Core competences for end of life care

Training for health and social care staff

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

To support the National End of Life Care Strategy

NHS National End of Life Care Programme

Skills for Health

skillsforcare

DH Department of Health

Contents

Foreword

The End of Life Care Strategy was published in July 2008.

It recognised that the delivery of quality end of life care services to individuals, their families and carers will require nothing less than a cultural shift in attitude and behaviour within the health and social care workforce.

The Department of Health, working with the NHS End of Life Care Programme, has commissioned three foundation projects based on the core common requirements for workforce outlined in the strategy to start taking this work forward:

- Developing competences and core principles
- Producing a suite of e-learning modules
- Identifying related communication skills training at all levels

This document reflects the work undertaken to date on developing workforce competences and core principles as they relate to end of life care. Skills for Care and Skills for Health working in partnership with the Department of Health and the NHS End of Life Care Programme have spent the past year on development and consultation with a wide range of expert groups and organisations. We recognise that the work has been challenging, as the outcomes must meet the differing needs of health care and social care and use a terminology that both can relate to. We believe that this work goes a long way to meeting those challenges and should be seen as a milestone in development and not a finished product. Thanks are extended to the people who participated in the development of this document - field test sites, stakeholder group members, the Department of Health, Skills for Care, Skills for Health, the National End of Life Care team and everyone who contributed actively to the consultation document.

Over the next 12 months work will continue to apply these competences and core principles to practical applications. The work will also include raising awareness and helping commissioners and providers of services to identify and address the necessary knowledge, skills and attitudes needed to support quality services as well as helping individual workers identify their own development needs.

Development of the workforce will take time but must not be taken as an excuse for inaction. Some employers and workers may not make an immediate connection to this area of work - but there are very few working across health and social care, and other sectors such as police and housing services, who will not at some time interact with the stages of the end of life care pathway.

We would therefore urge those of you who are reading this to become our 'champions' disseminating this document amongst your networks and contacts and encouraging them to work with us during the next stage. Working together we will be able to translate this work into some early benefits for individuals and their carers as well as being rewarding for those providing the services.

Andrea Rowe
Chief Executive
Skills for Care

John Rogers
Chief Executive
Skills for Health

Professor Mike Richards
National Clinical Director
End of Life Care

End of Life core competences and principles - overview

These common core competences underpin all levels of practice and are defined by:

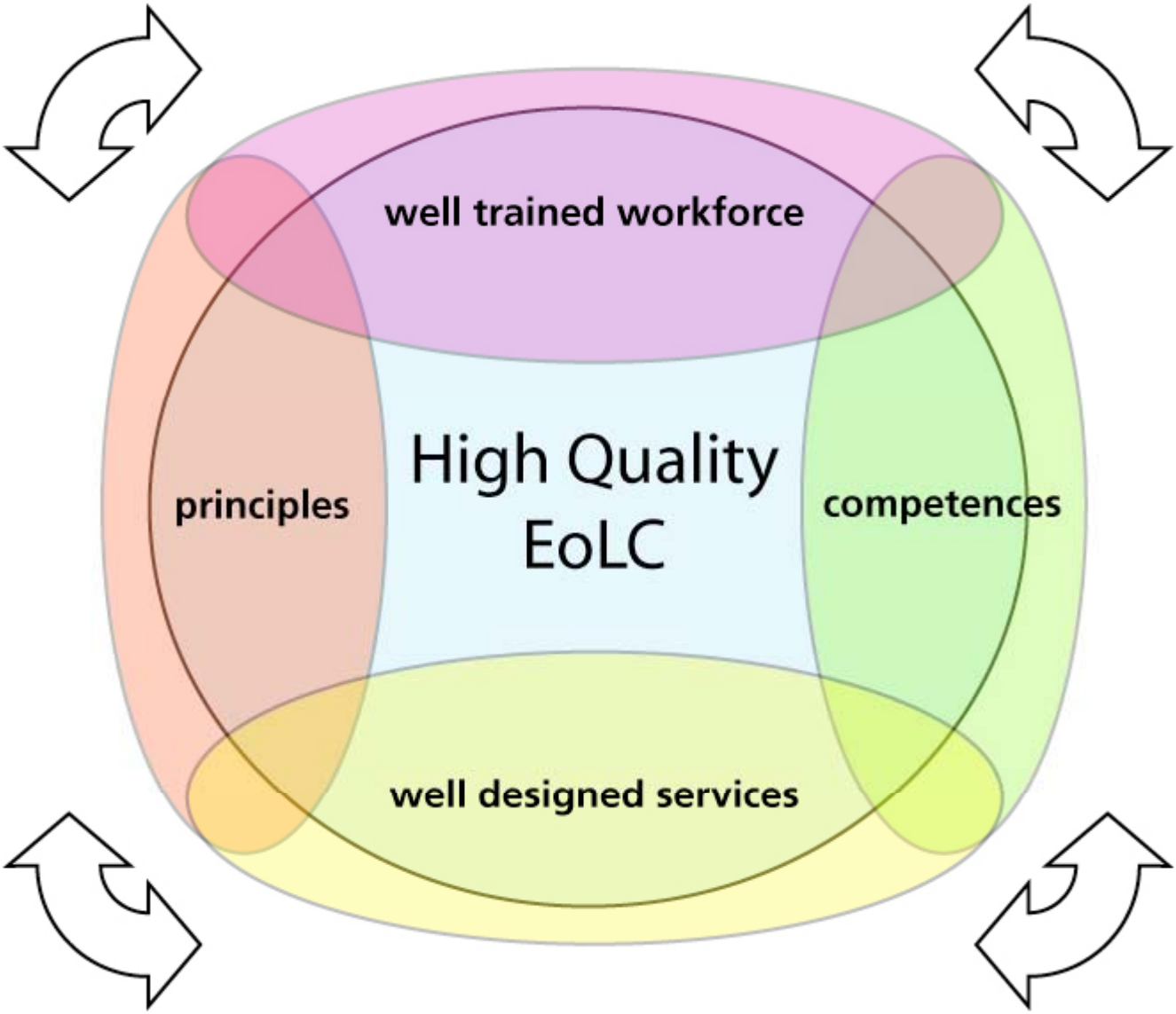
- Linkages to levels defined by nationally recognised frameworks - e.g. National Occupational Standards (NOS), Knowledge and Skills Framework (KSF), National Workforce Competences (NWC), Qualifications and Credit Framework (QCF), continual professional development (CPD)
- Basic, Intermediate and Specialist Groupings – to enable further flexibility for local developments

Communication Skills	Assessment and Care Planning	Symptom management, comfort and well being	Advance Care Planning
Values & Knowledge developments			

These seven principles underpin all workforce and service development, activity and delivery irrespective of level and organisation. They are:

1. Choices and priorities of the individual are at the centre of planning and delivery
2. Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity. Communication reflects an understanding of the significance of each individual's beliefs and needs
3. Delivery through close multidisciplinary and interagency working
4. Individuals, families and friends are well informed about the range of options and resources available to them to be involved with care planning
5. Care is delivered in a sensitive, person-centred way, taking account of circumstances, wishes and priorities of the individual, family and friends
6. Care and support are available to anyone affected by the end of life and death of an individual
7. Workers are supported to develop knowledge, skills and attitudes. Workers take responsibility for, and recognise the importance of, their continuing professional development

End of Life core competences and principles - application



Introduction

Traditionally, End of life care (EoLC) has been viewed as a specialist area of work, beyond the scope of most workers. For a relatively small number of workers that is indeed the case. However, EoLC is in reality far more than specialist care. It incorporates all elements of the daily lives of those people nearing the end of their lives - whether from disease progression or old age and that means a far wider group of workers is involved.

During the course of a working life many people will at some time find themselves supporting an individual who is in the final stages of their life. Even though this is not a key part of their day to day role, it is important that they are prepared and able to make a positive contribution when it is needed. This document is aimed at this broad group of workers, providing a framework to link this more specialist activity to the competences, expectations and outcomes more usually associated with their role. It will be applicable to workers from many disciplines[1] as they find themselves involved in supporting people approaching, or at, the end of their lives.

The principles and competences outlined in this document form a common foundation for all workers whose work includes care and support for people approaching, and at, the end of their lives, whether their primary involvement is healthcare related or social care and support. They do not replace those occupation - or service - specific standards and competences already in place; they are designed to be used alongside these, ensuring that all services are tailored to meet the needs of people at the end of their lives.

All care and support should centre around the needs, wishes and priorities of the individual receiving the service. As people approach the end of their lives these may change, or take on a different perspective. When this occurs workers need to be able to adapt their current practice to take account of this. Patterns of care should alter to accommodate a shift from cure, increasing independence and future planning to managing symptoms and concerns and ensuring that the individual and their family and friends are able to spend time in a way that is meaningful to them, and is as positive as possible.

For workers this may include developing some new knowledge, as well as refocusing their practice. It will also include developing flexible, co-ordinated, multi-disciplinary and multi-agency approaches in which care plans are regularly reviewed and amended to meet the individual's wishes.

The main purpose in developing competences and principles is to support workforce development, in its broadest sense, to ensure all workers are confident and able to work with people at the end of their lives. They reflect the principles, priorities and actions laid out in the End of Life Care Strategy published by the Department of Health in July 2008 and have been produced and refined following consultation and testing across a range of health and social care sites in England.

[1] The majority of these workers will come from health or social care settings, but many other people may be included, for example community workers, faith leaders, or people working in housing or education.

What is the purpose of this document?

The primary purpose of this document is to support workforce development, training and education, and to support the development of new and enhanced posts and roles. Responsibility for the creation of a well-developed workforce rests with everyone, not just HR or training specialists. It should be used by everyone engaged in developing, commissioning, supporting or delivering End of life care (EoLC). It is not intended for any single occupational group; one of its aims is to encourage effective multi-disciplinary and multi-agency work across boundaries, and it has been designed to make sense to workers whatever their occupational background or specialist area. It can be used by workers at any level, and with varying degrees of contact with people at the end of their lives. In many cases it will apply to those working with people with a terminal illness, but it is equally important to use it when working with very elderly people as they reach the final stages of their lives.

It can be used as a tool for a number of purposes (details of real examples can be found in appendix two):

- Service managers may find it a helpful tool when they are considering developing services and practice, as a way to ensure that workforce planning and development is integral to their activities. It will be helpful in creating job descriptions and in defining new roles. It may also be a useful tool when redesigning services to provide a multi-disciplinary approach to care delivery.

- Workforce leads can use it to ensure that the opportunities they are providing meet the needs of workers who look after people who are approaching the end of their lives. It will also be a useful reference document to support workforce planning.

- Education and training providers should also use the document as a checklist for curriculum design and delivery, to ensure that the workforce has the required competences and attitudes to work effectively in this area, and that these are linked to wider nationally recognised standards and frameworks.

- Supervisors can use it to inform supervision, particularly for identifying learning and development needs of their staff.

- Workers may also use it individually to support their continuing personal/professional development, and to refer to when working with someone who is nearing the end of their life. This will help to improve there awareness, confidence and skills in caring for someone at the end of life.

- Commissioners may use this as an indicator or measure that the services or organisations they contract with have the necessary knowledge and skills to deliver end of life care.

For people working as specialist palliative care practitioners there will be higher level expectations around both performance and knowledge, but these core competences and principles will still be meaningful to them, and a good understanding of them will be helpful when working with other organisations and/or other disciplines.

Using this document

Among the stumbling blocks to real multi-disciplinary and multi-agency working are the discrepancies in the language used by different groups of workers. This difficulty is compounded by the use of specialist terms. These are very important within a profession, but can be a barrier to understanding when working with different groups of people (including the individual receiving the service). In this document words that will make sense to everyone are used where possible. A glossary has been provided to give a fuller explanation of some of the more specialist terms, and to outline the range of profession-specific words that have been grouped together.

This document supports workforce development, recognising that without this it is impossible to create excellence in service delivery. Everyone involved in providing End of life care (EoLC) needs to be competent to work in this context. The range of areas in which workers need to be competent, and the level of skill they need to demonstrate, depends upon their degree of involvement in EoLC services and the level at which they would normally be expected to perform.

The End of Life Care Strategy divides the workforce into three broad groups to enable workforce development to be focused where it was perceived that the greatest need for development lay. Group B, which includes workers likely to be involved at the start of an individual's EoLC pathway was identified as the one that probably needed to be prioritised. However this should be determined by local service delivery needs. The competences and principles described in this document can be applied to workers within any of the three groups.

GROUP DEFINITION	MINIMUM SKILL AND KNOWLEDGE LEVEL
GROUP A: specialist palliative care staff, work entirely focused on people at the end of their lives.	Highest levels, through specialist training. To include all of common core competences.
GROUP B: staff who frequently deal with end of life care as part of their role.	Need to be enabled to develop or apply existing skills and knowledge to the principles and competences. May require additional specialist training.
GROUP C: staff working within other services who are involved with end of life care infrequently.	Good basic grounding in the principles and competences; alongside knowledge of where to seek expert advice or refer on to.

Using this document - continued

This document lays out a common foundation for all workers. It is one of several documents[2] that support workforce development. These other tools and guidance, including more detailed statements of competence, and links to other occupational standards and frameworks, can be accessed via www.endoflifecareforadults.nhs.uk. Other useful contacts are listed in appendix 4 of this document.

Those using these competences and principles should do so within the context of their own occupational standards and requirements, for example those working in the health sector will wish to make links to the Knowledge and Skills Framework and other national workforce competences developed by Skills for Health. For those working in social care they will want to refer to national occupational standards and the Qualifications and Credit Framework.

This work supports the ongoing development of EoLC services. It will need to continue to evolve over time, to be responsive to workforce needs, to share good practice as this develops, and to be shaped by the people who use it. Already a number of organisations are developing their own tools and guidance, using the national guidance in conjunction with local requirements. To facilitate sharing good practice and local developments a national database of useful information will be created, accessible to everyone via www.endoflifecareforadults.nhs.uk.

The following pages set out the 'dimensions' of each of the core competences (which will be further defined by levels as part of the next stage implementation plan) and the underpinning core principles. Summary case studies from the pilot sites illustrate how these have been put into practice and lessons learnt, and can be found in appendix two. More detailed case studies can be found on the website.

An outline implementation plan to cover the next steps is contained in appendix 3.

[2] Documents developed by a number of organisations.

The competences

Occupation- and profession-specific competences, which may also cover relevant overarching values and knowledge, exist for workers across health, social care and other sectors. However these will need to be built upon for times when they are working with people approaching, or at the end of their lives.

Expectations around the four key areas will vary according to circumstances. They should be interpreted and applied to the particular role and circumstances of the worker, or workers. They should link appropriately to the level required by service standards and the level the worker would normally be expected to perform at when providing the service, in conjunction with the degree of involvement in the individual's End of life care (EoLC). Overarching values and knowledge competences as they relate to EoLC should also be understood and demonstrated by all workers.

The competences may be used as a freestanding framework, but are also designed to be referenced to other occupational standards and frameworks, such as the Knowledge and Skills Framework, National Occupational Standards for Heath and Social Care, National Workforce Competences (Skills for Health) and the Qualifications and Credit Framework (QCF[3]) which will replace NVQs. Further work is planned to group the competences as basic, intermediate and specialist to allow local flexibility. Some work has already begun in making these links, and can be accessed via www.endoflifecareforadults.nhs.uk. This work will continue, and as progress is made further guidance and tools will be added.[4]

The main dimensions for each of the competence areas are as follows:

1. Communication Skills

a. In relation to EoLC, communicate with a range of people on a range of matters in a form that is appropriate to them and the situation.
b. Develop and maintain communication with people about difficult and complex matters or situations related to EoLC.
c. Present information in a range of formats, including written and verbal, as appropriate to the circumstances.
d. Listen to individuals, their families and friends about their concerns related to the end of life and provide information and support.
e. Work with individuals, their families and friends in a sensitive and flexible manner, demonstrating awareness of the impact of death, dying and bereavement, and recognising that their priorities and ability to communicate may vary over time.

2. Assessment and Care Planning

a. Understand the range of assessment tools, and ways of gathering information, and their advantages and disadvantages.
b. Assess pain and other symptoms using assessment tools, pain history, appropriate physical examination and relevant investigation.

[3] For further information see www.qca.org.uk/qcf

[4] See Implementation Plan appendix 3

The competences - continued

c. Undertake/contribute to multi-disciplinary assessment and information sharing.
d. Ensure that all assessments are holistic, including:
- Background information
- Current physical health and prognosis
- Social/occupational well-being
- Psychological and emotional well-being
- Religion and/or spiritual well-being, where appropriate
- Culture and lifestyle aspirations, goals and priorities
- Risk and risk management
- The needs of families and friends, including carer's assessments.

e. Regularly review assessments to take account of changing needs, priorities and wishes, and ensure information about changes is properly communicated.

3. Symptom management, maintaining comfort and well being

a. Be aware that symptoms have many causes, including the disease itself, its treatment, a concurrent disorder, including depression or anxiety, or other psychological or practical issues.
b. Understand the significance of the individual's own perception of their symptoms to any intervention.
c. Understand that the underlying causes of a symptom will have an impact upon how care should be delivered.
d. Understand the range of therapeutic options available, including drugs, hormone therapy, physical therapies, counselling or other psychological interventions, complementary therapies, surgery, community or practical support.
e. In partnership with others, including the individual, their family and friends, develop an EoLC plan which balances disease-specific treatment with other interventions and support that meet the needs of the individual.
f. In partnership with others, implement, monitor and review the EoLC plan.
g. Awareness of cultural issues that may impact on symptom management.

4. Advance Care Planning

a. Demonstrate awareness and understanding of Advance Care Planning, and the times at which it would be appropriate.
b. Demonstrate awareness and understanding of the legal status and implications of the Advance Care Planning process in accordance with the provisions of the Mental Capacity Act 2005.
c. Show understanding of Informed Consent, and demonstrate the ability to give sufficient information in an appropriate manner.
d. Use effective communication skills when having Advance Care Planning discussions as part of ongoing assessment and intervention.
e. Work sensitively with families and friends to support them as the individual decides upon their preferences and wishes during the Advance Care Planning process.
f. Where appropriate, ensure that the wishes of the individual, as described in an Advance Care Planning statement, are shared (with permission) with other workers.

The competences - continued

g. When appropriate, know what the Advance Care Planning statement contains, and how this will impact upon an individual's care delivery.

5. Overarching values and knowledge

a. In the context of EoLC, understanding and knowledge of:
- One's own professional/role boundaries
- Legal and ethical issues - adherence to legislation and advisory guidance around e.g. Mental Capacity Act and the Mental Health Act
- Professional codes of practice or conduct, and their impact on practice
- The role/contribution of other workers and organisations to ensure leadership commitment and innovation
- The impact of one's own beliefs on practice
- Approaches to risk assessment, management and taking
- Approaches to and theories of change, loss and bereavement
- Social models of care, and person-centred approaches.

b. Person-centred practice that recognises the circumstances, concerns, goal, beliefs and cultures of the individual, their family and friends, and acknowledges the significance of spiritual, emotional and religious support and the diversities in these regards that there might be between family or social group members.

c. Practice that is sensitive to the support needs of family and friends, including children and young people, both as part of EoLC, and following bereavement.

d. Awareness of the importance of contributing to evaluation and change of services, participating as appropriate, and of involving the people who use them in that process.

e. Taking responsibility for one's own learning and continuing professional development, and contributing to the learning of others.

The principles

These principles underpin the competences and all workforce development, irrespective of a worker's level of practice, occupational group or work setting.

1 The choices and priorities of the individual are at the centre of all End of life care planning and delivery.

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

The significance of cultural diversity, including the impact of faith, beliefs, religion and lifestyle, acknowledging the individual's right to make their own decisions, is recognised. People are encouraged and supported to make decisions based on their experience of their needs, and enhanced by appropriate professional support and guidance. People are supported in identifying and managing risk proportionately and realistically, and have an understanding of the notion of Informed Consent, best interest and Advance Decision to Refuse Treatment.

2 Effective, straightforward, sensitive and open communication between individuals, families, friends and workers underpins all planning and activity. Communication reflects an understanding of the significance of each individual's beliefs and needs.

Good communication and relationship skills are used to ensure that End of life care (EoLC) plans are clearly understood and shared by everyone involved in their planning and delivery.

Communication and relationship skills are used to encourage and support individuals to work with professionals and those providing their support to articulate their needs and wishes for their EoLC. This includes identifying strengths, abilities, concerns and priorities. Communication is used to work towards developing plans and, where possible, achieving solutions in a sensitive and appropriate manner.

Workers recognise the changing ability and desire of the individual, their family and friends to communicate, and adapt their own communication style accordingly. This includes recognising the impact of impairments, and of anxiety and loss upon the person. Where children and young people are among the family and friends, workers are aware of the significance of child development to communication and to ways of coping with loss and bereavement.

Effective communication recognises and takes account of the impact of culture, faith and life choices upon what constitutes appropriate communication. It is:

- Non-judgmental
- Empathic
- Genuine
- Collaborative
- Supportive

The principles - continued

And is based on:
- Active listening
- Reflection
- Legitimisation of people's views, valuing the knowledge and experience of their needs
- Partnership
- Respect.

3 High quality End of life care is delivered through close multi-disciplinary and inter-agency working. Through partnership working the needs of the individual are articulated, shared, understood and reviewed. By developing and utilising networks the right resources and support are identified and utilised.

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

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

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

4 Individuals, their families and friends are well informed about the range of options and resources available to them to enable them to be involved in the planning, developing and evaluating of End of life care plans and services.

Individuals, their families and friends are supported in their involvement in the development and delivery of care to support their chosen EoLC pathway, and in developing, where appropriate, Advance Care Plans. Workers have awareness and understanding of the significance of legal frameworks around EoLC and advance care planning, and are able to share this information as appropriate to their role.

Workers promote and encourage the involvement of individuals, their families and friends in the planning, development and evaluation of services they receive, as appropriate to their circumstances, recognising the different ways that people, including children, will choose to be involved.

Evidence-based information is provided in an appropriate manner and format, to ensure sufficient knowledge or information is available for the individual, their families and friends to make well-informed choices. Individuals have a good understanding of the benefits and risks of their chosen pathway.

The principles - continued

5 Care is delivered in a sensitive, person-centred way that takes account of the circumstances, wishes and priorities of the individual, their family and friends.

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

Workers support families and friends to take on caring responsibilities where that is desired, but recognise and accept that they may choose not to undertake this role.

Where conflict arises between the individual, their family and friends about the chosen EoLC pathway, or Advance Care Plan, the worker is able to work sensitively, and as appropriate to their role, with all parties, to work towards a resolution. This may involve contacting mediation or advocacy services in highly complex situations.

The concerns, fear and anxieties of individuals, their families and friends are recognised and responded to. The worker is aware of the impact that age, culture, religion, ability and other factors may have on an individual's response to grief, loss and bereavement, and recognises that the importance of spiritual support will vary from person to person, and may differ between the individual and their family or friends.

6 Care and support are available to, and continue for, anyone affected by the end of life, and death, of the individual.

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

Workers recognise the support needs of those who have chosen to take on a caring role, and take steps to ensure these are met, including undertaking carer's assessments (see glossary, appendix 1).

The worker recognises that the responses of children and young people affected by the death of someone close to them may be different from adults, and finds ways to ensure that their needs are met.

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

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

The principles - continued

7 Workers are supported to develop knowledge, skills and attitudes that enable them to initiate and deliver high quality End of life care or, where appropriate, to seek advice and guidance from other colleagues. Workers recognise the importance of their continuing professional development, and take responsibility for it.

Employers are aware of the ways in which adults learn, and the cultures in which they learn best, and ensure that workers are supported in their development. They recognise the link between a well-trained workforce, an open approach to organisational learning, and excellence in service delivery.

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

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

APPENDIX ONE

Glossary

Advance care planning The process of identifying future individual wishes and care preferences. This may or may not result in the recording these discussions in the form of an Advance Care Plan.

Advance Care Plan (ACP), statement of wishes and preferences An ACP sets out the wishes of the individual about the ways in which they will be supported and cared for in the future as their illness progresses and their condition deteriorates. Plans are based upon discussions between the individual and their care providers (both health and social care). It includes important information about concerns, values and preferences. ACPs should be documented, communicated to all those involved in the care plan, including family and friends if the individual wishes it. ACP is particularly important when an individual's communication skills are impaired.

Advance decision to refuse treatment People have the legal right to either consent to or refuse treatment. The courts have recognised that, for adults, decisions can be taken in advance. This decision must then be upheld if, at a later stage, the person loses the ability to make such a decision. Decisions can be revoked by the individual at any time.

Care/care and support Terms used to cover all of the interventions that are part of the individual's EoLC plan. This includes any of the activities that are part of this, for example, medical or surgical interventions, personal care, spiritual guidance, counselling, community involvement or specialist housing support.

Carer The family or friends who take on, in an unpaid capacity, some or all of the responsibility for the care and support of the individual. (This is as distinct from employed care workers, although in some other contexts 'carer' may refer to workers.)

Carer's assessment An assessment of the needs of the carer (see above) to enable them to care for the individual. Carers are entitled to ask social services departments for a carer's assessment.

Care plan, care pathway, management plan, care package, End of life pathway The document that describes the detail of the care and support that the individual will be given, the goals of the plan, and the ways in which it will be monitored, reviewed and evaluated. Unlike the ACP, it is present-oriented rather than future-tense.

Commissioning The mechanism to identify and purchase high quality safe services and resources tailored to meet identified needs. Commissioning may take place at the organisational or individual level, and includes mechanisms to monitor and evaluate the ongoing quality and appropriateness of services. Where an appropriate resource does not already exist, commissioning may include working with a provider to set up the service.

Competence A statement describing the behaviour, underpinning knowledge and values expected of workers to fulfil a specific role competently. Statements of competence are used both in creating job descriptions and as part of the training and assessment of workers.

The glossary - continued

Culture, cultural background, (chosen) lifestyle Terms used to encompass the range of ways in which people live, including religion, faith (or the absence of these), sexuality, and any other aspect of a person's lifestyle that will have an impact on their EoLC planning and decision making, for example language or disability.

End of life care (EoLC) All elements of support to people approaching the end of their lives. In addition to the highly-skilled and focused care and support that may be provided by those working as palliative care specialists, all of the other significant support that is given needs to take on a different focus and perspective to accommodate this stage of life. It encompasses the management of all symptoms including pain, and provides psychological, social, spiritual and practical support.

Family, friends The people, including children and young people, who are important to the individual; they may or may not have an agreed caring role in the EoLC plan. In this document, families and friends are included at all times, but it is recognised that people will decide for themselves who they wish to involve.

Individual, people, person, patient, service user, client The person at the centre of the care plan.

Informed Consent Informed consent is a patient's right to be presented with sufficient information to allow the patient to make an informed decision regarding whether or not to consent to treatment or a procedure. Information should include risks, side effects and any alternative treatments.

Mental Capacity Act The Mental Capacity Act 2005 came into force in October 2007 and is supported by the MCA 2005 Code of Practice. The Act provides a statutory framework to empower and protect people who may lack the capacity to make decisions. It makes it clear who can make decisions, in which situation and how to go about it.

Palliative Care An approach that improves the quality of life of individuals, their families and friends, as they face the problems associated with life-threatening illness, or very old age. By early intervention and high quality assessment, suffering, whether physical, psychosocial or spiritual, is prevented, reduced or relieved. It:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in

The glossary - continued

conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (World Health Organisation 2002).

Person-centred approach An approach to working with people that recognises that the views and experiences of the person receiving care are paramount.

Symptom management Any intervention used to help relieve the individual's pain, discomfort or other negative experiences that arise as either a direct or indirect result of their medical condition or the ageing process. This may include medication, physical therapy, social activities, or spiritual support. It is an integral element of the care plan, focusing on identifying and managing the individual's symptoms. It may concentrate on managing pain or other physical problems by medical or other intervention, but also takes account of other symptoms that the individual identifies as significant to them. Person-centred symptom management assesses and responds to the individual's needs, taking account of the wider context within which they live, their priorities, and the things that matter to them.

Prognosis The expected progression of a disease and its outcome for the individual.

Skills for Care is part of the Skills for Care and Development sector skills council responsible for ensuring that the social care workforce is well trained and properly competent to undertake its work. Skills for Care is concerned with adults' care in England. SSCs work in partnership with employers at regional and national level.

Skills for Health is the sector skills council responsible for ensuring that the health workforce is well trained and properly competent to undertake its work. SSCs work in partnership with employers at regional and national level.

Spirituality is difficult to define, as it can mean different things to different people, and its existence as a discrete phenomenon may be denied by some. In essence it is to do with making important connections which provide people with hope, purpose and comfort. This may also be confused with religion which relates to a belief system.

Statement of wishes and preferences/ACP A summary term that covers recorded (written or oral) information given by an individual about their wishes, preferences or other important factors related to their future treatment. It applies to both medical and social care. Although not legally binding, it should be used when determining a person's best interests if they lose the capacity to make decisions.

Support network The relationships, practical resources, emotional or spiritual support, and other activities that the individual identifies as important in their EoLC plan. It may include anyone identified as significant by the individual.

Worker Staff, employees, volunteers or practitioners who have a formal role or function in the delivery of EoLC.

APPENDIX TWO

Case examples - linking competences and principles to workforce development in health and social care

NHS Bradford and Airedale Clinical Network delivers boosted training for staff

As a well-established education and training provider, NHS Bradford and Airedale Clinical Network recognised that it could update its existing one and two day courses using the new competences and principles as a benchmark.

From September 2009, the revised one and two day courses for staff from care homes and care agencies will more closely reflect new initiatives in palliative and end of life care. These include advance care planning, preferred priorities of care and the end of life care pathways.

Catherine Scoggins, Palliative Care and End of Life Care Education Coordinator at NHS Bradford and Airedale, said: *"It means we can be confident that we are delivering exactly the right skills people need to reflect the new National End of Life Care Strategy. Using a framework based around end of life care gives greater credibility to the learning syllabus."*

The new focus will add to topics already covered in the courses including recognising pain, the grieving process, the principles of palliative care, effective communication, reflective practice and coping mechanisms.

Ms Scoggins said: *"Taking a more planned approach to end of life care calls for a greater understanding among the people who provide the 'hands on care'."*

It is hoped the revamped courses will develop the workforce so that staff are more confident, provide greater choice for patients, reduce emergency admissions to acute care and reduce the number of patients transferred from care homes to acute trusts in the last weeks of life.

For more information visit www.bradford.nhs.uk/palliativecare

Housing 21 uses competence based approach to give staff extra skills

The housing and care provider for the over-55s decided to review their end of life care provision, using the core competences as a starting point.

Valarie Anderson, Care Service Manager at Housing 21's extra care housing scheme in Gateshead, Callendar Court, said the competences reinforced the organisation's partnership approach to care delivery. The scheme managers and staff already work closely with district nurses and other health professionals to provide tenants in 200 extra care units with care as and when they need it.

The competences allowed Housing 21 a way to reinforce that partnership approach by giving their own domiciliary staff and court manager the skills they need to help tenants stay in their own home in line with their personal wishes.

Valerie said tenants told Housing 21 they wanted an End of life care service.

"We are now looking at how to develop individual end of life care plans with people so they can have their wishes met. Having appropriately trained staff is an important part of this work and the competences help us put the individual's needs first. They were very helpful in helping us to identify core areas for development."

The local palliative care team offered tailor-made half-day training sessions in end of life care.

As well as improving care and boosting staff confidence, the training has strengthened partnerships with local training providers and local health colleagues who deliver end of life care.

For more information visit www.housing21.co.uk

End of life care tools used to enhance staff development across East Sussex care homes

These organisations working across health, social care and independent care homes have used the core competences and principles to support appraisals and identify training needs across clinical and non-clinical staff in care homes.

Chris Banks, End of Life Care Practice Facilitator (East Sussex) for the PCTs, explained: *"The tools have given managers and senior clinicians a clear way to establish what understanding and knowledge is needed and how this can be used to support staff - whatever their role - in helping us to give better care for residents in the care homes."*

Managers reviewed the job descriptions and roles of all team members (including maintenance and kitchen staff) for the knowledge and skills expected in relation to end of life care. The requirements were mapped to the core competences and principles and staff used a questionnaire to assess their own knowledge and skills.

This was all used in staff appraisals to see if extra training and support were needed.

Managers are also using the tools to identify suitable education and learning programmes based around defined End of life care criteria - helping them to select appropriate courses from learning providers. Staff with high levels of understanding will be used as role models and in-house trainers and the competences and principles will shape future job descriptions.

Further identified benefits include:

- competences align to National Occupational Standards, supporting a consistent approach to End of life care
- a more explicit framework for appraisal enables a clearer process and evaluation of End of life care skills and
- better-motivated care teams with staff feeling more valued and recognised.

For more information call Chris Banks on 07879 415 724 or email Christine.banks@hastingsrotherpct.nhs.uk

NHS West Midlands Workforce Deanery embraces region-wide approach to End of life care

The workforce deanery used the principles and competences as the basis for a local consultation on improving End of life care.

Commissioners, social care planners, domiciliary care agencies, education providers, nursing and residential homes, hospices and acute and primary care trusts all took part.

The consultation confirmed widespread support for a Health and Social Care Network of End of Life Champions across the West Midlands. This will allow people to share resources and offer support in the development of best practice.

The work has helped develop a consensus about the skills required by the end of life care workforce. That information will now be used for:

- mapping End of life care knowledge and understanding to curriculum content in undergraduate, postgraduate and non-accredited education and training programmes
- designing a new programme for all workers involved in some End of life care i.e. generalists within health, social and independent sector workforces and
- identifying End of life care skills gaps in the current workforce and ensuring training is offered to the whole workforce, not just those at the "sharp end".

Nicole Woodyatt, Workforce Specialist for End of Life Care NHS West Midlands, said: *"Now the real work begins and we can make a start by ensuring the end of life principles become part of contracting and commissioning. We hope that the proposed regional forum for networking and sharing good practice will help us to embed the right practice and principles, so that we can all face end of life care in a more open and up front manner."*

For more information email Nicole.Woodyatt@westmidlands.nhs.uk

Dorothy House Hospice Care develops staff roles thanks to new tools

Dorothy House Hospice Care used the competences and principles to develop a new generic worker role.

Head of Education Helen de Renzie-Brett said: *"We used the new core competences for end of life care as a starting point. They allowed us to describe the ideal qualities for a person in this role - such as excellent communication skills, being able to recognise people's needs and deal with emotional circumstances - and then we made these 'ideal' qualities an explicit requirement within the job description."*

She feels the competences can be used to pinpoint the qualities needed for any role, whether it be specialist nurse or volunteer driver.

The competences will also support managers to identify the training and development needs of new recruits.

Helen says: *"What is really exciting is how this work is enabling us to describe precisely the skills an individual needs so they can offer exactly the right care, using a nationally-recognised standard. It also offers a career development opportunity for staff who could progress to the new role, which falls between a registered professional nurse and a healthcare support assistant."*

For more information visit www.dorothyhouse.co.uk

Derby-Burton local cancer network develops training to support End of life care

Three hospices have joined with the East Midlands Cancer Network and the Southern Derbyshire Workforce Development Team to pilot innovative training for healthcare staff.

The training package based on the core competences and principles - which was put together by Derby-Burton Local Cancer Network - will be launched in September 2009. The programme will be extended from healthcare staff to support staff if evaluation confirms its value.

The course is a response to an identified need for specialist training. It should help staff to identify with the person receiving care and to better understand their needs and those of family and friends.

Competences essential for care were 'hand-picked' to help create a work based learning and assessment programme which includes a scenario-based course delivered over three days and a workbook to support learning and e-learning.

Assuming the evaluation proves positive, the programme - which reflects strong collaboration between the East Midlands Cancer Network, the workforce development team, Nightingale MacMillan Unit, Ashgate Hospice and St Giles Hospice - will be recommended as the key introduction course for End of life care in the region.

Phil Mayor, Education Facilitator with the East Midlands Cancer Network, hopes that if the evaluation is positive commissioners will adapt it to their own needs.

He says: *"We see the evaluation of the pilot work as a critical stage as this will help in the development of a 'gold standard' in learning and education for healthcare staff providing end of life care."*

For more information visit www.mylearningspace.me.uk

Partnership approach by Stoke on Trent PCT heralds new focus on End of life care

Commissioners, providers and educators came together in Stoke-on-Trent to develop a training needs analysis using the core principles and competences.

Laura Janda, Service Improvement and Development Manager, said: *"It enabled us to use a more focused approach across commissioner, provider, education and training. By analysing training needs we were able to quickly establish what end of life care knowledge and understanding was missing and what we could do to address the need."*

Those involved in the work included representatives from both NHS Stoke-on-Trent commissioning and providing arms, the End of Life Clinical Lead for NHS Stoke-on- Trent, education representatives from the teaching PCT and End of life education providers from the Douglas Macmillan Hospice.

The training needs analysis was distributed to district nurses and their managers so that a workforce profile could be compiled.

Benefits include:

- allows the Douglas Macmillan Hospice and the provider arm education provider to devise courses to meet End of life care training needs
- helps to demonstrate how competence based training and development meets End of life care learning needs
- enables providers to identify and address End of life care training needs
- enables providers with evidence that staff are working to the End of life care principles
- a more confident workforce supports a better service for patients receiving End of life care
- NHS Stoke-on-Trent commissioners will use the competences when developing service specifications for new End of life services in the community
- helps ensure commissioned services are delivered to support patient wishes and their End of life care needs and
- offers a means to ensure that services provided by generalist staff are in keeping with the core principles
- Future investment for End of life care education and training can be targeted to address outstanding need and
- NHS Stoke-on-Trent will be able to include the End of life care competences as a measure in service specifications for workforce planning.

Laura says: "*As a commissioner having the end of life care resources has been useful because they have helped to get people moving in one direction. It is helped by the fact that the core principles and competences are sufficiently generic to work across different roles and occupations and meet a range of organisational needs."*

For more information email Laura.Janda@stokepct.nhs.uk

A 'joined up' approach to collaborative commissioning in North Central London

Five primary care trusts (PCTs) formed a collaborative partnership to improve the commissioning of End of life care, including the development of a sector-wide hospice inpatient tariff.

When they formed the group at the end of 2007 they set the ambitious target of ensuring that all patients approaching the end of life would be able to choose where they were cared for regardless of their condition or care setting.

They have worked to strengthen commissioning and improve cross-boundary working.

Claire Henry, National Programme Director End of Life Care, says: *"Commissioning can seem a daunting concept but in fact it is at the heart of all good care. In essence it's about finding out what people need and then ensuring it is delivered to the right people, at the right time and to the best standards possible."*

A crucial factor in the progress made has been the group's membership - PCT chief executives and directors of commissioning and finance.

A key achievement includes a costing and analysis for hospice activity and funding with a view to developing a sector-wide hospice inpatient tariff.

Initially this involved calculating the cost of core palliative care services - leading to an agreed price per bed day. Each PCT's activity - by hospice as well as current spend - was also analysed.

The PCTs are now considering a variety of options, ranging from a rate per bed day to rates relating to episodes of care based on current average length of stay and excess bed day rates. Agreement on a way forward for the sector is expected in the next few months.

www.nlcn.nhs.uk

APPENDIX THREE

End of Life Care (EoLC) competences and core principles project - next steps

TIMELINE

June 08 to June 09

Competences and core principles developed, consulted on and piloted across social and healthcare organisations. National conferences in June and July 09 to launch working document, case studies from pilot sites and implementation plan.

IMPLEMENTATION PLAN

July 09 to March 10

COMMUNICATIONS

Identify key stakeholders

- Map, plus level and type of engagement.
- Raise awareness across health and social care that the work exists utilising appropriate media
- Promote and provide support to organisations and individuals in using the competences and principles in workforce development at all levels
- Promote common terminology and understanding across health and social care EoLC workforce developments
- Ensure communications are linked with other EoLC Foundation Projects (communications and e-learning) as well as the EoLC Programme

IDENTIFY GAPS

- Within the four core areas (communications, ACP, assessment and symptom management
- Develop competences to complete existing framework
- Identify and develop additional related competences, e.g. spirituality and well-being, care after death, support for workers
- Issue updated guidance

TIMELINE

June 08 to June 09

Competences and core principles developed, consulted on and piloted across social and healthcare organisations. National conferences in June and July 09 to launch working document, case studies from pilot sites and implementation plan.

IMPLEMENTATION PLAN

July 09 to March 10

MAKE KEY LINKAGES

Levels

- Undertake work to link to recognised occupational standards and levels of development, e.g. Knowledge Skills Framework (KSF) and Qualifications and Credit Framework (QCF) plus others as appropriate

Other Professional Bodies

- Work with medical Royal Colleges/Association of Palliative Medicine and other health and social care professional bodies to ensure compatibility and consistency of approach across medical and non-medical workforce development
- Issue updated guidance

REVIEW AND UPDATE

- Identify review cycle processes to ensure competences are maintained, updated and still relevant
- Review uptake and application of competences as part of review cycle
- Ensure that review and update cycle is compatible and managed along with other EoLC projects
- Issue updated guidance

APPENDIX FOUR

Useful resources

Department of Health End of *Life Care Strategy* July 2008

Department of Health *Mental Capacity Act* 2005

Department of Health *The NHS Knowledge and Skills Framework (NHS KSF) and the Development Review Process* October 2004

Marie Curie Cancer Care *Spiritual and Religious Care Competences for Specialist Palliative Care*

National End of Life Care Programme/University of Nottingham *"Advance Care Planning: A guide for Health and Social Care Staff"*

St Christopher's guidelines for nursing competences

For individuals or organisations unable to access any of these documents electronically, these can be provided in paper form. Please contact us at The National End of Life Care Programme, 3rd Floor, St John's House, East Street, Leicester, LE1 6NB, listing the documents you are interested in, or telephone 0116 222 5103

Other internet links

www.dca.gov.uk/legal-policy/mental-capacity/mca-summary.pdf for a helpful summary of the Mental Capacity Act (2005)
http://www.endoflifecareforadults.nhs.uk/eolc/E551.htm takes you straight to the workforce page where there are links to lots of pieces of work already taking place to develop the EoLC workforce

http://www.endoflifecareforadults.nhs.uk/eolc//acprsp.htm takes you straight to a page linking to resources for professional education, including Advance Care Planning in care homes for older people, the Advance Care Planning guide, guidance around the Mental Capacity Act and lots more

www.helpthehospices.org.uk a really useful site for professionals, families and friends, includes information about carers' assessments, young carers, death and dying

www.ncpc.org.uk The National Council for Palliative Care (NCPC) is the umbrella organisation for all those who are involved in providing, commissioning and using palliative care and hospice services in England, Wales & Northern Ireland. NCPC promotes the extension and improvement of palliative care services for all people with life-threatening and life-limiting conditions. NCPC promotes palliative care in health and social care settings across all sectors to government, national and local policy makers

www.skillsforcare.org.uk or www.skillsforhealth.org.uk for a full description of the National Occupational Standards for Health and Social Care, and the Common Core Principles to Support Self Care
http://www.skillsforcare.org.uk/publications/publications_c.aspx

www.who.int/cancer/palliative/en website of the World Health Organisation, includes information about palliative care