them to express their feelings, preferences and needs alongside their strengths and abilities

c) understand the different barriers to communication at end of life, including where someone has additional care, support or communicate needs e.g. learning disabilities, cognitive impairment, sensory impairment, or where a situation makes it difficult to communication effectively e.g. noisy, distressing, emergency environments, and have strategies in place to overcome these barriers

d) know where to seek advice about difficult and complex matters or situations

e) understand how different customs and preferences, including religious and cultural customs, may impact on communication

f) be able to communicate appropriately across the age spectrum with people facing bereavement

g) 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 and that the ability and desire of individuals and those important to them to discuss end of life care issues may change over time

h) understand why silence is an important part of communication in end of life care, and feel confident in the value of silence

i) be able to use communication skills to ensure end of life care plans, and advance care plans, are understood and shared

j) be able to share information about the illness, its prognosis and support available to make informed decisions in a way that is accessible and uses appropriate language

k) be able to manage conflict where it arises between the individual and those important to them 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

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 2015
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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
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 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
- Person-centred approaches: A core skills education and training framework (due for release in 2017)
- 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

Dying Matters information and resources including:

- Being with someone when they die;

- Talking about death and dying;

- Family dynamics when someone is dying

e-ELCA (End of Life Care for All):

- Public access sessions, including: Communication Skills

- Modules requiring registration, including: Advance Care Planning; Assessment; Communication Skills; Symptom Management; Integrating Learning; Bereavement

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 and the people who are important to them.

Many aspects can be important to those experiencing end of life care and may affect an individual's experience and the support they need. These include beliefs, culture, disability, ethnicity, living conditions/circumstances, religion, spirituality, sexual identity and sexuality. Appropriate support should be made available. It should not be assumed that individuals and the people who are important to them share the same 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, and the people who are important to them experience end of life care. In a recent survey of people who had been bereaved, 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[18] These inequalities were further confirmed in 2016 when the Care Quality Commission published their report[19] on end of life care showing that some groups in society experience poorer end of life care than others because providers and commissioners do not always fully consider their specific needs. Addressing equality, diversity and inclusion in end of life care therefore also means ensuring 'each person gets fair access to care'[20].

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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

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18. Office for National Statistics (2015), National Survey of Bereaved People (VOICES)

19. Care Quality Commissioning (2016), A different ending: Addressing inequalities in end of life care

20. 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

Key learning outcomes

Tier 1

The learner will:

a) understand how bereavement and the grieving process may affect individuals 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 may hold different beliefs and values, or have had different life experiences

d) be able to distinguish between spirituality and religion

Tier 2 and Tier 3

Tier 1 learning outcomes plus the following:

The learner will:

a) understand the significance of diversity, including the impact that an individual's beliefs, customs, faith, life circumstances, religion, social norms, spirituality, sexuality and values can have on their preferences, their choices and the care provided, and be able to assess and support these needs and preferences

b) understand how an individual's awareness of spirituality may change as they approach death

c) be able to challenge poor, unethical or discriminatory practice

d) be able to recognise, assess and respond to the end of life care needs for individuals with a variety of diagnoses and in a variety of service and community environments

e) be able to find and facilitate access to specialist services or support groups to support individuals' diverse needs

f) be able to recognise where grieving and bereavement is complex and know who to refer to relevant services

g) understand the impact of social, environmental and economic issues on health and **wellbeing** for individuals and those important to them

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
- NICE guideline NG31 Care of dying adults in the last days of life (2015)

- 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
  - SCDHSC0234Uphold the rights of individuals
  - SCDHSC3111Promote 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
  - Function B2, B4

Additional resources

Dying Matters information and resources including:

- Bereavement

- Meaning, faith, belief;

- Talking about death and dying;

e-ELCA (End of Life Care for All):

- Public access sessions, including: Communication Skills

- Modules requiring registration, including: Advance Care Planning; Assessment; Communication Skills; Symptom Management; Bereavement: Spirituality

Subject 4: Community skills development in end of life care

Introduction

The 6th ambition within *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*[21] 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 and the people who are important to them. Death and dying are complex social events for which professional care is just one element[22].

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.

Health and social 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 and carers, as well as reaching out into the community to encourage engagement in end of life care discussions. 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;

- working alongside other specialist organisations to reach individuals or groups who are 'hard to reach' or who your organisation currently offers little or no support to

- 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 is from health and social 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[23].

21. 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

22. The National Council for Palliative Care (2016), Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six

23. The National Council for Palliative Care (2016), Each Community is Prepared to Help: Community Development in End of Life Care – Guidance on Ambition Six

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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 1

The learner will:

a) understand that supporting someone at the end of life and those important to them 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 and those important to them 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 and those important to them – 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 individuals should be seen within the context of their own community and be supported to participate and contribute to this as they wish

c) understand that the support needs of individuals and those important to them are wide ranging and extend far beyond the care, support and treatment provided by health and care professionals

d) understand how local community schemes could benefit individuals and those important to them

e) understand and be able to map the community assets available and how to access these to inform own practice, other staff and individuals and those important to them

f) be able to support individuals and those important to them to access local community groups and services and to understand the benefit this could bring

g) be able to support individuals and those important to them to consider their network of support (referred to as a 'caring network') which may extend beyond immediate family and friends

h) be able to develop the practical skills of individuals and those important to them to enhance networks, including: saying yes to offers of help and learning how to ask

i) understand the value of multi-disciplinary teams involving and including people from outside health and social care, e.g. community development workers, community leaders, individuals and their caring networks

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 to provide support for people approaching the end of life and those important to them

b) be able to promote and support effective relationships between communities, public bodies, voluntary organisations and other agencies that facilitate wellbeing at end of life for individuals, groups and communities

c) be able to facilitate learning opportunities for community development in relation to end of life care

d) be able to cascade information and skills in relation to community development in end of life care to colleagues, individuals and those important to them

e) be able to identify and overcome barriers to community skills development in end of life care

f) be able to promote the benefits of developing community skills and engaging with the local community amongst colleagues and senior managers/board members in relation to improving outcomes for individuals approaching the end of life and those important to them

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

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
  - SCDHSC3101Support the development of community networks and partnerships
  - SCDHSC3102Work 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
- Person-centred approaches: A core skills education and training framework (due for release in 2017)
- The Public Health Skills and Knowledge Framework
  - Function A2, B2

Additional resources

Dying Matters information and resources including:

- Community Pack

Dying Well Community Charter Pathfinder Project: Evaluation Report July 2016

e-ELCA (End of Life Care for All):

- Public access sessions, including:

- Modules requiring registration, including: Spirituality

NHS Choices End of Life Care Guide

Skills around the person: Implementing asset based approaches in adult social care and end of life care

Subject 5:
Practical and emotional support for the individual 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 their emotional, mental, psychological and spiritual wellbeing.

Having confidence in your 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 1

The learner will:

a) know how to offer support to someone who is dying

b) be able to ascertain from an individual what would make them comfortable and respond to this appropriately

c) understand the importance of promoting and maintaining the dignity of someone approaching the end of life

d) understand that the needs of individuals approaching the end of life in relation to food and drink may significantly reduce, especially within the last days of life

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 for more support

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) understand the process, types and different expressions of loss including; loss, bereavement, **grief** and mourning

b) be able to support individuals with thoughts associated with death and dying

c) understand the factors that could affect an individual's view of dying, including their physical, emotional, psychological, spiritual, cultural and religious needs

d) be able to undertake initial risk assessment of mental health and emotional needs including signs of depression

e) be able to demonstrate an awareness of the impact of dying

f) be able to assess when individuals need to be alone

g) be able to recognise and respond to individuals' concerns, fears and anxiety

h) be able to provide emotional, physical and psychological support to individuals to maintain comfort and well-being

i) 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

j) be able to provide individuals, through the use of networks and partnerships, with information on a range of resources, information and support available, how they might be accessed, and the potential risks and benefits

k) 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

l)   understand the need to be sensitive to the individual's changing circumstances, and adapt care and support accordingly

m) understand how to access advocacy services for individuals

Tier 3

Tier 1 and 2 learning outcomes plus the following:

The learner will:

a) understand internal and external coping strategies of individuals when facing death and dying

b) 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

c) be able to recognise complex grief, and refer to psychological services where appropriate

d) be able to advocate on behalf of the individual to ensure their voice is heard in family disagreements,

e) understand guidance, risks and benefits, and ethical considerations associated individual's food and drink related needs, including that related to clinically assisted nutrition and hydration

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 2015
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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
    - SCDHSC0226 Support individuals who are distressed
    - SCDHSC0350 Support 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

Dying Matters information and resources including:

- Being with someone when they die;

- Talking about death and dying

e-ELCA (End of Life Care for All):

- Public access sessions, including: Communication Skills

- Modules requiring registration, including: Communication Skills; Symptom Management; Integrated Learning;

NHS Choices End of Life Care Guide

Subject 6:
Assessment and
care planning in
end of life care

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 reflecting these needs ensure 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*[24], 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 a **Carer's Assessment** 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

24. Department of Health (2016), Our commitment to you for end of life care: The government response to the review of choice in end of life care

Key learning outcomes

Tier 1

The learner will:

a) understand the importance of having the individual's experiences, wishes and priorities included at all stages of assessment, planning and decision making, and be able to support individuals to express those wishes and beliefs

b) be able to encourage and support individuals to make decisions based on their own experience, utilising professional support and guidance

c) understand that the individual has a right to change their mind regarding the sort of care they want

d) 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**

e) understand how to plan for end of life care and future care for self or others, and how to access specialist support services

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) understand the importance of assessment and care planning being a **'holistic'** and person centred process

b) understand the content of individuals' care plans and advance care plans and the impact this has on care and support offered

c) understand when an end of life or advance care plan would be appropriate and be able to identify individuals who may benefit from these plans early

d) understand that individuals and those important to them have a choice in who they choose to discuss assessment and care planning with

e) be able to contribute to the assessment of a variety of needs individuals and those important to them may present in a person-centred, holistic, private and dignified way, using role-appropriate assessment tools, understanding the advantages and disadvantages of such tools

f) be able to provide information on **advance decision** planning for individuals and those important to them and check understanding

g) understand how an individual's beliefs, customs, faith, lifestyle, religion, social norms, spirituality and values may affect assessment and end of life care planning

h) understand why and how an individual's capacity will affect how assessment and end of life care planning takes place and when a mental capacity assessment may be required

i) know the importance of taking into account and acting on the observations and judgements of family and carers when planning end of life care, integrating their observations into assessment and care plans

j) understand why assessments and care plans need to be reviewed regularly and in partnership with others, including the individual and those important to them taking account of the changing needs and wishes of individuals

k) understand that some individuals will not wish to be involved in the care planning process, and respect this decision

l) be able to support and record decisions about advance care planning, understanding the difference between advanced decisions and advance statements

m) be able to use communication aids where appropriate to support assessments

n) be able to communicate and share information in an individual's care plan or advance care plan effectively with their permission with appropriate others, including ensuring that individuals' decisions, including advance care plan status and do not attempt cardiopulmonary resuscitation (CPR) instructions, can be seen 'at a glance'

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) be able to provide family with clear rationales for decisions made and make assessments openly

d) understand how to work in the best interests of an individual unable to participate in decision making

e) understand the complex variety of needs that should be considered when planning end of life care with individuals and those important to them

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)
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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 2010Data 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
  - SCDHSC0025Contribute to implementation of care or support plan activities
  - SCDHSC0328Contribute to the planning process with individuals
  - SCDHSC0329Support individuals to plan, monitor and review the delivery of services
  - SCDHSC0414Assess 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

Dying Matters information and resources including:

- Legal and ethical issues;

- Planning ahead;

- Planning for your future care

E-Learning for Health: e-ELCA (End of Life Care for All):

- Public access sessions, including: Advance Care Planning; Assessment; Communication Skills

- Modules requiring registration, including: Assessment; Advance Care Planning; Communication Skills; Symptom Management; Social Care

NHS Choices End of Life Care Guide

Subject 7:
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 and the people who are important to them 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 and the people who are important to them know when to alert professionals to deterioration and/or ask for extra support.

Health and social 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

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 the 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 or other treatment, especially at weekends and holidays

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) understand common symptoms associated with the approach of end of life

b) understand how different factors can alleviate or exacerbate pain and discomfort

c) understand the importance of a holistic understanding and assessment of the individual's perception of their symptoms and the impact this may have on their choices

d) understand the range of therapeutic options available including practical support or psychological therapy , for symptom management available to them and any potential risks and benefits

e) understand that symptoms have many causes and that different causes may require different approaches to treatment, care and support

f) understand that symptom and pain management should be organised around the needs of the individual, and delivered in a co-ordinated manner

g) be able to support the individual retain dignity during symptom management

h) understand the importance of, and know how to, provide regular symptom relief and measure its effectiveness

i) understand when to refer concerns about an individual's symptoms to specialist colleagues

j) understand local and national policy relating to medicines management

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-informed strategies to inform holistic assessment and management of symptoms associated with end of life in accordance with the individuals needs

c) understand the use of anticipatory treatments

d) be able to evaluate the significance of an individual's own perception of their symptoms

e) be able to work in partnership with others, including the individual and those important to them 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

f) understand the World Health Organisation's analgesic ladder and apply appropriately in accordance with local and national guidelines

g) understand implications of co morbidities and how to manage them

h) 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
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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
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, 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

Dying Matters information and resources including:

- Being with someone when they die;

- Understanding death and dying

E-Learning for Health: e-ELCA (End of Life Care for All):

- Public access sessions, including: Symptom Management

- Modules requiring registration, including: Symptom Management

NHS Choices End of Life Care Guide

Subject 8:
Working in partnership with health and care professionals and others

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 organisations, in delivering quality end of life care, as well the key role professionals working outside health and social care services play in end of life care, for instance financial and legal advisors or community workers and leaders.

Importantly, professionals should work collaboratively and communicate effectively with 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: Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3: Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 1

The learner will:

a) know who is involved in an individual's end of life care and be able to work in partnership with them to deliver care in a coordinated way organised around the individual's needs, knowing who to contact with any issues or questions

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) be able to work in partnership with others, exploring and integrating the views of wider multi-disciplinary teams to deliver care in a co-ordinated way, showing an understanding the role of others, to meet the needs of the individuals and those important to them

b) be able to share information, including that which relates to an individual's wishes, in a timely and appropriate manner with those involved in an individual's end of life care, taking into account issues of confidentiality and ensuring that where information is already available, the person is not asked to provide the same information repeatedly

c) understand referral criteria and processes for referral to specialist services to meet the needs of individuals and those important to them

d) understand the potential emotional impact of death and dying upon others and provide support

Tier 3

Tier 1 and 2 learning outcomes plus the following:

The learner will:

a) be able to develop self and others in relation to end of life care

b) be able to engage in challenging conversations with other professionals, demonstrating a commitment to partnership working to facilitate care

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
- NICE guideline NG31 Care of dying adults in the last days of life (2015)

- 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
  - SCDHSC0433Develop joint working arrangements for health and social care services
  - SCDHSC3100Participate in inter-disciplinary team working to support individuals
  - SCDHSC0399Maintain 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
  - Function B2

Additional resources

Dying Matters information and resources including:

  - Advice and resources for carers;

E-Learning for Health: e-ELCA (End of Life Care for All):

  - Public access sessions, including: Assessment; Symptom Management

  - Modules requiring registration, including: Assessment; Advance Care Planning; Communication; Symptom Management; Spirituality

Subject 9:
Support for carers

Introduction

The people important to the individual approaching the end of life should be at the centre of their support[25]; involved in discussions about, and the delivery of care; and have the opportunity to provide feedback[26]. Not only will individuals and the people who are important to them need support to do this, but they will also be experiencing a host of feelings including loss and grief, and will need support to manage and explore these feelings.

Many family members and loved ones will not recognise themselves as carers or understand the important role they play or the support they may require or are entitled to. 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.

It is important to recognise that grieving may start long before an individual's death, and that the support offered shouldn't stop upon an individual's death. Instead, families and carers may need time to explore their thoughts and feelings throughout their loved one's end of life care and beyond, and need 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 it is important to ensure that the individual and the people important to them are sensitively put in touch with other 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

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25. The 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
26. Department of Health (2016), Our commitment to you for end of life care: The government response to the review of choice in end of life care

Key learning outcomes

Tier 1

The learner will:

a) understand what it means to be a 'carer'

b) understand what support, services and resources are available, including practical and emotional support services, and know how to access them

c) understand how to access support for family conflicts

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) be able to offer support to someone who is bereaved and grieving

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) understand that carers may need support to recognise they have taken on a caring role

b) understand the importance of recognising the expertise of carers and important others and support them to continue performing tasks should they wish to do so

c) be able to recognise where a child or young person has taken on a caring role and refer to appropriate support services

d) be able to communicate effectively with carers to support them express themselves freely

e) understand the impact of, and different factors that may affect carers' response to, death grief, loss and bereavement

f) understand the need to be sensitive to carers' changing circumstances and needs, and adapt care and support accordingly

g) be able to use networks and partnerships to identify resources, information and support for carers in their community, and make referrals where appropriate

h) be able to support those important to the individual to maintain their relationships

i) be able to offer assessment to carers

j) understand the duty of local authorities to undertake carer's assessments

k) be able to sensitively support those important to the individual when individuals are making advance care planning decisions

l) be able to offer guidance and/or training to carers on practical aspects of care

Tier 3

Tier 1 and 2 learning outcomes plus the following:

The learner will:

a) be able to undertake appropriate bereavement risk assessment

b) be able to provide support to, and communicate effectively with, children and young people who have taken on a caring role

c) be able to explain to families their role in **best interest decision** making

d) understand how conflicts may arise between individuals and those important to them and be able to navigate these complex relationships

e) 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

f) be able to evaluate models and theories of loss and grief

g) be able to provide additional support around practical issues to family and carers where death has been unexpected, e.g. post mortems, coroners, death verification and 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
- Carers Strategy (2014)
- 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)
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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
- Common Core Principles for Working with Carers
- Care Certificate Standards
  - Standards 5 and 6
- National Occupational Standards
  - SCDHSC0387Work in partnership with carers to support individuals
  - SCDHSC0426Empower families, carers and others to support individuals
  - SCDHSC0427Assess 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

Dying Matters information and resources including:

- Advice and resources for carers;

- Bereavement;

- Carers: information for professionals, services and decision-makers;

E-Learning for Health: e-ELCA (End of Life Care for All):

- Public access sessions, including: Communication; Symptom Management

- Modules requiring registration, including: Assessment; Symptom Management; Bereavement

NHS Choices End of Life Care Guide

Subject 10:
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 psychological 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 is 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: Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3: Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 1

The learner will:

a) understand the importance of caring for yourself and others providing caring roles

b) understand the potential emotional impact of death and dying on oneself and others involved in caring for the person at end of life

c) know how to access support to help oneself and others involved in caring for the person at end of life, including accessing a caring network

Tier 2

Tier 1 learning outcomes plus the following:

The learner will:

a) understand the potential impact the death of an individual may have on own feelings

b) understand the importance of making good use of the support available (for example through formal supervision or informally from colleagues), reflecting on practice, identifying learning needs and accessing further support for such needs

c) be able to offer support to colleagues

d) understand what is mean by 'emotional **resilience**' and be able to access support to build this

e) understand how own experiences, views and beliefs relating to death, dying, loss and bereavement may affect the care provided to individuals.

f) understand own role and the limits of own knowledge and competence, and know where to seek support

Tier 3

Tier 1 and 2 learning outcomes plus the following:

The learner will:

a) understand the potential impact of frequent exposure to death and bereavement

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 information and resources including:

- At the bedside;

- Practicalities to think about when someone is dying

E-Learning for Health: e-ELCA (End of Life Care for All):

- Modules requiring registration, including: Symptom Management

Subject 11:
Care after death

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 the people who are important to the individual), 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

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, including preparing the body for family and carer visits where appropriate

b) understand and follow legal and ethical requirements, agreed ways of working, processes and procedures following death

c) understand which organisations should be contacted following an individual's death, and the purpose of such contact

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) understand what details need to be recorded when caring for and transferring a deceased person, including recording property and valuables

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
- Care After Death: Guidance for staff responsible for care after death
- 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
Human Rights 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

Dying Matters information and resources including:

  - What to do after someone dies

E-Learning for Health: e-ELCA (End of Life Care for All):

  - Modules requiring registration, including: Assessment; Integrating Learning

Subject 12:
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*[27], 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 is 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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

27. The Choice in End of Life Care Programme Board (2015), What's important to me: A Review of Choice in 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, implications and legal status of **statements of wishes and preferences**, **informed consent**, best interest decisions, advance care plans and advance decision to refuse treatment

b) understand the provisions of the **Mental Capacity Act 2005**

c) understand own role in safeguarding individuals

d) understand the legal and ethical requirements and agreed ways of working that protect the rights of individuals at the end of life, and know how to access expert advice regarding these

Tier 3

Tier 1 and 2 learning outcomes plus the following:

The learner will:

a) understand legal and ethical aspects of decision-making to inform discussions within the multi-professional team, and with individuals, families and carers

b) be able 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

c) understand the process of addressing conflicts and continuing differences of opinion including seeking a second opinion, facilitating communication and when a court ruling needs to be sought

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)
- NICE guideline NG31 Care of dying adults in the last days of life (2015)
- 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 abuse
  - 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 Aware 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

Dying Matters information and resources including:

- Concerns about end of life care;

- Legal and ethical issues;

- What to do after someone dies

E-Learning for Health: e-ELCA (End of Life Care for All):

- Modules requiring registration, including: Assessment; Advance Care Planning; Communication; Social Care; Bereavement; Spirituality

Subject 13:
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.

A Care Quality Commission report[28] 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: Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3: Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

Key learning outcomes

Tier 2

The learner will:

a) be able to provide support for colleagues to develop their skills and confidence when working with individuals at the end of life and those important to them

b) be able to provide effective supervision and support regarding end of life care, enabling team members to manage their own feelings, reflect on practice and improve service delivery

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28. Care Quality Commission (2015), State of health care and adult social care in England 2014/15

c) be able to facilitate workers to offer support and guidance to each other regarding caring for individuals at the end of life

d) be aware of local and national policies shaping the delivery of end of life care and how these influence service delivery

Tier 3

Tier 2 learning outcomes plus the following:

The learner will:

a) be able to implement, local and national policies shaping the delivery of end of life care and influence service delivery

b) be able to implement evidence-based research, innovations and developments in end of life care

c) 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 individuals at the end of life

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 implement strategies to empower and support staff involved in the delivery of end of life care to ensure positive outcomes for individuals and others

f) be able to critically reflect on methods for measuring the end of life care service against national indicators of quality

g) understand the importance of collecting quality assurance information including from individuals and those important to them, and act on feedback received

h) understand how integrated service provision that crosses traditional boundaries achieve better outcomes for individuals, including integrating with the community

i) be able to analyse how reflective practice approaches can improve the quality of end of life care services

j) be able to analyse the features of effective partnership working within own work setting

k) understand how legislation and regulation influence partnership working, including how information is shared

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 wellbeing 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
  - Function C1, C2 and C4

Additional resources

E-Learning for Health: e-ELCA (End of Life Care for All):

- Modules requiring registration including Learning pathways for social care managers and healthcare managers

Subject 14:
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:   Health and social care professionals who require some knowledge of how to provide person-centred, high quality end of life care as they often encounter individuals who need such support within their working environment.

Tier 3:   Health and social care professionals who require in-depth knowledge of how to provide care and support for an individual approaching the end of life because they work in services that primarily offer care and support for individuals approaching the end of life, their family and carers.

For full tier descriptions, please refer to the 'Scope of the framework' section.

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

e) understand how to use the national end of life intelligence network data and other data sources to determine population needs

Tier 3

Tier 2 learning outcomes plus the following:

The learner will:

a) understand how evidence can be collected and used to develop and improve the care provided for the individual and those important to them and improve service delivery

b) be able to analyse how local and national policy and the outcomes of research in end of life care can inform and impact on workplace practices and care delivery

c) understand principles and underpinning rationale of initiatives to facilitate better end of life care

d) understand the options available to further develop research skills such as advanced practice, clinical academia and research roles

e) be able to evaluate how a plan or policy in end of life care can support individuals and those important to them

f) be able to evaluate own care service delivery involving individuals and those important to them

g) understand how to critically review evidence to determine relevance to own decision-making

h) be able to critically reflect on how the outcomes of national and international research can inform your workplace practices and service delivery

i) understand ways to address end of life population needs across health and social care and organisational boundaries

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
  - Function A1

Additional resources

- E-Learning for Health: e-ELCA (End of Life Care for All):
  - Modules requiring registration, including: Integrating learning

Appendix 1:
Sources of further guidance and information

The following are sources of further guidance and information. *This is not an exhaustive list of the information and guidance available regarding end of life care.* Click on the links below to access the relevant web sites:

- Ambitions for Palliative and End of Life Care

- Age UK

- Citizens Advice Bureau

- British Medical Association

- Dying Matters

- End of Life Care for All

- Find Me Help

- Health Education England (HEE)

- General Medical Council

- Gold Standard Framework

- Macmillan

- Marie Curie Cancer Care

- National Council for Palliative Care (NCPC)

- National End of Life Care Intelligence Network

- 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

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

Active listening	Includes: • Ability to pick up on non-verbal cues • Listening for key words as signposts to emotions • Understanding the meaning of silence • Using body language and facial expression to indicate interest and empathy
Active participation	A way of working that recognises an individual's right to participate in the activities and relationships of everyday life as independently as possible; the individual is regarded as an active partner in their own care or support, rather than a passive recipient
Advance Care Planning	The voluntary process of discussion between an individual and their care providers to make clear the individual's wishes regarding their ongoing care in the context of anticipated deterioration of their health with loss of capacity to make decision or communicate wishes in the future
Advance decision to refuse treatment	A decision, made by the individual, specifically related to the refusal of medical treatment in certain circumstances to come into effect when the individual has lost capacity to give or refuse consent to treatment.
Agreed ways of working	Will include policies and procedures where these exist
Asset-based approach	A way of working that considers the strengths and potential of individuals and communities.
Barriers	These can include barriers of culture, gender, religion, language, literacy, health issues, disability, sensory or physical impairment
Bereavement	Period of mourning after a death
Best interest decisions	A decision made on an individual's behalf because they no longer have the capacity to make the decision themselves. A best interest decision is based on the individual's previously expressed wishes and preferences and should be the least restrictive option available.
Carer	A carer is someone who spends a significant amount of their time providing unpaid support to a family member or friend.
Carer's Assessment	An assessment the local authority must inform carers of their right to. It assess carers' own needs and the services that are available to support them

Caring network	An informal group of people who come together to provide care and support to an individual approaching the end of life or those important to them. The make-up of a caring network is dependent upon the needs of the individual at the centre of the network. Some networks include friends and family. Others will include health and care professionals. Others will include members of the community, neighbours, community groups or online support groups.
Community development	How local people can engage with their communities and be empowered to share their skills and knowledge with others to improve wellbeing across their community. A community may be based on geography, interest or identity.
End of Life	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
End of Life Care	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.'
Grief	Intense feelings of sorrow
Holistic	A holistic approach considers the whole person. It considers internal physical, emotional, mental, spiritual aspects of an individual as well as the external context of an individual's experiences.
Individuals	The person receiving support or care
Informed Consent	An individual must give permission before they receive any care, support or treatment. For consent to be valid, it should be given voluntarily, be based on accurate information including risks and benefits, and the individual giving consent must have the capacity to do so.
Lasting power of attorney	Anyone who has the capacity to do so may choose a person to take decisions on their behalf should they subsequently lose capacity.
Mental capacity	The ability to make your own decisions based on an accurate understanding of information, retaining the information long enough to make a decision, weighing up information and communicating a decision.
Mental Capacity Act	A legal framework for acting and making decisions on behalf of adults who lack the capacity to make particular decisions for themselves. It is designed to protect and restore power to those vulnerable people who may lack capacity to make certain decisions, due to the way their mind is affected by illness or disability, or the effects of drugs or alcohol. It also supports those who have capacity and choose to plan for their future.

Others	May include: Partner, family, friends, neighbours, health and care professionals, anyone else involved in providing end of life care to the individual
Person-centred care	Care that takes account of and actively promotes individuality, rights, choices, privacy, independence, dignity, respect and partnership
Resilience	The ability to cope under pressure
Statement of wishes and preferences	A summary term used to describe a range wishes and preferences recorded by the individual in relation to their future care. They can cover medical and non-medical matters. Although not legally binding, statements of wishes and preferences should be used to determine what is in the individual's best interest if they lose capacity to make decisions themselves.
Wellbeing	A person's wellbeing may include their sense of hope, confidence and self-esteem, their ability to communicate their wants and needs, to make contact with others, to show warmth and affection, and to experience and show pleasure or enjoyment

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Using the framework at Cedar Lodge

The following scenario has been adapted from *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*[29] which has been superseded by this End of Life Core Skills Training and Education Framework.

Scenario:

Alec is an 87 year-old widower living at Cedar Lodge, a residential care home. He has lived in the home for the past two years, and during that time has had the same key worker, Amana.

Alec's three children are all regular visitors to the home.

He has recently been diagnosed with renal failure, and his life expectancy is only a few months without dialysis. In the past Alec has made it clear that when his "time comes" he wants to be able to stay at Cedar Lodge, and "go quietly". He has stated that he does not want any treatment that will prolong his life. This means he has chosen not to accept dialysis.

A planning meeting, involving Alec, his family, and health and social care workers has taken place, and a care and support plan has been put in place to help Alec to live comfortably at Cedar Lodge. This has included a discussion, led by Alec, about his wishes. He has made it clear that he does not want any medical intervention to prolong his life, and this has been recorded in an 'advance care plan'. Alec's two daughters are supportive but his son, Martin, has difficulty accepting the decision.

As well as input from his GP, Alec will be receiving regular support from specialist nurses to manage his symptoms and keep him comfortable. Day-to-day care and support will continue to be provided by Cedar Lodge care workers. Alec's daughters and Martin will spend time with their father each day.

This is the first time since she began working at the home that Amana has been closely involved with someone who is dying, and she is both upset and anxious about caring properly for Alec and discusses her concerns, feelings and where she sees gaps in her experience with her line manager, Maggie.

As the home manager, and Amana's line manager, Maggie is responsible for ensuring that Amana and other employees are properly trained and supported so that Alec's needs, the needs of his family and the needs of others in similar situations, are properly addressed.

Maggie decides to use the End of Life Core Skills Education and Training Framework (EoLC CSETF) with her workers to assess gaps in knowledge and skills, prioritise these gaps and implement learning and development opportunities.

Maggie and her team recognise that, whilst they are eager to begin their end of life care development, it will take significant commitment in terms of time and resources to achieve competence in every area of the End of Life Core Skills Training and Education Framework alongside their current work

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29. 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

and development commitments. They each prioritise areas to work on first and agree short term (1-6 months), medium term (6-12 months) and long term (12-18 months) action plans.

Examples of how four workers intend to develop their knowledge and skills in end of life care are described below. These are hypothetical plans intended to provide the health and social workforce with ideas of how they can implement this framework within their organisation to improve the quality of care provided for individuals approaching the end of life. Examples assume best practice in learning and development is taking place.

Senior Care Worker (Tier 3)

Robert is a Senior Care Worker at Cedar Lodge. In his self-assessment, he was confident he could demonstrate most of the learning outcomes at Tier 2 in all but two of the subject areas (*Community skills development* and *Leading end of life care services and organisations*) due to previously working for a number of years in a hospice, but worried he was 'out of practice'.

He was less confident in his abilities at Tier 3 but still felt there were a significant number of learning outcomes he had already achieved and could demonstrate competence in.

Robert expressed an interest in developing more specialist knowledge and skills in end of life care and Maggie agreed that, over time, Robert would develop competences at Tier 3 to enable him to lead on end of life care at Cedar Lodge.

Robert and Maggie agreed that his priority would be to use his current experiences in a hospice to support the development of the rest of the workforce.

Robert's short term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes

To support others develop knowledge and skills in the subject areas they have prioritised	• Prepare and deliver short information sharing sessions at team meetings in the following areas:
	  • Communication in end of life care
	• Practical and emotional support for the individual approaching the end of life
	  • Assessment and care planning
	  • Support for carers
		• Timely development of care worker and non-care worker knowledge and skills to support Alec and his family in a more confident and capable way.
		• Improved knowledge and skills of the workforce
			Tier 2 and 3 in:
			• Leading end of life care services and organisations

Consider how Cedar Lodge could support residents to access community groups and services outside the care home environment	• Work with a small internal team to generate information about other services and activities available to Cedar Lodge residents and loved ones in the locality – focusing initially on the interests, hobbies and support needs of Alec and his family, but also those of other residents	Identification of appropriate or specialised support services for Alec, his children and other residents	Tier 1 and 2 in: • Community skills development Tier 1, 2 and 3 in: • Support for carers

| Improve confidence in supporting someone at the end of life | • Identify e-elca sessions to refresh knowledge and skills in supporting individuals at the end of life and their loved ones.
• Complete sessions pertinent to supporting Alec and his family identified as:
   • *'What will it be like?' – talking about the dying process*
   • *'Why me?' – discussing spiritual distress*
   • *Dealing with challenging relatives*
• Share refreshed knowledge with colleagues. | • Provision of improved, more personalised support for Alec and his family | Tier 2 and 3 in:
• Communication in end of life care
• Equality, diversity and inclusion in end of life care
• Practical and emotional support for the individual approaching the end of life
• Support for carers |

Robert's medium term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes

Address the knowledge and skills gaps at Tier 3 highlighted through self-assessment, prioritising where largest gaps are:
• Symptom management in end of life care
• Working in partnership with health and care professionals and others
	• Complete medication administration training update
	• Use resources contained with the EoLC CSETF and elsewhere to research information to support Tier 3 learning outcomes
	• Complete additional e-elca sessions including sessions under:
	   • *Symptom management: last days of life*
	   • *Symptom management: pain*
	   • *Condition specific case studies*
	   • *Social care*
		• Improved, coordinated care provision for individuals approaching the end of life and those important to them	Tier 3:
			• Symptom management in end of life care
			• Working in partnership with health and care professionals and others

Continue to support others in delivering end of life care in subject areas they have prioritised	• Offer further information sharing sessions to internal colleagues	• Continued development of care worker and non-care worker knowledge and skills to support individuals and those important to them in a more confident and capable way	Tier 2 and 3 in: • Leading end of life care services and organisations

Become the lead worker and point of contact for end of life care at Cedar Lodge	• Represent Cedar Lodge at end of life care planning meeting (initially with support from Maggie) • Become a point of contact and support for internal and external colleagues regarding end of life care (initially with support from Maggie)	• Improved access to external services for individuals and those important to them • Improved wellbeing and quality of life for individuals and those important to them • Improved awareness, relationships and reputation within the community	Tier 3 in: • Working in partnership with health and care professionals and others • Maintain own health and wellbeing when caring for someone at the end of life • Leading end of life care services and organisations

Participate in developing knowledge and skills related to:
 	
• Community skills development
	• Following initial work to generate information about other services and activities available to Cedar Lodge residents those important to them in the locality, Robert will:
	
	  • Use some of the guidance and resources referred to in the EoLC CSETF to develop his understanding of this subject further
	
	  • Work alongside colleagues to ensure the needs of individuals approaching the end of life care and those important to them are reflected in community skills work
		• Improved access to external services for individuals and those important to them
		
		• Improved wellbeing and quality of life for individuals and those important to them
			Tier 1, 2 and 3:
			
			• Community skills development in end of life care

Care Workers (Tier 2)

At any one time it is normal for several residents of Cedar Lodge's residents to be diagnosed with life limiting conditions and for one or two residents to have end of life care plans. To ensure care workers are competent to provide end of life care, Maggie and her team therefore agree they will work towards achieving outcomes at Tier 2.

Whilst Maggie recognises that several of her care workers have not had specific training on areas such as advance care planning or carers' rights, she is initially surprised by Amana's concerns, and those expressed by other experienced workers, in relation to areas such as *Communication and Equality, diversity and inclusion*. She views her team as being extremely competent and caring and receives positive feedback about them from residents and their loved ones. It becomes clear though that Amana and her colleagues' concerns are in relation to how they apply the skills and knowledge they demonstrate every day to caring for someone at the end of their life. They worry about saying the 'wrong thing' to Alec and his family; they want to be able to answer Alec's questions, and those of this family, confidently; they want to make sure they can make Alec's last days as comfortable as possible and reduce any distress he or his family face.

Amana has raised a specific interest in supporting Cedar Lodge engage with the community better. They agree that the next steps will be to explore how they can support residents to access more varied services outside the care home to improve their wellbeing and quality of life.

Amana's short term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Develop confidence in providing end of life care for Alec, specifically in areas of: • Communication • Practical and emotional support for the individual approaching the end of life	• Attend and participate in information sharing sessions at team meetings delivered by Senior Worker, Robert. • Identify e-elca sessions to address gaps in knowledge and skills • Complete sessions pertinent to supporting Alec and his family identified as: a selection of sessions within the Communication module • Participate in role-play scenarios with line manager, Maggie, to practice skills • Participate in peer-to-peer observations of skills (with Alec's consent) • Give, receive and act on feedback from observations • Reflect on practice, challenging situations and positive experiences	• Timely development of knowledge and skills to support Alec and his family in a more confident and capable way	Tier 1 and 2: • Communication • Practical and emotional support for the individual approaching the end of life

Develop own understanding of the impact of death and build resilience	• Use supervision to discuss the expected and actual impact of residents' deaths • Use formal and informal support systems e.g. team meetings and coffee breaks to share feelings and gain/ offer emotional support • Research external services	• Ability to access support, understand own feelings, build resilience and cope with emotions and feelings associated with death and bereavement	Tier 1 and 2: • Maintain own health and wellbeing when caring for someone at the end of life • Care after death
Develop confidence in supporting Alec's family by achieving outcomes in: • Support for carers	• Attend and participate in information sharing sessions at team meetings delivered by Senior Worker, Robert. • Participate in role-play scenarios with line manager, Maggie, to practice skills • Give, receive and act on feedback from observations	• Timely development of knowledge and skills to support Alec's family in a more confident and capable way	Tier 1 and 2: • Support for carers
Consider how Cedar Lodge could support residents to access community groups and services outside the care home environment	• Work with a small internal team to generate information about other services and activities available to Cedar Lodge residents and loved ones in the locality – focusing initially on the interests, hobbies and support needs of Alec and his family, but also those of other residents	• Identification of appropriate or specialised support services for Alec, his children and other residents	Tier 1 and 2: • Community skills development • Support for carers

Amana's medium term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Address the knowledge and skills gaps at Tier 2 highlighted through self-assessment, prioritising where confidence is lowest: • Equality, diversity and inclusion in end of life care	• Use the resources referred to in the EoLC CSETF to develop knowledge and understanding of the subject • Identify e-elca sessions to address gaps in knowledge and skills • Complete a selection of sessions within the *Spirituality, Assessment and Symptom Management* modules • Participate in role-play scenarios with line manager, Maggie, to practice skills • Participate in peer-to-peer observations of skills (with Alec's consent) • Give, receive and act on feedback from observations	• Development of knowledge and skills to support Alec, his family and other residents in a more confident and capable way	Tier 1 and 2: • Equality, diversity and inclusion in end of life care

| Participate in developing knowledge and skills related to:

• Community skills development | • Following initial work to generate information about other services and activities available to Cedar Lodge residents and loved ones in the locality, Amana will:

  • Use the guidance and resources referred to in the EoLC CSETF to develop her understanding of this subject further.

  • Lead work, alongside colleagues, to develop better links within the community and support residents access a wider variety of services and groups | • Improved access to external services for individuals and those important to them

• Improved wellbeing and quality of life for individuals and those important to them | Tier 1, 2 and 3:

• Community skills development in end of life care |

Following her sessions with Robert, Amana expresses an interest in delivering some sessions later on about what she has learnt about the community and use team meetings as a forum to plan how to develop these links further. Maggie suggests that they work steadily towards this given the other learning and development commitments Amana has taken on

Amana's long term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Share understanding of what the local community has to offer and develop relationships for the benefit of residents	• Prepare and deliver short information sharing sessions at team meetings on what Amana has learnt about their community and what support is available • Lead team meeting discussions to explore how to support residents and their loved ones make the most out of what the community has to offer	• Improved access to external services for individuals and those important to them • Improved wellbeing and quality of life for individuals and those important to them	Tier 1, 2 and 3: • Community skills development in end of life care

Non-Care Workers and volunteers (Tier 1)

Maggie wants to ensure that everyone working at Cedar Lodge, regardless of whether they provide care for residents or not, is able to behave in a person centred, caring and compassionate manner and able to respond to situations regarding end of life care appropriately. She also recognises that the knowledge, understanding and skills detailed within the EoLC CSETF can support people to be able to support someone at the end of life outside the workplace or to plan for one's own death.

Maggie decides that workers who do not provide care, e.g. the receptionists, maintenance worker and kitchen staff at Cedar Lodge, meet the criteria for Tier 1. These workers will have contact with individuals approaching the end of life and with their visiting family and friends from time to time.

Maggie also manages a small team of volunteers who carry out various activities at Cedar Lodge including gardening, art therapy and activity evenings. Maggie assesses her volunteers as currently meeting the criteria for Tier 1, however recognises that if they take on additional roles or more responsibility, they may require some knowledge and skill at Tier 2.

Kamran is a cook at Cedar Lodge. Kamran often drops into the residents' lounge after his shift or into the dining room at meal times for a chat, but Alec's family often visit at these times or take him out for lunch. However, Kamran realises that as Alec's health deteriorates he'll likely see more of him and wants to be able to offer support. Kamran is really pleased that Maggie has agreed for him and his team to undertake some end of life care training. He also asks Maggie if Alec might need a special diet or if he'll need to make any other changes to meal preparation.

Kamran's short term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Develop confidence, knowledge and skills in understanding end of life care and offering appropriate support	• Attend and participate in information sharing sessions at team meetings delivered by Senior Worker, Robert • Complete the open access e-elca sessions	• Understanding of end of life care in the context of the individual and their environment • Ability to engage in a caring and personalised way with individuals approaching the end of life and their loved ones	Tier 1: • Communication in end of life care • Practical and emotional support for the individual approaching the end of life • Support for carers
Understand any special dietary requirements associated with deteriorations of Alec's health	• Have an initial discussion with one of Alec's specialist nurses • Liaise with Amana regarding Alec's care plan	• Meeting Alec's changing nutritional requirements • Maintain Alec's comfort and wellbeing	Tier 1: • Practical and emotional support for the individual approaching the end of life

Kamran's medium term action plan:

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Develop confidence, knowledge and skills in understanding end of life care and offering appropriate support	• Attend and participate in information sharing sessions at team meetings delivered by Senior Worker, Robert. • Review e-elca sessions available and complete those relevant	• Understanding of end of life care in the context of the individual and their environment • Ability to engage in a caring and personalised way with individuals approaching the end of life and their loved ones	Tier 1 in a variety of subject areas

Care Home Manager (Tier 2 and in some cases Tier 3)

Maggie's self-assessment showed she was confident in her ability to meet most of the knowledge and skills outcomes in each subject under Tier 2 but there were certainly gaps and areas for improvement noted.

Maggie decides she wants to ensure she is able to meet the learning outcomes in Tier 3 for several subjects too but prioritises: *Law, ethics and safeguarding; Leading end of life care services and organisations*; and *Improving quality in end of life care through policy, evidence and reflective practice*. She feels these areas will enable to her to better support her workforce and drive improvements for individuals approaching the end of life.

In addition to these areas, Maggie decides to work towards achieving Tier 2 and Tier 3 outcomes in *Community skills* development. Maggie is pleased that Amana wants to lead this work and that Robert will be involved, but feels that support and involvement from management would be beneficial and help extend their reach and operate at a more strategic level.

Maggie's short term action plan: *In addition to supporting her workforce achieve their action plans*

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes

Refresh confidence in supporting someone at the end of life, and support others to do this	• Use the recommendations provided through the 'Learning Pathways' resources on the e-lfh website to identify e-elca sessions to complete as a priority to support Alec, his family and her workforce
	• Complete identified e-elca sessions:
	  • 'Am I dying?' 'How long have I got' – handling challenging questions
	  • 'What will it be like?' – talking about the dying process
	  • Discussing 'do not attempt CPR' decisions
	• Use the resources referred to in the EoLC CSETF to develop knowledge and understanding of the subject
		• Provision of improved, more personalised support for Alec and his family
		• Improved ability to support the workforce
			Tier 2 and 3:
			• Communication in end of life care
			• Law, ethics and safeguarding
			• Leading end of life care services and organisations

Maggie's medium term action plan: *In addition to supporting her workforce achieve their action plans*

Need	Action	Outcome	Relevant EoLC CSETF learning outcomes
Review end of life care at Cedar Lodge to assess effectiveness of short and medium term action plans. Plan for further learning and development	• Assess the knowledge and skills of the workforce against the EoLC CSETF – making comparison to initial self-assessments • Work with residents and their loved ones to assess their experiences of end of life care at Cedar Lodge • Research initiatives and evidence bases that demonstrate effective responses to caring for individuals at the end of life • Plan activity to address any skills gaps or concerns and enable further development	• Understanding of current knowledge and skills • Evidence of how learning and development activity has affected knowledge, skills and confidence of workers • Evidence of how residents and their loved ones experience care • Plans for further improvements in end of life care for individuals and their loved ones	Tier 2 and 3: • Improving quality in end of life care through policy, evidence and reflective practice
Participate in developing knowledge and skills related to: • Community skills development	• Work alongside Amana in contacting and building relationships with community groups and services • Develop strategic relationships with others services	• Improve the wellbeing and quality of life for Cedar Lodge residents and their loved ones	Tier 1, 2 and 3: • Community skills development in end of life care