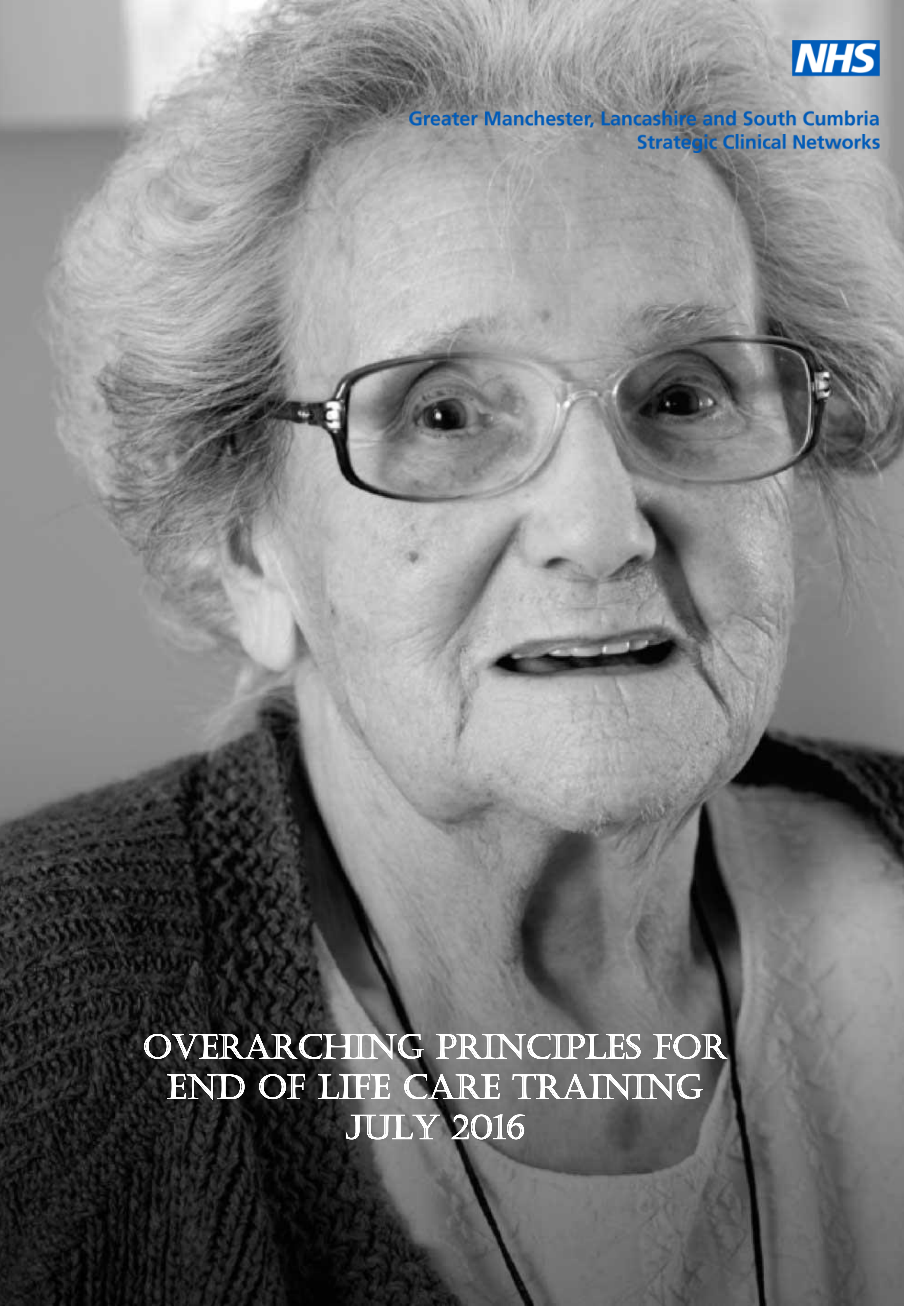
Greater Manchester, Lancashire and South Cumbria
Strategic Clinical Networks



OVERARCHING PRINCIPLES FOR END OF LIFE CARE TRAINING

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OVERARCHING PRINCIPLES FOR END OF LIFE CARE TRAINING

Introduction

Education and training in palliative and end of life care is a key part of improving standards of care of patients in this crucial part of their lives. Various national policies have emphasised the need for adequate education provision in this area to enable this.

This document is intended to support commissioners and providers, both of care and training, to understand why a focus on end of life care is important. It covers the key principles that drive how such training can be delivered effectively and the key elements it is likely to contain. It was originally written by London Strategic Clinical Networks, and is adopted and recommended in full by Greater Manchester, Lancashire and South Cumbria Strategic Clinical Network.

It is for all staff, working in health and social care settings, whether in a clinical or other role. The amount and type of training will vary according to the role they have and the level of contact they have with individuals requiring end of life care. It does not cover education for members of the public.

Acknowledgements

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A special thank you goes to all the members of the Education and Training Special Interest Group for their time and commitment in agreeing and adopting this guide in full.

It is acknowledged that this document has been adopted in full from the London Strategic Clinical Networks overarching principle for end of life care training document.

HOW TO DELIVER TRAINING

PRINCIPLE 1 – APPROPRIATE LEVELS OF MANDATORY TRAINING

A Mandatory Basic Level of Training Should be in Place for All Staff, Then Tailored to the Level at Which Each Individual will Deal with End of Life Care

Pre-qualification

Education commissioners will seek assurance from foundation course providers that End of Life awareness is included within all curricula, so that learners have an opportunity to explore their responsibilities towards a dying person in any specialty or care setting.

Awareness of timeframes in the dying process should be core training: It also supports honest and open communication, more person-centred care and support for families, being inclusive of sensitivity to people's cultural and spiritual beliefs.

Principles such as "total pain" should be well understood by all staff so that holistic team-based support can be offered in a timely way to people when they are dying. Enabling people to remain as active as they can and to live as well as possible up to the moment of their death should be driving the delivery of care in all settings – home, care home, hospital and hospice.

It is important that all staff are able to recognise when someone is approaching the end of their life and particularly when someone is entering the dying phase so that appropriate treatment and holistic support can be offered to them and their family or carers. It enables people to engage in their own future, make choices about treatment options, address psychological issues and to make practical and emotional preparations for death with their family or carers - such as making a will, thinking about any treatments they would refuse, advance decision to refuse treatment, and/ or set up a Lasting Power of Attorney. Some people may need to consider the care of dependents; others may like the opportunity to repair relationships, to say something important to significant people in their lives, or to think about how they would like to be remembered. All staff need training to recognise the end of life care needs of all people no matter their condition. This especially means conditions other than cancer, such as long term conditions, frailty and dementia. Staff need to be able to recognise the principles of comfort care, pain management, nutrition and hydration as well as psychological and spiritual care (and to take a broad view, for example that a distressed agitated patient may have a blocked catheter that requires attention). The goals of treatment in the palliative care should be understood by all professionals.

HOW TO DELIVER TRAINING

Following on from basic level EoLC training, individual groups of staff should have additional training tailored to their role and level of responsibility so that they can deliver care safely, competently and compassionately.

It is helpful for all new staff as part of induction to receive this training to help ensure coverage of the workforce as well as regular updates for all staff.

PRINCIPLE 2 – CONTINUOUS LEARNING

A Process of Continuous Learning Should be in Place

Continued learning is crucial in order to progress with continued improvement in the quality of patient care and prevent complacency.

To achieve this, it may be helpful to add in to other learning programmes.

PRINCIPLE 3 – ALL STAFF

Include all Staff, Not Just Clinical Staff

Emphasises the importance of teamwork. It is not uncommon for someone to "open up" to a more familiar healthcare assistant, one of the catering staff or to a volunteer worker in a hospital or hospice setting rather than ask a doctor who may appear too remote or busy. All staff need to be able to give an answer to the individual who asks about his or her future.

More junior and non-clinical staff will need to know who and how to refer people on. For example, they could have a mentor, one of their senior colleagues, so that they feel supported and so that follow up information can be given as appropriate to the individual or family. Staff should be aware of their own limitations and should know to whom they can report to enable sensitive conversations to be taken further.

Including all staff enables career development opportunities.

HOW TO DELIVER TRAINING

PRINCIPLE 4 –VARIED APPROACHES

A Variety of Approaches should be used to Meet Different Learning Styles

People learn in different ways. Employing different styles of delivery is likely to influence subsequent behaviour in a diverse team of staff to a greater extent. Also it will improve team cohesion as more people will feel more confident to undertake the roles and responsibilities of caring for individuals if their particular learning style is addressed.

Make it memorable – for example by involving individuals and carers.

Reflective practice is of particular importance (see below for self-care of professionals) and multi-professional collaborative training courses.

It is ideal to have a range of learning approaches because people absorb information in different ways. E-learning is a great resource and (for some people) especially suited to imparting technical information, but person-to-person learning will always be essential, especially for communication skills, cultural sensitivity and emotional intelligence.

Options to consider include: role modelling, mentoring, placements, appraisals, use of case studies, videos, patient shadowing, goldfish bowl technique, action learning and supervision.

PRINCIPLE 5 – LEADERSHIP IN CARE

Leadership should be used to Drive Improvements in Care and Changes in Practice

Good leadership will contribute to improving effective teamwork, staff self-confidence and communication across professional teams (e.g. patients who are re-admitted).

At an organisational level this means that the Senior Lead in EoLC knows and understands the skills and gaps of the organisation’s workforce and has a plan in place to take this forward.

HOW TO DELIVER TRAINING

An End of Life Care Team Lead should oversee activities such as ensuring that people are identified appropriately, that the palliative care approach is fully explained to individuals and their families, and that the opportunity for advance care planning is not overlooked, including establishing the individual's own wishes and preferences for their future care.

Essentially to ensure that each individual and/ or their family are aware of what is happening, and that they can have a say. They will be a support to less confident staff and will coordinate good holistic end of life care in these settings.

There is a need to ensure that staff are aware a Senior Clinician is identified to manage end of life care planning and the clinical management of every patient identified to be actively dying, in all settings (in line with Leadership Alliance for the Care Dying People recommendations).

PRINCIPLE 6 – TAILORING TRAINING

Training should be Tailored to Reflect the Location and Context Where Care is Delivered

Staff in all settings will have many learning needs in common, but other elements of EoLC training will be tailored.

For example, there will be themes in common such as ensuring improvements in the quality of care given to all end of life patients, more effective assessment of individual and family needs, communications with individuals and families, more involvement in their own care plans and better bereavement care and support. Underpinning all this is the need for all staff to feel confident about having sensitive conversations about illness progression and the potential for dying, so a common training need will be communications skills with individuals and families – to include issues like resuscitation, nutrition and hydration.

However, effective training will reflect the need of the setting. So in GP surgeries this might focus on use of the care register leading on identifying people who have EoLC needs. In care homes staff may benefit from training in when to call for help and where and how they access services and support (24/ 7) when a resident's condition deteriorates. Deliver the training as close to the care setting as possible.

Accessibility is important so staff have time and space to undertake the training.

HOW TO DELIVER TRAINING

PRINCIPLE 7 – EVALUATE EFFECTIVENESS

To Evaluate Maximum Effectiveness and Impact, Establish an Evaluation Process

It is important to be able to demonstrate that training makes a difference to the way that professionals act and deliver care in their everyday work. It would be ideal to establish an assessment process in each establishment to monitor the effect of training on what people have learnt in relation to end of life care; for example, the practicalities of symptom control, holding sensitive conversations, providing effective psychological support, dignity and compassion. To ensure this evaluation is sound it should be progressive over a period of time and not only when the training has been completed.

Establish a baseline, which will also help inform you of gaps in understanding and priorities for training and to be able to assess the learning that is taking place. This is as true in social care settings as healthcare, but there may be see existing work to draw from.

Consider how to test and assess skills, ability to deliver and competency, not just knowledge. Examples might include;

- Access the opinion of relatives to identify areas that may need improvement
- Record the proportion of individuals who die in any setting who have evidence of having written an advance care plan and where preferred place of death has been identified
- Proxy markers; how many people were offered spiritual care, what proportion had an electronic record (EPaCCS) created with relevant information about their future care plan, personal wishes, ceiling of treatment, resuscitation status etc.
- Confidence levels of staff in dealing with end of life care healthcare
- Line managers' impression of improvement

These processes will also identify areas of good practice, where learning is embedded.

PRINCIPLE 8 – COMMUNICATION SKILLS

Ensure Staff Have the Skills and Confidence to Engage in Sensitive Conversation with People who are Approaching Death

Basic communication skills training will help to give professionals the confidence to engage in sensitive conversations with people who are approaching death. If staff lack confidence, and do not have these conversations, individuals will not get access to the services that they need and may not have the opportunity to focus on what is most important to them with the time that is left.

It will facilitate compassionate discussions enabling individuals to raise their concerns and fears, and to make choices about their future care. It can be taught to any member of staff (e.g. healthcare assistants, nurses, doctors, therapists, admin staff, therapists, social workers and volunteers) in contact with distressed people (not just patients) in any setting (e.g. hospital, home, nursing home and social care).

Key topics are likely to include;

- Knowing when to have the conversation
- Tackling difficult issues
- Importance of empathy
- Knowing when to stop
- What is and is not appropriate to discuss in non-face to face situations
- Understanding uncertainty in end of life care

Training may also cover appropriately raising challenges to end of life care decisions, to safeguard individuals who are handed an end of life care plan and uncertain that the determination is valid or it may need revisiting if new facts are available.

Some professionals may be reluctant to take the step of identifying people for end of life care, as it precipitates that conversation about prognosis, the future direction of care and the potential for dying with the individual and/ or their family (this is particularly the case in people who have long term conditions and general frailty).

They may be anxious about causing distress to the individual or family members. Whilst some individuals and families may not want or be ready to engage in advance care planning conversations, many people do want to be told the truth about their condition, to be prepared for what is to come and to have time to put their affairs in order.

One outcome of training in this area will be to help professionals to recognise when it's the right time to initiate conversations about what is likely to happen as their illness progresses, how much to say, how to impart bad news sensitively and with compassion and knowing when to stop, leaving further information for another day. It will support staff to recognise psychological distress and how to work with the person's own ideas. By promoting these conversations individuals will be given the opportunity to express their wishes and preferences for their future care, enabling the professional better to direct services to meet requests, reducing uncertainty and improving their quality of life.

PRINCIPLE 9 – QUALITY DOCUMENTATION

Ensure Documentation is Relevant and of High Quality

Ensures relevant, local end of life care and advance care planning documents are used.

Professionals will also want to ensure compliance with the relevant professional bodies.

KEY ELEMENTS OF TRAINING

PRINCIPLE 10 – ASSESSMENT OF NEEDS

Effective Care Plans Consider Every Aspect of Need – Physical, Social and Psychological

Central to good care of dying people is developing effective personalised care plans, based on clinical need (to obtain best possible symptom control) psychological support, spiritual care, practical and social support for individuals and their families/ carers.

Training for generalists in what can be done to support individuals holistically (e.g. what services are available in the local hospice out-patients department) should improve awareness of when it is appropriate to engage specialist palliative care services. Assessments should be inclusive of psycho-social factors, spiritual needs and cultural/ ethnic preferences. Professionals may need training in understanding all these issues to fully support individuals who are approaching their end of life.

Professionals will need to plan for religious needs before and after death, within the context of an awareness of differing beliefs of health, care and death. [The Redbridge case study - To Comfort Always - is a helpful guide].

This should include awareness of the potential impact on the individual's psychological health, for example, stress and anxiety as well as the effect on any cognitive difficulties. Consider support from family, carers and friends, support from voluntary organisations e.g. disease specific societies, community support (in some cultures) and access to specialist psychological or bereavement support where needed.

Individuals may have particular needs that need to be addressed (e.g. the hostel and street homeless population, people in prison…)

PRINCIPLE 11 – RECOGNISING DETERIORATION

Training Should Include an Understanding of When Someone's Condition Becomes Unstable

Timeframes of the dying process are complex and are not necessarily linear. Training in recognising when someone's condition becomes unstable, when disease progression is irreversible and when dying begins will help generalist professionals to know when it is appropriate to hold sensitive discussions with their patients and/ or their families and carers, enabling them to feel more engaged in the planning of future care, what to expect, enabling more choice, and access to appropriate services. Communicating this to individuals and families will also be important (see above, Principle 8).

This will include prognostic identification and use of tools to help this. Explore with staff the barriers they face in attempting to prognosticate e.g. emotional, language, cultural.

PRINCIPLE 12 – CHOICE IN FUTURE CARE

The Concept of Choice and Voice is Essential to End of Life Care for Individuals and Their Families

This is central to the concept of choice and being able to have a say in what happens regarding future care. It can only happen if professionals (a) feel confident about holding sensitive conversations about prognosis and the potential for dying and (b) are able to recognise deterioration in a timely way and is specifically tailored to individual need, not a generic service offer.

How to manage choice in the context of personal and practical circumstances of each individual, including their home environment, and the limits of what is possible for the individual.

PRINCIPLE 13 – ADVANCE CARE PLANNING

Advanced Planning Supports Excellent Care Across Organisations

Advance care plans enable and document planning for care, and support all agencies involved in an individual’s care to work together. Training is likely to include how to initiate discussions, what core elements ideally should be included and the importance of ensuring the plan is accessible and known to other significant people including family members and carers.

When documented, these plans belong to the individual. Ideally family members are aware and involved. There are a number of supporting tools that can be used, including EPaCCS.

KEY ELEMENTS OF TRAINING

Professionals need to be able to offer the opportunity to make a formal legally binding Advance Decision to Refuse Treatment if the individual wishes.

The principal of "best interest" under the Mental Capacity Act 2005 should be followed where individuals lack capacity to complete an advance care plan.

PRINCIPLE 14 – SUPPORT OF CARERS

Carer Fatigue is a Key Reason for People Coming in to Hospital

Recognising the needs of carers, working with them as partners in care, and being able to inform them where to refer on to for more support. Carer fatigue is a key reason for people coming into hospital.

The Care Act 2014 now gives carers the same recognition, respect and parity of esteem with those they support, with legal rights to assessment and support for the first time.

This can include;

- Individual budgets to purchase tailored support
- Domiciliary care at home for the person they care for
- Practical support, e.g. hospital bed at home, options for meals
- Emotional/ psychological support
- Accessing benefits and entitlements
- Overnight care
- Respite
- Volunteer befriending service
- Bereavement services
- Voluntary sector support

PRINCIPLE 15 – SUPPORT OF PROFESSIONALS/ SELF CARE

Peer Support Provides an Opportunity to Learn and Share Lessons and a Common Outlet of Experience

Support for professionals to undertake review of cases to learn from them, to unburden themselves, and to gain psychological support for their practice and learning from colleagues, and to understand the role of leadership in this context.

Examples of tools that can be used are;

- Reviews after a death in a supportive environment such as after death analysis or Schwartz rounds are an effective way for developing good team dynamics and improving an individual's confidence in difficult situations, particularly when dealing with emotional or social care issues
- Exploring audits and research in end of life care
- Sourcing guidance on end of life care.

PRINCIPLE 16 – COMPASSION IN CARE

Compassionate Care Includes Treating Individuals with Dignity and Comfort

The delivery of compassionate care is integral to all care and must be included in all education and training programmes. Descriptions of compassionate care include treating individuals with dignity and comfort, taking time and patience to listen, to offer explanation and demonstrate other communication attributes, demonstrate empathy, kindness and warmth; demonstrating relationship centred care including involvement, choice and connection. Health and social care staff should respect patients and carers for who they are, use language that they understand and recognise the pace at which they want to talk about things to do with their future care.

Training issues include competencies around the delivery of practical everyday care for dying people such as how they are moved or fed.

Evidence suggests that in order to give compassionate care, the carer must receive it. This links to self-compassion, mindfulness and resilience for the carer.

PRINCIPLE 17 – COORDINATION OF CARE

Care for Individuals Should Ensure a Holistic Approach Across the Whole Pathway

Knowledge of services available in the local care pathway and how to access them is important to support individuals and carers and to ensure safe transfers of care. This is essential if good care is to be achieved and individuals' wishes and choices are to be achieved. Training issues include the practicalities of timely and appropriate referrals to other health and social care providers including handover to out-of-hours services.

Professionals need to have knowledge of when to raise issues, how to do this sensitively, and when to back off if the individual indicates they would rather not know all the facts.

Central to good clinical care as is self-awareness; knowing when to intervene and when it is appropriate to refer to a colleague or for more specialist help. This applies equally to doctors, nurses, healthcare assistants, therapists and social care workers.

Multidisciplinary working across all boundaries is helpful (see also Principle 3 regarding MDT training to help teams work together).

Knowing how to identify the named individual or clinician in charge of end of life care planning for a patient.

Staff need to know how to determine who is responsible for a patient's plan – for example, named GPs for care coordination of care home residents. They may need to know about local IT systems that support this.

KEY ELEMENTS OF TRAINING

PRINCIPLE 18 – SAFETY AND SAFEGUARDING

Staff Should Have Thorough and Ongoing Knowledge of Safety and Safeguarding and of Legal Rights and Responsibilities

Social care, health and voluntary sector staff should have knowledge of their duties and responsibilities under the Mental Capacity Act 2005 and the Care Act 2014, in particular with relation to mental capacity and safeguarding.

Staff should be aware of their duty of care and the above principles however, there is a role for positive risk taking for people at the end of life which can empower individuals and enable choice and control.

There needs to be a general understanding that people must be allowed to change their mind, and that patients can challenge end of life care decisions.

Useful documents

Common core principles and competences for social care and health workers working with adults at the end of life, Skills for Care and Skills for Health (2014) | http://bit.ly/1FJWQlQ

End of life care, House of Commons Health Committee, Fifth Report of Session 2014–15 (March 2015) | http://bit.ly/1Id6IHB

End of life care advisory group plan, Health Education North Central and East London | http://bit.ly/1PRHW4Z

Equity in the provision of palliative care in the UK: Review of evidence, Marie Curie/PSSRU at the London School of Economics and Political Science (April 2015) | http://bit.ly/1avgTeU

Palliative and end of life care education and training strategy, Health Education South London, working in partnership with the South London Palliative Care Oversight Group and the Health Innovation Network, (February 2015) | http://bit.ly/1DH0Wy2

One chance to get it right: How health and care organisations should care for people in the last days of their life, Leadership Alliance for the Care of Dying People (June 2014) | http://bit.ly/1IKOrof

Public health approaches to end of life care: A toolkit, Middlesex University, Public Health England, National Council for Palliative Care | http://bit.ly/1OdOabL

Workforce skills and development strategy (2013-2018), Health Education North West London | http://bit.ly/1zk7Unm

Workforce skills and development plan (2013-18), Health Education North Central and East London | http://bit.ly/1NPxg8u

About the Strategic Clinical Networks

Greater Manchester and East Cheshire Strategic Clinical Networks

April 2016 marked the beginning of a new dawn for Greater Manchester, Lancashire and South Cumbria Strategic Clinical Networks (GMLSC SCNs) with a geographical change.
From 1st April 2016, Greater Manchester encompassed parts of East Cheshire and will be known as Greater Manchester and East Cheshire Strategic Clinical Networks (GMEC SCNs) with new NHS identity. The Networks will be joining the Academic Health Science Network (AHSN) as they forge ahead, the GMEC Strategic Clinical Network to support the Greater Manchester Health & Social Care Partnership.
Lancashire and South Cumbria joined Cheshire and Merseyside Strategic Clinical Networks to become the North West Coast Strategic Clinical Networks (NWC SCNs).

These changes have come from a combination of the Greater Manchester Health & Social Care Partnership and as a result of the recommendations in the review of centrally funded improvement and leadership development functions led by Ed Smith, Deputy Chair, NHS England and published in July 2015.

The review outlined the importance of the role of the Clinical Networks continuing to support health systems and improve health outcomes of local communities by connecting commissioners, providers, professionals, patients and the public across a pathway of care to share best practice and innovation, measure and benchmark quality and outcomes, and drive improvement.