

Annex C:

Priorities for Care of the Dying Person

Priorities for Care of the Dying Person

Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out five Priorities for Care in the last few days and hours of life. There are corresponding documents which set out:

- duties and responsibilities of health and care staff who are involved in the care of dying people; and
- implementation guidance for service providers and commissioners who have a responsibility to ensure that health and care staff have the right education, training and support to achieve these priorities.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, the Priorities have been set out below in sequential order.

The principles of palliative and end of life care apply from a much earlier point in a person's life-limiting illness. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping the individual to live well until they die. This document deals specifically with the priorities for care when a person is imminently dying, i.e. death is expected within a few hours or very few days.

If it is established that a person lacks capacity at the relevant time to make the relevant decision, then a decision must be taken in their best interests in accordance with the Mental Capacity Act 2005. The person making the decision must, if it is practicable and appropriate to do so, consult:

- anybody named by the person as someone to be consulted on either the decision in question or similar issues;
- anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare;
- any holder of a lasting power of attorney or enduring power of attorney; and
- any deputy appointed by the court to make decisions for the person.

This is referred to below as a 'best interests decision'. Further guidance on how this decision should be made is provided in the Mental Capacity Act Code of Practice.⁵⁴ If the person lacks capacity and there is a registered person with a lasting power of attorney who has the power to make the relevant decision, then the attorney should make the decision in the best interests of the person. It is also important to respect valid and applicable advance decisions.

⁵⁴ The Mental Capacity Act Code of Practice can be found on the Ministry of Justice website at: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

All health and care staff who care for dying patients must ensure that they are aware of and follow up to date guidance and local best practice. They must recognise that the evidence on which this is based will continue to evolve, so a commitment to lifelong learning is fundamental.

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die soon, i.e. within a few hours or days. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented, and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these must be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

Annex D:

Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff

Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out Five Priorities for Care in the last few days and hours of life. It also sets out the Duties and Responsibilities of Health and Care Staff to ensure the Priorities are achieved when they are involved in the care of dying people.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, they have been set out below in sequential order.

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Health and care staff who are involved in the care of dying people have duties and responsibilities as set out in this document. These are aligned with professional regulatory guidance and relevant legal requirements, including the obligations on staff set out in the Mental Capacity Act 2005 (the MCA) and its supporting Code of Practice.⁵⁵ Health and care staff will need the appropriate education and training to enable them to recognise and deliver these responsibilities in practice. Their employers and the system in which such staff work must support them in doing this. There is corresponding implementation guidance which sets out the requirements for commissioners and service providers to enable staff to deliver the five Priorities for Care and includes advice for educators.

⁵⁵ The Mental Capacity Act Code of Practice can be found on the Ministry of Justice website at: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act.

This document deals specifically with the priorities for care when a person is imminently dying, i.e. death is expected within a few hours or very few days. However, it should be noted that, for people living with life-limiting illness, the general principles of good palliative and end of life care (reflected in the Duties and Responsibilities) apply from a much earlier point. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping any individual to live well until they die.

The Duties and Responsibilities relate to care and treatment decisions made when a person has capacity to decide and when someone lacks capacity to make a particular decision. Anyone who works with or cares for an adult who lacks capacity to make a decision must comply with the Mental Capacity Act 2005 when making decisions or acting for that person. The Act makes clear who can take decisions in which situations, how they should go about this, who they must consult and involve, and the legal principles that they must apply to ensure that decisions are within the law. The Duties and Responsibilities statements take account of the requirements in the Mental Capacity Act and its Code of Practice, in particular the obligation on staff and others to make decisions in the 'best interests' of the person who lacks capacity to decide.⁵⁶

As with other areas of practice, all health and care staff who care for dying people must ensure that they are aware of, and follow, up-to-date guidance and local best practice. They must recognise that the evidence on which good care is based will continue to evolve, so a commitment to lifelong learning is fundamental.

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the doctor judges that the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, taking into account the views of others caring for the person, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented, and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

⁵⁶ See also the 'Reminder about the law on capacity' in the 'Generic good practice reminders' section of this document, below.

To achieve this:

1. The person whose condition has deteriorated unexpectedly must be assessed by a doctor who is competent to judge whether the person's change in condition is potentially reversible or they are likely to die in the next few hours or few days.
2. If it is clear that reversing the deterioration in a person's condition is possible their consent to treatment must be sought including discussion of the benefits, burdens and risks. If it is established that the person lacks capacity at that time to make the decision about treatment, a decision must be taken about whether providing treatment would be in their best interests, following the requirements of the Mental Capacity Act and related Code of Practice.
3. If the doctor judges that the person is likely to die soon, s/he must clearly and sensitively communicate this to the dying person (if conscious). This includes explaining when and how death might be expected to occur and the basis for that judgement, acknowledging and accepting any uncertainty about the prognosis, and giving the dying person the opportunity to ask questions. The same communication must take place with those important to the dying person and others involved in that person's care. The responsibility for communicating this information may be delegated by the doctor to another clinician who has the appropriate training and competence.
4. The decision must be reviewed at the next available opportunity by a senior clinician within the person's care team who is competent to assess whether the person has reached the stage where they are dying. The views of the wider multi-professional team must be taken into consideration in making this assessment.
5. The goals of treatment and care must be discussed and agreed with the dying person, involving those identified as important to them and the multidisciplinary team caring for the person. These discussions must be clearly documented and accessible to all those involved in the person's care, taking into account the person's wishes about sharing their confidential information. Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis.
6. If it is established that the dying person lacks capacity to make decisions about the goals of treatment and care, the goals must be discussed and agreed with any holder of a lasting power of attorney to make healthcare decisions on the person's behalf and discussed with those identified as important to them, with the aim of reaching a consensus on what future treatment and care would be in the person's best interests.
7. The dying person must be reviewed by a senior clinician within the person's care team at least daily thereafter – or sooner if there is an unanticipated change in the person's condition – to assess whether they are still likely to be dying (given the uncertainties of prognosis), and if the plan of care remains appropriate. The senior clinician may delegate this responsibility to another clinician who has appropriate training and competence but will remain accountable for the overall care of the dying person.
8. The senior clinician must consider whether involvement of a specialist would be helpful if there is uncertainty whether or not the person is dying.
9. Doctors, nurses and other health and care staff responsible for the person's care must seek out opportunities to communicate about any deterioration or change in the dying person's condition with those identified as important to that person.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

To achieve this:

1. Health and care staff must make time to talk with dying people, their families and those identified as important to them, including carers. They must listen, respond sensitively to their issues and concerns, provide information in a way that meets their communication needs and check that explanations and information are understood.
2. All relevant discussions must be in simple, appropriate, straight forward language without using euphemisms.
3. Sensitive communication includes the need for health and care staff to respect the wishes of people who have made it clear that they do not wish to have open conversations about their condition or what is happening to them.
4. Health and care staff must ask the person who they want to be contacted and with whom they wish information about their condition to be shared. They must also ask if there are specific individuals with whom they do not wish information to be shared. This must be clearly recorded and shared with all who care for the person particularly if they move between care settings, e.g. hospital to home.
5. Health and care staff have legal duties and ethical responsibilities to protect confidential information about a patient. Professional and other guidance set out the circumstances in which confidential information can be shared with the person's family and others. Within those guidelines, health and care staff must recognise and address the communication and information needs of the dying person's family and others identified as important to them. Where there is no record to the contrary and the person does not have capacity to give consent, it is reasonable to assume that they would want their family and those important to them to be informed about their condition and prognosis.

6. The content and outcome of all discussions must be documented and accessible to all those involved in the person's care. This includes conversations about prognosis, goals of treatment and care plans at each point in time, and particular concerns that the person, their family and those identified as important to them have expressed.
7. Difficult conversations must not be avoided but must be carried out sensitively, recognising that communication is an on-going process and not a one-off event.
8. When it has been established that a dying person lacks capacity to make a particular decision, the Mental Capacity Act requires that any decision made is in the best interests of the dying person. It also sets out who can make decisions about the person's health and welfare. What this means in practice, for the role of family members and others important to the dying person, should be explained in clear, understandable language by health and care staff involved in the care of the dying person.
9. Assumptions must not be made about the frequency of communication that might be acceptable to the person, their families and those important to them. Staff must check this with them.
10. The way in which information about the person's needs, wishes and views can be shared with those identified as important to them and staff, must be discussed with the person, so that the method used is in accordance with individual preferences. For example, shared information folders or diaries may be a helpful way of enhancing communication for some. Those who have visual impairment may prefer to use other means for conveying their wishes, e.g. using a CD or DVD.
11. When the dying person is being cared for at home, the named GP, senior responsible doctor or named nurse responsible for the person's care must ensure that families and carers of the dying person are given clear, reliable and consistent information about how to seek urgent help when this is needed, including who to ring, what number(s) to use at any time of day or night, and what key information they should provide that will facilitate the most appropriate response. This must include information about what to do when the person dies.
12. As soon as possible after the death of the person, and depending on the family's wishes, a health care professional should offer to attend the person to ensure their body is appropriately cared for and the immediate practical and emotional needs of those present and those important to the person are attended to.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and

those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

To achieve this:

1. Clinical teams must give the dying person, their families and those important to them the name of the senior doctor in the team who has overall responsibility for providing appropriate treatment and care for the dying person, and explain how that responsibility is handed over in times of absence or change in care arrangements or settings. This must be clearly documented and accessible to all those involved in the person's care.
2. The name of the nurse responsible for leading the care of the dying person must also be given to the person and those important to them with an explanation of how this responsibility is handed over. This must be clearly documented and accessible to all those involved in the person's care.
3. Health and care staff must give the dying person the information they need or are asking for in a way they can understand, and the support they need to make informed decisions about treatment options.
4. All decisions must involve consideration of the potential benefits, burdens and risks of treatment (or non-treatment) for the individual person. Individuals must be supported to make informed decisions as much as possible and to the extent they wish.
5. The dying person's wishes about the extent to which families and those important to them are involved in discussing their treatment and care must be respected and supported.
6. Health and care staff must understand the difference between explaining what is going on (including any decisions made); seeking the person's consent for specific interventions or actions; and consulting the person's family and those important to them about making a best interests decision.
7. The dying person should be given all the help and support they need to make a decision before anyone concludes that they cannot make their own decision. Any actions taken or decisions made on behalf of someone who lacks capacity must be done in their best interests, after considering what is known about their preferences (and any relevant and valid advance decision to refuse medical treatment), and wherever possible still involving them in making the decision.
8. Doctors, nurses and other healthcare professionals must carefully consider which decisions need to be made on-the-spot to ensure the person's comfort and safety, and which can and must wait for a review of the person's condition by the senior doctor who has responsibility for the person's treatment and care (who may know the person better and/or have relevant competence and information to inform treatment decisions) or a clinician with the appropriate training and competence to whom the responsibility has been delegated.
9. The starting point of communication between health and care staff and the family and those important to the person must be that all parties wish to act in

the person's best interests. Differences in opinion, about how to work towards agreement on what would be best for the dying person, must be discussed openly and additional advice sought, including a second opinion, where there is a continuing difference of opinion or if additional reassurance would be helpful.

10. The dying person's senior doctor is responsible for ensuring that adequate information is available to support decision-making by those involved in caring for the person when the senior doctor is not available.
11. If a healthcare professional is considering withdrawing or not starting a potentially life-prolonging but burdensome treatment, because it is not considered clinically appropriate in managing the person's care, they must explore in a sensitive way how willing the dying person might be to know about and discuss this or whether they would prefer that this is discussed with those identified as important to them.
12. If there is a continuing difference of opinion about the treatment or care of a dying person, or if additional reassurance about a decision would be helpful, health and care staff must consider obtaining a second opinion and getting support to facilitate communication to reach a consensus, for example from a social worker, advocacy worker or a chaplain or faith community leader, especially if the difference of opinion is expressed in relation to religious beliefs or concerns. If significant disagreement remains, staff must seek advice on applying to the court for an independent ruling and inform the dying person (and those important to them) as early as possible.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these should be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

To achieve this:

1. Health and care staff must regularly assess and address (if possible) the needs of families and those important to the dying person, and offer information about getting access to other sources of help and support.
2. Health and care staff in in-patient facilities must ensure families are welcome and enabled to spend time with the dying person to the extent that they and the dying person wish.

3. Family or important others who wish to participate in caring for the dying person in an in-patient facility must be supported by staff to do so, e.g. by showing them simple practical techniques, but assumptions must not be made about their ability or wish to do so.
4. In some situations, the dying person, or their family or carer may be more skilled at performing certain tasks than the health and care staff. Their expertise must be acknowledged and they must be supported to continue performing these tasks while they remain willing and able to do so.
5. Where the person's family or those identified as important to them are involved in the care of the dying person, their observations and judgements must be taken into account as part of the ongoing discussion and planning of care.
6. Health and care staff must acknowledge that the needs of the dying person, their families and those important to them may differ. Differences must be acknowledged and addressed in a sensitive way. For example, children and elderly people important to the dying person may have particular needs for practical and emotional support that require careful consideration by health and care staff.
7. Some families do not wish to talk openly about death and dying. This must be respected but health and care staff must find a sensitive way to remain clear in their communication, and to avoid euphemisms.
8. If the dying person is in hospital or another institution, staff must pay attention to the wellbeing of families and those important to the dying person by showing them where the toilets are located, where to make drinks, how they can rest, etc.
9. Health and care staff must offer information and explanations to the dying person's family and those important to them, including carers, to prepare them for what happens when a person is close to death, whether the death is occurring at home or in an institution.
10. When a person is imminently dying, the responsible nurse or other healthcare professional must check with the dying person's family and those important to them about how they would best wish to be supported. Some prefer to be left alone; others prefer a staff member to briefly check in with them every now and then; others may need more support. Importantly, they need to know where staff are if they are needed.
11. The family and those important to the dying person, including carers, may have their own spiritual and religious needs which may, or may not, be similar to that of the dying person. Staff must involve chaplains or relevant religious leaders if the family and those important to the person want this.
12. When a person has died, the wellbeing of the bereaved family and carers must be considered, and health and care staff must ensure adequate support is available for their immediate needs. They must be allowed time with the deceased person, if they wish, without being put under pressure.
13. Families and those important to the dying person will require additional support if the death has been unexpected or if it occurs after a very short deterioration, for example help to understand post mortem, coroners' and death certification procedures, and to have their questions answered.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

To achieve this:

Planning care

1. Health and care staff must offer the dying person the opportunity to discuss, record and update their wishes and preferences as part of individualised care planning. Ideally, this planning should have started earlier in the illness and the plan updated as the situation changes. The extent to which the dying person wishes to be involved in developing a plan of care must be respected; so must their wishes about who else to involve in these discussions.
2. Where a nominated friend/family member has been identified by the dying person to take part in care planning, they must be involved in the preparation of the plan of care.
3. Health and care staff must take account of and give weight to the views, beliefs and values of the person in agreeing the plan of care. If it is established that a dying person lacks capacity to make particular decisions and their wishes and views about future care cannot be ascertained, then the decisions made must be in the person's best interests. The observations and judgements of those involved in the person's care (formal and informal) must be taken into account in ongoing discussions and planning of care.
4. The individual plan of care must be agreed, communicated, adhered to and regularly reviewed, with the person and, if they agree, those important to them.

Assessment

5. The person's physical, emotional, psychological, spiritual, cultural and religious needs must be assessed to formulate personalised plans to address these needs, in discussion with the dying person and, if they wish, their family or those important to them.
6. Assessment must be conducted with respect for personal privacy and dignity. Aids to communication that the person normally uses, e.g. spectacles, hearing aids, dentures, must be used.

7. The frequency of review and how the person's comfort is monitored, including the use of assessment tools, must be individualised and agreed with the person and, if it is established that the person lacks capacity to make decisions about these matters, the decisions made must be in the person's best interests.
8. Health and care staff must ensure that important assessments of a patient's condition, capacity to decide, or treatment and care needs (e.g. swallowing) are conducted openly and family and others important to the dying person are provided with clear explanations and involved where that may provide helpful information about the dying person to ensure an effective assessment is made, provided this does not delay attending to the dying person's needs.
9. Health and care staff must ensure that disagreement about the outcome of assessments are swiftly acknowledged and acted upon, creating opportunity for discussion, reflection and allowing alternative opinions. If there is significant disagreement about a person's capacity to make a decision, which has not been resolved through informal, local procedures, staff must seek advice about obtaining a ruling from the court (as required by the Mental Capacity Act).

Food and drink

10. The dying person must be supported to eat and drink as long as they wish to do so and there is no serious risk of harm (for example through choking). However if there is likely to be a delay in assessing their ability to swallow safely, alternative forms of hydration must be considered and discussed with the person. Nursing and medical records on the assessment of intake must be kept.
11. If a dying person makes an informed choice to eat or drink, even if they are deemed to be at risk of aspiration, this must be respected.
12. If the dying person is unable to swallow, decisions about clinically assisted hydration and nutrition must be in line with the General Medical Council 2010 guidance *Treatment and care towards the end of life: good practice in decision-making* and relevant clinical guidelines.
13. Health and care staff must pay attention to the dying person's mouth care and other personal care needs to maintain their comfort and dignity.

Symptom control

14. All medications, including anticipatory medicines, must be targeted at specific symptoms, have a clinical rationale for the starting dose, be regularly reviewed, and adjusted as needed for effect.
15. The reason for any intervention, including the use of a syringe driver, must be explained to the dying person and to those important to the dying person. Other than in exceptional circumstances, this should be done before it is used.
16. The likely side effects of specific interventions, especially those that may make the person sleepy, must be discussed with the dying person to enable them to make informed decisions, and explained to those important to the dying person if the person wishes.
17. Health and care staff must ensure that medicines, equipment and other aids that can improve the dying person's comfort and dignity are obtained as soon as this is needed, or in anticipation of needs if the person is not in hospital.

18. If paramedical or ambulance staff are called to a dying person at home or in a care home because the person has symptoms, they must assess and wherever possible manage symptoms in accordance with the person's preferences and agreed care plans. This may include decisions about whether or not to transfer the dying person to hospital or another care facility. Where the dying person's preferences or care plan are not known or clear, ambulance clinicians must seek senior ambulance clinical advice and/or contact the GP/primary care out of hours provider if required to obtain urgent clinical advice first.
19. Clinical teams must refer to specialist palliative care for advice or assessment when the person's needs (or the needs of those important to them) are beyond their competency to provide for, or when initial measures have failed to provide adequate relief within at most 24 hours.

Spiritual and religious care

20. When specialist spiritual/religious support is identified as required, health and care staff must ensure that the dying person, and those important to them, have ready access to information about the available chaplaincy and/or spiritual care provision.
21. The chaplains must have information about local faith leaders to enable, where requested by the person, referral to church or faith community leaders.
22. Staff, must find out from the dying person, their family and those important to them, the details of any cultural or religious-specific requirements, including what constitutes respectful treatment of the body after death.

Co-ordinating care

23. Health and care staff must ensure they provide accurate and timely handover to teams taking over care, particularly regarding the person's wishes.
24. Adequate care planning information about the dying person must be available to ensure safe and appropriate clinical decisions are made regarding care and treatment, taking into account the individual's prior wishes, in the event that the dying person is unable to participate in the decision at the time.
25. If a dying person has to move between care settings, a clear emergency plan must be made and communicated so that action appropriate to the person's needs and preferences can be taken if their condition changes unexpectedly.
26. Where there is inadequate time to determine the person's wishes about, or suitability for, attempts at cardiopulmonary resuscitation, DNACPR (Do Not Attempt Cardio-pulmonary Resuscitation) documentation from another care setting or care provider should be taken into account, and followed where the healthcare professional making the decision is certain that s/he has sufficient information about the person to judge that the DNACPR is valid and applicable.

Generic good practice reminders:

1. Health and care staff must note that dying people who cannot communicate easily, either because their first language is not English or because they have a sensory, physical or mental impairment, will require additional time and assistance, and these staff must know how to seek specialist help, including an interpreter, or special aids if required.

2. The coordination of care requires a certain amount of information about the person to be shared. Staff must be aware of and follow relevant national and local guidelines for protecting and sharing information about the person, including understanding the circumstances in which they can rely on the person's implied consent to sharing information with those important to the person and health and care staff involved in providing care.
3. Staff must ensure that the person understands what information is being shared and how this will be used and shared.
4. Staff must be aware of, and manage, the potential risks caused by multiple sets of documentation.
5. Staff must draw on the experience and skill of the multidisciplinary team to undertake and reinforce discussions as necessary.
6. Staff must be aware of the role of advocates as an independent voice (formal and informal), offer an advocate to patients and families and utilise advocates where necessary.
7. Staff must consider the particular needs of families and those important to the dying person who may have specific disability or impairment; in discussion with families and those important to the dying person, staff should consider how to support them.

Reminder about the law on capacity

8. Staff must operate within the legal framework provided by the Mental Capacity Act 2005 (MCA) and its Code of Practice. The Act makes clear who can take decisions in which situations, and how they should go about this. Anyone who works with or cares for an adult who lacks capacity must comply with the MCA when making decisions or acting for that person. The Act sets out five statutory principles that must guide decisions, including requirements that staff ensure that those who may lack capacity to decide are empowered to make as many decisions for themselves as possible and that any decision made, or action taken, on their behalf is made in their best interests.
9. If an Advance Decision to Refuse Treatment exists and is valid and applicable (within the terms of the Act and Code), it must be followed. Individuals who have been nominated by the dying person to be involved in decisions and those who hold Lasting Powers of Attorney (LPA) relating to health and welfare issues must be involved in decisions. Those who hold a registered LPA for health and welfare may have legal authority under the terms of the LPA to make the decision on behalf of the dying person.⁵⁷

⁵⁷ Detailed advice about obligations of staff under the Act and Code is available on the website of the Ministry of Justice: www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

References:

- GMC 2010 guidance, *Treatment and care towards the end of life: good practice in decision-making* ⁵⁸
- Mental Capacity Act 2005 and the MCA Code of Practice (with accompanying guides for staff and members of the public) ⁵⁹
- *Standards of Conduct, Performance and Ethics*, HCPC (2008: updated 2012 to reflect name change) ⁶⁰

⁵⁸ www.gmc-uk.org/End_of_life.pdf_32486688.pdf

⁵⁹ www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act

⁶⁰ www.hcpc-uk.org/publications/standards/index.asp?id=38

Annex E:

Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners

Priorities for Care of the Dying Person

Implementation Guidance for Service Providers and Commissioners

The NICE Quality Standard for End of Life Care (2011) describes what a high quality service for the last year of life should look like, and sets the context for this work, which focuses on care in the last few days and hours of life. Caring for people who are close to death demands compassion, kindness and a skilled application of knowledge. This document sets out the expectations for commissioners, service providers and employers to ensure that the five Priorities for Care of the dying person can be delivered in a safe, effective and person-centered way, whatever the care setting. Health and care staff who are involved in the care of dying people have duties and responsibilities, set out in a separate document, for achieving these priorities. They must be enabled and supported by their employers and the system in which they work, whether this is in the public, private or voluntary sector.

The principles of palliative and end of life care apply from a much earlier point in a person's life than is common practice currently. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping the individual to live well until they die. These processes are individually time consuming and complex, requiring time and skill to deliver. Identifying people with multiple conditions and/or frailty which may together limit life expectancy is a key step in beginning this process.

All health and care staff who care for dying people must ensure that they are aware of, and follow, guidance and local best practice. They should recognise that the evidence on which this is based will continue to evolve, so a commitment to lifelong learning and continuous improvement is fundamental.

The Priorities are all equally important to achieving good care in the last few days and hours of life. Each supports the primary principle that individual care must be provided according to the needs and wishes of the person. To this end, they have been set out below in sequential order.

Priorities for Care

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

An expanded explanation for each Priority for Care follows:

Priority 1

The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Expanded explanation:

When a person's condition deteriorates, unexpectedly, and it is thought they may die soon, i.e. within a few hours or very few days, they must be assessed by a doctor who is competent to judge whether the change is potentially reversible or the person is likely to die. If the change in condition is potentially reversible, prompt action must be taken to attempt this, provided that is in accordance with the person's wishes or in their best interests if it is established that they lack capacity to make the decision about treatment at that time. If the doctor judges that the person is likely to be dying, this must be clearly and sensitively explained to the person in a way that is appropriate to their circumstances (if conscious and they have not indicated that they would not wish to know), and their family and others identified as important to them. The person's views and preferences must be taken into account, and those important to them must be involved in decisions in accordance with the person's wishes. A plan of care must be developed, documented and the person must be regularly reviewed to check that the plan of care remains appropriate and to respond to changes in the person's condition, needs and preferences.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Expanded explanation:

Open and honest communication between staff and the person who is dying, and those identified as important to them, including carers, is critically important to good care. Clear, understandable and plain language must be used verbally and in all other forms of communication with the dying person and those important to them. If the dying person needs additional support to understand information, communicate their wishes or make decisions, these needs must be met. Communication must be regular and proactive, i.e. staff must actively seek to communicate, not simply wait for the person or those important to them to ask questions. It must be two-way, i.e. staff must listen to

the views of the person and those important to them, not simply provide information. It should be conducted in a way that maximises privacy. Communication must be sensitive, respectful in pace and tone and take account of what the dying person and those important to them want and feel able to discuss at any particular point in time. Staff must check the other person's understanding of the information that is being communicated, and document this.

Priority 3

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Expanded explanation:

Individuals vary in the extent to which they wish to be involved in decisions about their own treatment, though most would want to make or influence decisions about the care they receive, and the way this is delivered. This includes day to day decisions about food, drink and personal care, as well as clinical and treatment decisions. Individuals also vary in the extent to which they wish their families and those important to them to be involved in decision-making. Sensitive communication is needed to ascertain the wishes of the dying person and their wishes must be respected. The person, and those important to them, must be told who is the senior doctor in the team who has responsibility for their treatment and care, whether in hospital or in the community, and the nurse leading their care. Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Expanded explanation:

Families and those important to the dying person, including carers, have their own needs which they, and others, can overlook at this time of distress. They are often tired, both physically and emotionally, and may be anxious and fearful, especially if they are the dying person's main caregiver at home. Even those who may appear to be coping well appreciate an acknowledgement that the imminent death of somebody they love is hard and that they have a role in ensuring that their loved one receives a good standard of care as they near the end of life. Where they have particular needs for support or information, these should be met as far as possible. Although it is not always possible to meet the needs or wishes of all family members, listening and acknowledging these can help. If a person who is dying lacks capacity to make a decision, the decision-making process should be explained to those people who are supporting the dying person and they should be involved as much as possible.

Priority 5

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Expanded explanation:

A plan for care and treatment must be developed to meet the dying person's own needs and wishes in relation to how their care should be managed and any treatment preferences they may want to express. This plan must include attention to symptom control (e.g. relief of pain and other discomforts) and the person's physical, emotional, psychological, social, spiritual, cultural and religious needs. The person must be supported to eat and drink as long as they wish to do so, and their comfort and dignity prioritised. There must be prompt referral to, and input from, specialist palliative care for any patient and situation that requires this. The plan of care must be documented so that consistent information about the person's needs and wishes is shared with those involved in the person's care and available at the time this information is needed.

Expectations of Commissioners, Service Providers and Employers

Commissioners, service providers and employers play specific roles in enabling and ensuring good care for the dying person. The requirements set out below should be read in the context of wider expectations set out in other publications about health and care provision, including the guide 'How to ensure the right people, with the right skills, are in the right place at the right time' published by the National Quality Board (see Annex (i) for detail on the expectations), the report 'Future Hospital' by the Royal College of Physicians and the current work on Transforming Urgent and Emergency Care Services led by NHS England. These references and additional useful links are set out in Annex (ii).

The main responsibility for delivering quality care lies with health and care staff, service providers and those who commission, fund and arrange local services. The Care Quality Commission monitors, inspects and regulates services to make sure they meet fundamental standards of quality and safety, including in end of life care. As part of its quality assurance process, the General Medical Council is able to identify how the education standards it sets are being met by all those involved with the organisation and delivery of medical education and training, including local education providers.

The Role of Commissioners

The details of what is required of service providers and employers to enable the five Priorities for Care of the dying person to be delivered are set out below. As part of their commissioning responsibility, Clinical Commissioning Groups, NHS England and Local Authorities must consider how these requirements are included in their contractual and service specification arrangements for end of life care, both in terms of service provision, and the necessary education and training for its workforce. Responsibility for the latter extends to the Local Education and Training Boards. The National Quality Board sets out the expectation that 'commissioners actively seek assurance that the right people, with the right skills, are in the right place at the right time within the providers with whom

they contract'.

Commissioners have a crucial role in influencing and expecting service providers and health and care employers to have leadership and governance arrangements in place that enable and ensure good quality care for people in their last days of life. Commissioners should also draw on the NICE Quality Standard for End of Life Care which includes a specific quality statement about care in the last days of life.

To achieve the Priorities for Care of the dying person, service providers and employers must:

Leadership, accountability and responsibility

1. Provide strong managerial leadership and a strong governance framework which prioritises care of dying people with Board level accountability.
2. Provide strong clinical and cultural leadership and implement a local policy which recognises that care of the dying person is a priority and the responsibility of all health and care staff, not just those working in specialist palliative care, as long as they have any contact with dying people and their families or those important to them.
3. Provide strong leadership and implement a local policy which recognises that all health and care staff, and the service providers they work for, have a responsibility to contribute to, and learn from, audit, evaluation and research that is necessary to continually improve the quality of care and the evidence base for care of dying people.

Education, training and support (see Annex (iii) for further details)

4. Provide mentorship, support and direct involvement from senior clinical staff in recognising when dying is likely in the next few days or hours, and in assessing and reviewing the dying person's needs and preferences.
5. Require and enable health and care staff to acquire and maintain the necessary competences for delivering the Priorities for Care of the dying person, commensurate with the individual's role and responsibility, by providing protected learning time and resources for education and training, as part of induction, continuing professional development and regular updates.
6. Require and support health and care staff to develop the high level of communication skills they need to communicate effectively with people and those important to them in the last days and hours of life, and with people who have been bereaved.
7. Ensure that health and care staff have access to locally agreed advice for palliative and end of life care based on current best available evidence.
8. Recognise that conversations about dying and death are difficult and health and care staff need support, and time and opportunity for reflection, if they are to continue to have resilience to do this in an effective and compassionate manner.
9. Recognise, through clearly defined support structures, teams and working patterns, that caring for the dying person requires ring fenced time and investment of emotional energy.
10. Work with commissioners to ensure access to an adequately resourced specialist palliative care workforce to provide leadership, education and training, including for pre-qualifying education, and support to non-specialist front-line health and care workers.

Culture of care and compassion

11. Promote and support an organisational culture which prioritises care, compassion, respect and dignity as fundamental to caring for dying people.
12. Ensure and enable care for a dying person to be delivered with consistency, compassion and effectiveness with clear local advice/requirements.
13. Ensure that food and drink is provided and the dying person supported to eat and drink if they wish to do so.
14. Ensure access to assessment for, and provision of, clinically assisted hydration where this is in the dying person's best interests and wanted by the person.
15. Implement and support mechanisms for feedback which facilitate service improvement.
16. Work with commissioners and specialist palliative care professionals to ensure adequate access to specialist assessment, advice and active management. 'Adequate' means that service providers and commissioners are expected to ensure provision for specialist palliative medical and nursing cover routinely 9am-5pm, seven days a week, and a 24 hour telephone advice service. Where this service does not already exist, service providers and commissioners should formulate an action plan and commit to provision of such services within defined timelines. This should ensure the provision of specialist cover over 24 hours including face to face assessment in the exceptional circumstances where this is necessary.
17. Ensure arrangements are in place for enabling a second opinion to be offered for the dying person's care where this is required, and that staff are aware of how to seek this.
18. Ensure that health and care staff know:
 - a. When and how to seek senior and/or specialist support in any aspect of assessment or delivering care and treatment when this is beyond their competence, including clinical, psychological, emotional, social, spiritual and/or religious support.
 - b. When to offer the services of an interpreter for dying people and their families who may not have English as their first language, (or other forms of communication support, such as signing) and ensure that such services are readily accessible.
 - c. How to find out about the specific needs of dying people, and those important to them, who have disability or impairments, and ensure that they can obtain any necessary aids, equipment or expert help as quickly as possible.
19. Ensure that health and care staff are aware of the role of advocates as an independent voice (formal and informal), including when this is required under the Mental Capacity Act, offer this to patients and families and enable advocates to be utilised where necessary.
20. Ensure that families and those important to the dying person, are welcomed and enabled to spend time with the dying person to the extent that they, and the dying person, wish, relaxing visiting times if necessary.

21. Ensure that families and carers who wish to participate in care are actively encouraged, enabled and empowered to do so, e.g. by being shown how to carry out tasks. But those who do not wish to do so must not be made to feel that they need to do so because of staffing levels.
22. Ensure that health and care staff understand that their duty of care to the dying person extends beyond death to the care of the deceased body and the administration of practical requirements (including death certification), and that they are supported to carry out these duties.
23. Ensure that when a person has died, the wellbeing of the bereaved family and those important to that person, including carers, is considered, and that adequate support is available according to their needs, including timely access to viewing the body of the deceased person.
24. Promote awareness of the impact of the dying person on other people in an institutional environment, e.g. other patients and residents in a care home, and other staff, and ensure that they are supported and kept appropriately informed.

Environment

25. Ensure there is suitable provision for making the environment sensitive to the needs of the dying person and those important to them, including dignity, privacy and suitable space for care and difficult conversations to take place.
26. Provide information and facilities to support families and those important to the dying person to spend time with them, including where and how to obtain food and drink for themselves, appropriate seating, etc.

Clinical governance and systems of care

27. Put in place local governance arrangements so that the senior doctor with overall responsibility for the dying person's care is identified to the person and those important to them.
28. Put in place local governance arrangements so that the nurse leading the care of the dying person at any one time, including during each shift if the person is in hospital or care home, is identified to the person and those important to them.
29. Ensure that there are explicit policies in place which require those delivering end of life care to document:
 - a. their decisions about drug treatments and interventions with justifications based on the needs and preferences of the individual as well as best practice;
 - b. the content and outcome of all discussions, including conversations about prognosis, decisions, treatment goals and care plans at each point in time, and any concern that the person, and those important to them, have expressed;
 - c. plans of care for the dying person which are current, reviewed and individualised, taking into account their needs and wishes, and adapted as required;
 - d. names of the senior doctor with overall responsibility for the dying person's care and the nurse leading the care of the dying person at any one time, are documented and accessible to those involved in the person's care.

30. Ensure that policies about care and treatment for the dying person, including food and drink, facilitate and support informed choices by the person.
31. Ensure ready access and availability of medicines and equipment at all times of day and night, including pharmaceutical advice when required. Where a delay may be anticipated, e.g. at weekends, these should be prescribed and delivered in advance if appropriate and the person and family agree.
32. Put in place arrangements to enable health and care staff to give families and carers clear, reliably and consistent information about how to seek urgent help when this is needed, including who to ring, what number(s) to use at any time of day or night, and what key information they should provide that will facilitate the most appropriate response, when the dying person is being cared for at home.
33. Ensure that there are clear and adequate mechanisms for handover within the organisation, and work in partnership across the health and care community to develop and maintain information sharing systems to enable coordinated care across organisational boundaries.
34. Ensure clear arrangements for transfers across settings by ambulance or other means if this is necessary, including clear agreements about timescale.

Annex (i)

Source: How to ensure the right people, with the right skills, are in the right place at the right time. A guide to nursing, midwifery and care staffing capacity and capability. National Quality Board (2013)

- Expectation 1: Boards take full responsibility for the quality of care provided to patients, and as a key determinant of quality, take full and collective responsibility for nursing, midwifery and care staffing capacity and capability.
- Expectation 2: Processes are in place to enable staffing establishments to be met on a shift-to-shift basis.
- Expectation 3: Evidence-based tools are used to inform nursing, midwifery and care staffing capacity and capability.
- Expectation 4: Clinical and managerial leaders foster a culture of professionalism and responsiveness, where staff feel able to raise concerns.
- Expectation 5: A multi-professional approach is taken when setting nursing, midwifery and care staffing establishments.
- Expectation 6: Nurses, midwives and care staff have sufficient time to fulfil responsibilities that are additional to their direct caring duties.
- Expectation 7: Boards receive monthly updates on workforce information, and staffing capacity and capability is discussed at a public Board meeting at least every six months on the basis of a full nursing and midwifery establishment review.
- Expectation 8: NHS providers clearly display information about the nurses, midwives and care staff present on each ward, clinical setting, department or service on each shift.
- Expectation 9: Providers of NHS services take an active role in securing staff in line with their workforce requirements.
- Expectation 10: Commissioners actively seek assurance that the right people with the right skills are in the right place at the right time within the providers with whom they contract.

Annex (ii)

- *How to ensure the right people, with the right skills, are in the right place at the right time. A guide to nursing, midwifery and care staffing capacity and capability.* National Quality Board, (2013): www.england.nhs.uk/wp-content/uploads/2013/11/nqb-how-to-guid.pdf
- *Future Hospital.* Royal College of Physicians, (2013): www.rcplondon.ac.uk/projects/future-hospital-commission
- *Transforming Urgent and Emergency Care Services.* NHS England, (2013): www.nhs.uk/NHSEngland/keogh-review/Pages/about-the-review.aspx
- RCGP commissioning guidance for EOLC: www.goldstandardsframework.org.uk/cd-content/uploads/files/Primary%20Care/EOLC%20Commissioning%20Guidance%20Final%20-Apr13.pdf
- *Commissioning guidance for specialist palliative care: helping to deliver commissioning objectives.* National Council for Palliative Care (2012) - Developed in collaboration with: Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care and Palliative Care Section of the Royal Society of Medicine: www.ncpc.org.uk/sites/default/files/CommissioningGuidanceforSpecialistPalliativeCare.pdf

Annex (iii)

Recommendations on desired characteristics of education and training programmes for care in the last days of life – for use by those who commission, fund or procure such programmes for health and care staff involved in care of the dying person.

As a minimum, such education and training programmes should include:

Learning Objectives

These are high level objectives as they need to be adapted to suit the programme, its duration and format, and its intended learners. Depending upon role they should focus from awareness to application to complex assessment and decision-making. They should include:

By the end of the training programme, learners are able to:

- Describe how to assess and act upon the needs of a dying person: physical, psychological, emotional, social, spiritual, cultural, religious.
- Explain how to address the dying person's comfort, specifically in relation to food, fluids and symptoms.
- Discuss how to approach and implement individualised care planning including shared decision-making.
- Demonstrate how to communicate about dying with the person, and those who are important to them.
- Describe how to assess and act upon the needs of the dying person's family and those important to the person.
- Describe the importance of and act upon maintaining own and team resilience through reflective practice and clinical supervision.
- Demonstrate understanding of how Mental Capacity Act should be applied when the dying person lacks capacity.
- Demonstrate understanding of the impact of loss and grief, including how to support individuals who are bereaved.

Additionally, for clinicians:

- Describe how to recognise that dying may be imminent, assess reversibility, make appropriate decisions and plans for review, and communicate uncertainty

Content

- Assessing the person whose condition has changed, including how to gather information from that person and those important to them, and other health and care team members, make professional judgements about the potential reversibility of the condition (and if so, whether or not reversing the condition is the right thing to do) and take appropriate action, including seeking senior advice or second opinion if necessary.

- Assessing and discussing the physical, psychological, emotional and social needs of the dying person.
- Assessing and discussing the spiritual and/or religious needs of dying patients, and those important to them.
- Specific attention to the topics of nutrition and hydration: assessment, discussion and shared decision-making with the person (where possible), and those important to them and other health and care team members
- Symptom management: assessment, communication and shared decision-making wherever possible about use of medication (including route of delivery), physical measures (including repositioning) and safe and accurate prescribing.
- Assessing and addressing the needs of those important to the dying person, including in bereavement.
- Communication skills, including empathy and recognising emotional response to stress and distress, discussing uncertainty, conversations about limits of treatment including 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR), withholding and withdrawing treatment, preferred place of care and death, etc.
- Clarity in verbal and written handovers between professionals, and across shifts/duty periods and settings (e.g. community and hospital care) to ensure consistent care and communication with the person and those important to them.
- An appreciation that caring for people in the last days of life is not just about 'doing' or 'fixing' things. It is concerned with supporting the person and those that are important to them during the dying period.

Educational approaches

- Employer commitment to ensure the delivery of appropriate end of life education programmes to health and care workers.
- Employee commitment to attend and implement learning from end of life education programmes.
- Explicit learning outcomes which include how to apply learning to practice, and supports implementation of advice from the Leadership Alliance for the Care of Dying People.
- Teaching methods which include some element of experiential learning, and encourages reflective practice as part of continuing professional development, and life-long learning
- Evaluation methods which can demonstrate achievement of outcomes and ideally extend beyond the immediate end of the course/training event.

Annex F:

Terms of Reference for the Independent Review of the Liverpool Care Pathway

The Review's terms of reference were as follows:

'The review will:

- examine systematically the experience of patients and families of the use of the Liverpool Care Pathway
- examine the experience and opinions of health professionals about the use of the Liverpool Care Pathway
- examine hospital complaints about end of life care and in particular those about the Liverpool Care Pathway
- review the literature about the Liverpool Care Pathway in practice;
- consider the role of financial incentives in this area
- make recommendations about what steps can be taken to:
 - improve care
 - ensure that patients are always treated with dignity and are involved in decisions about their care wherever possible
 - ensure that carers and families are always properly involved in the decision-making process
 - restore public confidence.

The review will report to Department of Health Ministers and the NHS Commissioning Board with its conclusions and recommendations by summer of 2013.'

Annex G:

Glossary of terms

End of life	<p>Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:</p> <ul style="list-style-type: none"> (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events. <p>In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.</p>
Care pathway	<p>A care pathway is: "anticipated care placed in an appropriate time frame, written and agreed by a multidisciplinary team."</p> <p>"It has locally agreed standards based on evidence where available to help a patient with a specific condition or diagnosis move progressively through the clinical experience."</p> <p>"It forms part or all of the clinical record, documenting the care given."</p> <p>"It facilitates and demonstrates continuous quality improvement. It includes patient milestones and clinical interventions noted on the day or stage that they are expected to occur."</p> <p><i>(Welsh National Leadership and Innovation Agency for Healthcare guide to integrated care pathways, 2005).</i></p>
Clinical pathway	<p>A standardised set of actions aiming to optimise care for a particular clinical problem, in line with evidence of guidelines.</p> <p><i>(King's Fund, 2012)</i></p>

NICE Pathways	<p>NICE Pathways are interactive topic-based diagrams which aim to provide users with a way to quickly view and navigate all NICE guidance recommendations on a particular topic. A NICE Pathway starts with a broad overview of a topic and allows the user to explore NICE recommendations and advice in increasing detail. Relevant topics are linked together forming a network of NICE information. A NICE Pathway provides a useful starting point for new users to a topic while giving specialists easy access to NICE recommendations. NICE Pathways do not provide a comprehensive management pathway for individual patient care.</p>
Protocols	<p>A plan or set of steps that defines how something will be done.</p>
Guidelines/ guidance	<p>NICE uses the term 'guidance'/'guidelines' interchangeably, to refer to evidence-based recommendations on the most effective and cost-effective treatment and care of people with specific diseases and conditions, and recommendations for populations and individuals on interventions that can help prevent disease or improve health.</p> <p>The professional regulators (GMC, NMC, HCPC and GPhC), produce regulatory 'guidelines'/'guidance' on how professional standards should be achieved.</p> <p>The LACDP has produced implementation 'guidance' for service providers and commissioners on delivering the Priorities for Care of the Dying Person.⁶¹</p> <p>Alliance members have agreed that they will not use the terms 'guidelines' or 'guidance' in relation to care in the last few days and hours of life other than in the three specific contexts described above.</p>
Standard operating procedures	<p>Detailed, written instructions to achieve uniformity of the performance of a specific function.</p> <p><i>(International Conference on Harmonisation(ICH))</i></p>
Best practice models	<p>A method or technique that has consistently shown results superior to those achieved with other means, and that is used as a benchmark. In addition, a 'best' practice can evolve to become better as improvements are discovered.</p>

⁶¹ The Priorities for Care of the Dying Person – Implementation Guidance for Service Providers and Commissioners can be found at: Annex E of *One Chance to Get it Right: improving people's experience of care in the last few days and hours of life*, the system-wide response to the Independent Review of the Liverpool Care Pathway.

Advance Care Planning (ACP)	<p>Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. An ACP discussion might include:</p> <ul style="list-style-type: none"> • the individual's concerns and wishes, • their important values or personal goals for care, • their understanding about their illness and prognosis, • their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these. <p>(Advance Care Planning: A Guide for Health and Social Care Staff NHS End of Life Care Programme, Published February 2007, Revised August 2008.)⁶²</p>
Advance statement	<p>A statement that conveys a person's preferences, wishes, beliefs and values regarding their future care. The aim is to provide a guide to anyone who might have to make decisions in the person's best interest if that person has lost the capacity to make a decision.</p>
Advance Directive/ Advance Decision/ Advance Decision to Refuse Treatment (ADRT)	<p>This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.</p> <p>An advance decision to refuse treatment:</p> <ul style="list-style-type: none"> • can be made by someone over the age of 18 who has mental capacity; • is a decision relating to refusal of specific treatment and may also include specific circumstances; • can be verbal, but if an advance decision includes refusal of life-sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk'; • will only come into effect if the individual loses capacity; • only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision; • is legally binding if valid and applicable to the circumstances. <p>(<i>Capacity, care planning and advance care planning in life limiting illness</i> February 2012 - National End of Life Care Programme)⁶³</p>

⁶² See: www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf

⁶³ See: www.nhs.uk/resource-search/publications/eolc-ccp-and-acp.aspx

Best interests (in the context of patients lacking capacity to make a particular decision)	<p>Any decisions made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests. The Mental Capacity Act 2005 (England and Wales) sets out how a best interests decision should be made. Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests of that person for each relevant decision, setting out:</p> <ul style="list-style-type: none"> • how the decision about the person's best interests was reached; • what the reasons for reaching the decision were; • who was consulted to help work out best interests; and • what particular factors were taken into account.
Equality Act 2010 – nine protected characteristics	<p>In accordance with the public sector equality duty (section 149 of the Equality Act 2010), public authorities must have due regard to the need to eliminate discrimination, harassment and victimisation and other conduct prohibited by the Act; advance equality of opportunity between people who share a protected characteristic and those who do not; foster good relations between people who share a protected characteristic and those who do not. These aims of the public sector equality duty apply to the following protected characteristics: age, disability, gender, gender reassignment, pregnancy and maternity, race, religion or belief, sexual orientation, and marriage and civil partnership (but only in regards to the aim of eliminating discrimination and harassment).</p>
Independent Mental Capacity Advocate (IMCA)	<p>If a person who lacks capacity has no close family or friends to support or represent them or no-one whom it is appropriate to consult, then an <i>Independent Mental Capacity Advocate</i> (IMCA) must be instructed and consulted regarding decision-making about serious medical treatment or about placement in hospital for longer than 28 days or a care home for longer than 8 weeks. The only exception is when an urgent decision is needed. An ICMA may be appointed in some other circumstances.</p>
Lasting Power of Attorney (LPA)	<p>An LPA is a statutory form of power of attorney created by the Mental Capacity Act 2005 (England and Wales). Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity. There are two types of LPAs: (a) for personal welfare (which includes healthcare and consent to medical treatment); and (b) for property and affairs.</p>

Mental capacity	<p>A person must be assumed to have mental capacity unless it is established that they lack capacity. An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. Under the Mental Capacity Act 2005 (England and Wales), anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity:</p> <ul style="list-style-type: none"> • Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) • If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made? <p>A person is unable to make a decision for himself if he is unable to understand the information relevant to the decision, retain that information, use or weigh that information as part of the process of making the decision or to communicate the decision (whether by talking, sign language or any other means).</p>
Palliative care	<p>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:</p> <ul style="list-style-type: none"> • 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 patient's illness and in their own bereavement; • uses a team approach to address the needs of patients and their families; • enhances quality of life and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. <p>Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.</p> <p><i>(World Health Organisation)</i></p>

Specialist palliative care	<p>Specialist palliative care is the active, total care of patients with progressive, advanced disease and [of] their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training.</p> <p><i>(Tebbit, National Council for Palliative Care, 1999)</i></p>
Quality standards	<p>Alliance members have agreed that, to avoid confusion, they will avoid using the term 'quality standards' in relation to end of life care other than for NICE 'quality standards' and any 'quality standards' produced by the professional regulators (GMC, NMC, HCPC and GPhC) which describe how professional standards should be achieved.</p>
Spiritual care	<p>Spiritual care is that care which recognises and responds to the needs of the human spirit when faced with trauma, ill health or sadness and can include the need for meaning, for self-worth, to express oneself, for faith support, perhaps for rites or prayer or sacrament, or simply for a sensitive listener. Spiritual care begins with encouraging human contact in compassionate relationship, and moves in whatever direction need requires.</p> <p><i>(NHS Education for Scotland, 2009)</i></p>

Annex H:

End of life care in existing training for professionals

End of life care in existing training for professionals

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Section A

Background on the coverage of end of life care in standards, guidance and in curricula for health and care staff

1. GMC's Education Standards

Tomorrow's Doctors, 2009 (standards and outcomes for undergraduate medical education)

Under the section which sets out the areas in which individuals will be expected to demonstrate that they can diagnose and manage clinical presentations, part 14j states that they must:

'Contribute to the care of patients and their families at the end of life, including management of symptoms, practical issues of law and certification, and effective communication and team working.'

Curricula for undergraduate medical education

Curricula for undergraduate medical education are set by the medical schools.

An overview of the coverage of end of life care in medical school curricula is provided.

The Foundation Programme

The standards for Foundation training are contained in the *Trainee Doctor*, published in 2011, including the outcomes for provisionally registered Foundation Year 1 doctors.

The 2012 Foundation Programme Curriculum and the related outcomes for F1 and F2 doctors currently state that trainees will:

'Take part in a multidisciplinary approach to end of life care utilising tools such as the Liverpool Care Pathway'

The Foundation Programme Curriculum and the outcomes for F1 and F2 - drawn up by the Academy Foundation Committee under the Academy of Medical Royal Colleges – are approved by the GMC. The UK Foundation Programme Office operationalise the curriculum and outcomes, for example, ensuring that it is embedded in the e-portfolio.

Attached at Section B(i) are extracts from the outcomes for the Foundation Programme covering end of life care and some of the professional elements which underpin and are generic to good clinical care.

Please note that arrangements have been made to remove references to the Liverpool Care Pathway from the Foundation Programme Curriculum and specialty curricula and assessment systems.

Postgraduate specialty education and training

The standards governing postgraduate specialty medical and education, including GP, training are set out in the *Trainee Doctor*.

These standards are high level and do not specify what the content or outcomes of specialty training should be. The content and outcome requirements are specified in each of the 65 specialty curricula produced by the medical Royal Colleges and faculties

and approved by the GMC against the separate Standards for Curricula and Assessment Systems.

The GMC and the Academy of Medical Royal Colleges are currently developing a framework for generic professional capabilities that will be embedded in all 65 specialty curricula. These will include a theme around end of life care.

2. Postgraduate - Foundation and Specialty curricula and guidance

The curricula and outcomes for the Foundation Programme are approved by the GMC.

The curricula for specialty training are also approved by the GMC.

Section B(i) provides a summary of end of life care and some underpinning professional and clinical skills in Foundation training. Section B(ii) provides a summary of end of life care coverage in specialty curricula.

3. GMC ethical guidance - *Treatment and care towards the end of life: good practice in decision making*

The guidance provides a framework for good practice when providing treatment and care for patients who are reaching the end of their lives. It is aimed at doctors primarily but may be helpful to patients.

It is based on long-established ethical principles, which include doctors' obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity; and to make the care of their patients their first concern. It expands on the principles of good practice in the GMC's *Good medical practice* (2013) and *Consent: patients and doctors making decisions together* (2008), and replaces the booklet *Withholding and Withdrawing Life-Prolonging Treatments* (2002).

4. *Consensus syllabus for undergraduate palliative medicine for Great Britain and Ireland, 2006*

In 1992, the Association of Palliative Medicine of Great Britain and Ireland developed a palliative medicine curriculum for doctors and students. This was updated for undergraduate medical education in 2006 in view of the fact that new medical schools had been established and more medical schools include palliative medicine as a regular question in the final examination.

This revised syllabus was endorsed by the Association for Palliative Medicine. It has developed from a research study by Paul Paes and Bee Wee to gain a consensus among experts in palliative medicine across Great Britain and Ireland as to what should be included. The document recognises the diversity of undergraduate medical programmes in different medical schools as well as the amount of time allocated to palliative medicine. It has been designed as a reference document to help individuals develop and enhance palliative medicine teaching within the undergraduate medical education programmes in their own institutions.

5. NMC

The NMC's standards for pre-registration nursing education state that all nurses '*... must support and promote the health, wellbeing, rights and dignity of people, groups, communities and populations. These include people whose lives are affected by ill health, disability, ageing, death and dying*'.

In addition, for those nurses who specialise in adult nursing, nursing those with learning disabilities and mental health nursing, the standards for pre-registration nursing education also state that they: '*Must understand and apply current legislation to all service users, paying special attention to the protection of vulnerable people, including those with complex needs arising from ageing, cognitive impairment, long term conditions and those approaching the end of life.*'

The NMC has three documents which are relevant to end of life care and which contain some generic themes:

- *The Code: Standards of conduct, performance and ethics for nurses and midwives;*
- *Guidance for the Care of Older People; and*
- *Essential skills clusters* – these form part of the pre-registration nursing education standards and contain elements that speak more directly to end of life care such as:
 - care, compassion and communication;
 - organisational aspects of care;
 - infection prevention and control;
 - nutrition and fluid management; and
 - medicines management.

These essential skills clusters (ESCs) are meant as guidance. How they are incorporated into education programmes is left to local determination by the approved education institution (AEI) delivering the training concerned. The programme providers can use the ESCs to develop learning outcomes at different levels or to map them against existing programme learning outcomes.

6. National end of life qualifications

Skills for Care has developed a range of qualifications for those working in social care which can equip them not only to recognise end of life situations but to manage them more effectively, working in partnership with the individuals, their families and carers and other organisations to deliver the best quality of care.

The new end of life care qualifications have been developed in conjunction with a wide range of employers including Marie Curie Cancer Care, the UK Home Care Association and Barchester Care in addition to a number of hospices as a direct response to this framework.

Supporting people to live and die well (2010): Units EOL 306 and EOL 307 – 'Support individuals during last days of life' are core for this area of work but many other units are also appropriate as indicated in the matrix. The units are already mapped to the 'Six Steps to Success' programme.

The range of qualifications at level 2, 3 and 5 enable social care staff to develop their knowledge and skills in communication, advance care planning, managing symptoms and pain, supporting spirituality, supporting individuals with loss and grief before death, and also in leading and managing effective end of life care.

www.skillsforcare.org.uk

7. National Common Core Competences and Principles for 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, developed workforce competences and core principles as they relate to end of life care.

They were produced following consultation with a wide range of expert groups and organisations.

The primary purpose of this development is to support workforce development, training and education, and to support the development of new and enhanced posts and roles across health **and** social care based on one common foundation.

Common 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
- The Common Core Competences are:
 - Communication skills
 - Assessment and care planning
 - Symptom management, comfort and well being
 - Advance care planning

Underpinned by values and knowledge

Seven principles underpin all workforce and service development, activity and delivery irrespective of level and organisation. All of these link with the areas identified in the matrix. 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.
3. Communication reflects an understanding of the significance of each individual's beliefs and needs 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.

Section B(i)

Summary of coverage of end of life care – including the underpinning competencies and outcomes - in the curriculum for doctors training in the Foundation Programme

Coverage includes references to:

- palliative care;
- nutrition/hydration;
- practical issues re clinical skills;
- consent;
- breaking bad news;
- relationship with patients;
- effective team working – referring up to seniors;
- audit – multi-disciplinary team meetings; and
- probity.

Foundation year 1 and 2 outcomes

Section		F1 and F2 outcomes	Relevant competences
1. Professionalism	1.1 Behaviour in the workplace	<ul style="list-style-type: none"> Acts with professionalism in the workplace and in interactions with patients and colleagues 	<ul style="list-style-type: none"> In all interactions with both patients and colleagues takes account of factors, where relevant, pertaining to patients' age, colour, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, or social or economic status Respects and supports the privacy and dignity of patients.
1. Professionalism	1.4 Team-working	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> Displays understanding of personal role within their team including supporting the team leader and listening to the views of other healthcare professionals <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> Organises and allocates work within their clinical team to optimise effectiveness 	<ul style="list-style-type: none"> Integrates and interacts appropriately with their clinical team Contributes to multidisciplinary team (MDT) meetings Encourages open and appropriately directed communication within teams Demonstrates clear and effective communication within the healthcare team Cross-checks instructions and actions with colleagues e.g. medicines to be injected

2. Relationship and communication with patients	2.1 Treats the patient as the centre of care within a consultation	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Prioritises the needs of patients above personal convenience without compromising personal safety or safety of others • Works in partnership with patients in an open and transparent manner, treats patients as individuals and respects their perspective/views on their own treatment <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Works with patients and colleagues to develop sustainable individual care plans to manage patients' acute and long-term conditions 	<ul style="list-style-type: none"> • Considers the patient as a whole, respecting their individual needs, dignity and right to privacy, autonomy and confidentiality • Discusses management options with patients • Recognises patients' expertise about their care • Respects patients' views and encourages patients with knowledge of their condition to make appropriately informed decisions about their care • Demonstrates understanding to the whole clinical team that respect of patients views and wishes is central to the provision of high quality care • Considers care pathways and the process of care from patients' perspectives • Respects patients' right to refuse treatment or take part in research • Recognises and responds to patients' ideas, concerns and expectations • Deals appropriately with angry or dissatisfied patients.
2. Relationship and communication with patients	2.2 Communication with patients	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Communicates effectively and with understanding and empathy in 	<ul style="list-style-type: none"> • Ensures sufficient time and appropriate environment for communication • Listens actively and enables patients to express

		<p>straightforward consultations</p> <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Demonstrates increasing ability and effectiveness in communicating more complicated information in increasingly challenging circumstances • Deals increasingly independently with queries from patients and relatives 	<p>concerns and preferences, ask questions and make personal choices</p> <ul style="list-style-type: none"> • Recognises that patients may have unspoken concerns and communicates in an empathic manner to elicit and address these • Responds to patients' queries or concerns • Seeks advice promptly when unable to answer patients' queries or concerns • Explains options clearly and checks patients' understanding
2. Relationship and communication with patients	2.3 Communication in difficult circumstances	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Breaks bad news to patients or carer/relative effectively and compassionately, and provides support, where appropriate <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Recognises where patient's capacity is impaired and takes appropriate action 	<ul style="list-style-type: none"> • Demonstrates involvement with others in the team when breaking bad news • Considers any acute or chronic mental or physical condition that may have an impact on communication understanding • Considers patients' personal factors including relevant home and work circumstances • Ensures sufficient time and a suitable environment for discussions • Deals appropriately with distressed patients/carers and seeks assistance as appropriate

			<ul style="list-style-type: none"> • Manages three-way consultations e.g. with an interpreter or with a child patient and their family/carers • Understands how the communication might vary when the patient or carer has learning or communication difficulties themselves e.g. deafness • Deals appropriately with angry or dissatisfied patients, trying to calm the situation and seeking assistance as appropriate.
2. Relationship and communication with patients	2.5 Consent	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Obtains consent as appropriate in accordance with Consent: patients and doctors making decisions together (2008) including for core procedures <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Increases the breadth of procedures for which consent is taken in accordance with GMC guidance 	<ul style="list-style-type: none"> • Practises in accordance with Consent: patients and doctors making decisions together (GMC, 2008) and does not take consent when contrary to GMC guidance • Describes the principles of valid consent and obtains valid consent after appropriate training • Gives each patient the information they 'want' or 'need' in a way they can understand in order to obtain valid consent • In patients who lack capacity understands and applies the principle of 'best interests' • Ensures that the patient with capacity understands and retains information long enough to make a decision

4. Ethical and legal issues	4.1 Medical ethical principles and confidentiality	<p><i>F1 and F2 outcomes</i></p> <ul style="list-style-type: none"> Practises in accordance with the principles of Good Medical Practice, The Trainee Doctor and Confidentiality 	<ul style="list-style-type: none"> Provides care and treatment in accordance with the principles of patients' best interests, autonomy and rights
4. Ethical and legal issues	4.2 Legal framework of medical practice	<p><i>F1 and F2 outcomes</i></p> <ul style="list-style-type: none"> Takes personal responsibility for and is able to justify decisions and actions 	<ul style="list-style-type: none"> Demonstrates the knowledge and skills to cope with ethical and legal issues that occur during the management of patients with medical problems or mental illness Discusses the implications of a living will or advance decision to refuse treatment.
7. Good clinical care	7.3 Diagnosis and clinical decision-making	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> Makes appropriate differential diagnosis and formulates a management plan <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> Reviews initial diagnosis (with F1), refines problem lists and plans appropriate strategies for investigation and management 	<ul style="list-style-type: none"> Works towards an appropriate differential diagnosis and establishes a problem list Constructs a management plan and communicates requests/instructions to other healthcare professionals Makes a judgement about prioritising actions on the basis of the differential diagnosis and clinical setting

7.6 Safe prescribing (including fluids)		<p><i>F1 outcomes</i></p> <p>..... Prescribes medicines, blood products and fluids accurately and unambiguously and regularly reviews drug chart</p>	<ul style="list-style-type: none"> • Chooses appropriate intravenous fluids as vehicles for intravenous drugs and calculates the correct volume and flow rate
8. Recognition and management of the acutely ill patient	8.4 Manages pain	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Safely prescribes and administers common analgesic drugs including patient controlled analgesia <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Anticipates and prevents pain whenever possible • Ensures safe prescribing tailoring to changing requirements throughout patients' care journey 	<ul style="list-style-type: none"> • Recognises importance of pain control • Evaluates the cause and severity of pain (ideally using a verified pain score) • Manages pain safely and effectively • Prescribes analgesic drugs in a safe and timely manner • Communicates changes to analgesic prescriptions with other health carers in the community and hospital including acute pain and palliative care teams.
9. Resuscitation and end of life care	9.2 End of life care and appropriate use of Do Not Attempt Resuscitation (DNAR) orders/ advance decisions	<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Understands the principles of providing high quality end of life care including the use of DNAR orders as outlined in Treatment and care towards the end of life: good practice in decision making (GMC, 2010) 	<ul style="list-style-type: none"> • Understands the value of 'diagnosing dying' • Prioritises symptom control as part of end of life care • Understands where and how to access specialist palliative care services • Demonstrates an awareness of Advanced Care Planning in end

		<p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Takes part in discussions regarding end of life care and DNAR orders <p>Uses the local protocol for deciding when not to resuscitate patients</p>	<p>of life care and the times when it may be appropriate</p> <ul style="list-style-type: none"> • Discusses patients' needs and preferences regarding end of life care wherever possible • Understands the ethics of transplantation and identifies potential donors to senior medical staff • Discusses and plans for preferred place of death wherever possible • Takes part in a multidisciplinary approach to end of life of life care utilising tools such as the Liverpool Care Pathway • Understands the importance of adequate discussion and documentation of DNAR orders • Describes the criteria for issuing DNAR orders and the level of experience needed to issue them • Discusses DNARs with the multidisciplinary team, the patient, long-term carers (both medical and non-medical) and relatives • Understands the accountability of the responsible clinician when a DNAR decision is made • Understands the role of the individual and the family in the communication of DNAR orders
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			<ul style="list-style-type: none"> • Recognises actual and potential conflicts between patients and their relatives • Recognises and acts appropriately when DNAR decisions are challenged/conflicts arise between interested parties • Facilitates the regular review of DNAR decisions.
10.3 Nutrition		<p><i>F1 outcomes</i></p> <ul style="list-style-type: none"> • Takes a basic nutrition history and considers this in planning care <p><i>F2 outcomes (in addition to F1)</i></p> <ul style="list-style-type: none"> • Ensures adequate nutrition (including nutritional supplements) for patients with acute illness and long-term conditions 	<ul style="list-style-type: none"> • Recognises nutritional disorders are common in patients with long-term conditions • Performs basic nutritional screen and recognises patients with potential for nutritional deficiencies and considers this in planning care • Formulates a plan for investigation and management of weight loss or weight gain • Demonstrates the knowledge, skills, attitudes and behaviours to assess patients' basic nutritional requirements • Recognises major nutritional abnormalities and eating disorders and establishes a management plan, where relevant with other healthcare professional input

			<ul style="list-style-type: none"> • Works with other healthcare professionals in addressing nutritional needs and communicating these during care planning • Makes nutritional care part of daily practice • Considers the additional effects of long-term ill-health on nutritional status and the effect of poor nutrition on long-term health.
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Section B(ii)

Coverage of end of life care in the curricula for postgraduate medical specialty education and training. (Specialty training takes place after Foundation training.)

1. General practice⁶⁴

Statement 3.03: *Care of Acutely Ill People*, page 11 - under the heading: *The essential features of you as a doctor*

Also under sub-heading *EF2 Attitudinal features*, the focus is on a trainee's professional capabilities, values, feelings and ethics and the impact these may have on the patient care they provide when dealing with end of life patients.

Para: *EF2.5* notes how the trainee must learn to manage the difference between what they think is an appropriate medical course of action and the course of action desired by patients, their relatives and their carers. Para: *EF2.5.1* states that this is particularly important for patients receiving palliative or end-of -life care.

Statement 3.05: *Care of Older Adults*, page 7 under the sub-heading *2 Person-centred care* sets out that:

One of the areas of competence trainees are assessed for is about understanding and relating to the context of their patients as individuals, and developing the ability to work in partnership with them. This means that a trainee should know the special features of prognosis of disease in old age and be able to apply the knowledge to produce an appropriate plan for further investigation and management which includes end of life care.

Page 9 of the statement under the sub-heading *EF1 Contextual features* focuses on where the trainee must understand their own context as a doctor and how it may influence the quality of the care they provide. Important factors are the environment in which the

⁶⁴ All page and subheading references under this heading refer to General Practice Specialty Curricula statements which can be found online at: www.gmc-uk.org/education/gp.asp

trainee works, including working conditions, community, culture, financial and regulatory frameworks. An example of this is provided in para *EF1.1* where trainees are required to learn to understand moral, ethical and emotional issues relating to the end of life.

The trainee is also referred to see statement 3.09 of the General practice curriculum on *End of life Care* as well as after death e.g. living wills, palliative care.

Also within statement 3.05: page 10 under the heading *EF2 Attitudinal features* are references to the trainee's professional capabilities, values, feelings and ethics and the impact these may have on the patient care they provide when dealing with end of life patients. An example of this is provided in para *EF2.2* where trainees are required to learn to recognise personal attitudes to the elderly, to the processes of growing old, becoming frail and to dying.

Statement 3.09: *End of life-care*, page 6, lists all the learning outcomes or objectives which relate specifically to end of life care and which are an important part of the General Practitioner's wider palliative care role. These learning outcomes are in addition to those detailed in the core statement *Being a General Practitioner*. The core statement and this statement should be used in conjunction with the other curriculum statements.

Trainees are also asked to refer to statement 3.04: *Care of Children and Young People* for palliative care for children.

In order to demonstrate the core competences in the area of end of life care, trainees are required to gain knowledge, skills and attitudes in the following areas:

- 1 Primary care management
- 2 Person-centred care
- 3 Specific problem-solving skills
- 4 A comprehensive approach
- 5 Community orientation
- 6 A holistic approach

EF1 Contextual features

EF2 Attitudinal features

EF3 Scientific features

Trainees must also acquire outcomes via the work-based learning environment in primary and secondary care as well as non-work based learning in the form of e.g. local hospices, courses, e-learning courses to help consolidate and build on knowledge gained in the workplace. For General Practice trainees, their specialty training programme should also offer case-based discussions where end of life care can be shared.

Statement 3.11: *Care of people with intellectual disability*, page 9 under the sub-heading *A holistic approach*, explains that trainees are assessed on their ability to understand and respect the values, culture, family structure and beliefs of their patients, and understand the ways in which these will affect the experience and management of illness and health. This means as a General Practitioner, trainees should understand that by the time the patient with intellectual disability has reached adulthood, the parents have gone through a different series of transitions to other parents; and, subsequently if their child dies, they may go through a bereavement process that differs from those whose child without intellectual disability dies.

2. Palliative medicine⁶⁵

Page 26 under the sub-heading *2.15 Public Health Related to Palliative Care*, trainees are required to gain knowledge competence to recognise ways to influence and improve the general health of a community in relation to relevant preventive, supportive and end of life care. Trainees must learn to recognise the influence of culture and beliefs on perceptions of health, illness and end of life care, and they are assessed on this via case-based discussions (CbDs) and mini clinical evaluation exercises (mini-CEX).

Page 33, under the sub-heading *2.21 Delivering Shared Care*, trainees must learn to demonstrate a positive attitude towards shared medical care and be able to deliver palliative care whatever the environment (hospital, hospice, nursing homes, day-care and the patient's home). Trainees are expected to acquire skills competence in planning for end of life care and are assessed on this via case-based discussions and mini clinical evaluation exercises.

Page 50, under the sub-heading *7.2 Theoretical Ethics and Applied Ethics in Clinical Practice of Palliative Medicine*, trainees are expected to demonstrate skills in ethical reasoning and decision-making in end of life care, at consultant level, both for their own patients and for those that are referred to them in an advisory capacity. Trainees are required to gain knowledge competence in explaining the challenges of resource allocation and futility in respect of the end of life, and they are assessed on this via case-based discussions.

Page 85 under the heading *4.2 Teaching and learning methods*, sub-heading *Formal Study Courses*, a list of courses are recommended for trainees to attend. One of these is a course on *Ethical issues in end of life care*.

3. Core Medical Training (CMT)

Of particular relevance are the 2012 Core Medical Training curriculum competences around the management of patients requiring palliative and end of life care (which can be found on p113 of the Core Medical Training curriculum).⁶⁶ This is accompanied by a supplementary document containing additional palliative and of life care competences. This more detailed supplementary document contains competences for both CMT and General (internal) medicine (GIM) curricula, and should therefore be read in conjunction with these documents.⁶⁷ They also refer to Advance Care Planning.

4. General (internal) medicine

Page 85 contains reference to palliative and end of life care, although the competences appear to overlap completely with the Core Medical Training level competences. See curriculum statement on the GMC website at: www.gmc-uk.org/2009_GIM_curriculum_revised_Aug_2012pdf.pdf_51545072.pdf

⁶⁵ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Palliative Medicine which can be found online at: www.gmc-uk.org/Palliative_Curriculum_220410_V0.13.pdf_32485351.pdf

⁶⁶ See Joint Royal Colleges of Physicians' Training Board (JRCPTB) website at: [www.jrcptb.org.uk/trainingandcert/Documents/2009%20CMT%20framework%20\(revised%20Aug%202012\).pdf](http://www.jrcptb.org.uk/trainingandcert/Documents/2009%20CMT%20framework%20(revised%20Aug%202012).pdf)

⁶⁷ This is available online at JRCPTB website: www.jrcptb.org.uk/SiteCollectionDocuments/Management%20of%20Patients%20Requiring%20Palliative%20and%20End%20of%20Life%20Care%20CMT.pdf

5. Acute internal medicine Curriculum (AIM)

Page 97 contains reference to palliative and end of life care, although these competences are again identical to the competences found on page 85 of the General (internal) medicine curriculum and page 113 of the Core Medical Training curriculum. There is also a link on the Acute internal medicine section of the website to the supplementary palliative and end of life care competences document mentioned above, although the supplementary document itself does not specifically refer to Acute internal medicine, only Core Medical Training and General (internal) medicine. See curriculum statement on the GMC website at: www.gmc-uk.org/2009_AIM_Curriculum__AMENDMENTS_2012_.pdf_51544444.pdf

6. Broad Based Training

The Broad Based Training (BBT)⁶⁸ curriculum (a core training equivalent) has managed to integrate the legacy and updated palliative and end of life care competences more successfully than the Acute internal medicine, Core Medical Training or General (internal) medicine (page 51 of the Broad Based Training curriculum refers).

All doctors who complete Core Medical Training should have addressed certain competences specifically related to palliative and end of life care, as will all acute and general physicians, and all physicians in medical specialties who have followed a dual specialty-specific-and-General (internal) medicine pathway through higher specialty training.

7. Geriatric medicine⁶⁹

On page 68, under the sub-heading *Community Practice Including Continuing, Respite and Intermediate Care*, trainees are expected to acquire knowledge on end of life care including advanced care planning, and they are assessed on this competence via case-based discussions, mini clinical evaluation exercises and specialty certificate examinations.

Also on page 82, under the sub-heading *Intermediate Care and Community Practice*, trainees are expected to acquire knowledge on current national publications regarding end of life care and are assessed on this via specialty certificate examinations and case-based discussions.

8. Intensive care medicine (ICM)⁷⁰

On pages 1 to 5, under the introduction sub-heading *1.2 Definition of ICM*, Intensive care medicine is also referred to as critical care medicine i.e. as the body of specialist knowledge and practice concerned with the treatment of patients, with, at risk of, or recovering from potentially life-threatening failure of one or more of the body's organ systems. It includes the provision of organ system support, the investigation, diagnosis, and treatment of acute illness, systems management and patient safety, ethics, end of life care, and the support of families.

⁶⁸ See JRCPTB website at: www.jrcptb.org.uk/trainingandcert/Documents/2012%20BBF%20curriculum%20with%20Assessment%20Grid.pdf

⁶⁹ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Geriatric Medicine which can be found online at: www.gmc-uk.org/2010_Geriatric_Medicine_Curriculum__AMENDMENTS_2013_.pdf_53858086.pdf

⁷⁰ All page and subheading references under this heading refer to the Specialty Curriculum Statement for Intensive Care Medicine which can be found online at: http://www.gmc-uk.org/20111007_CCT_in_ICM__COMPLETE__Aug2011_v1.0_.pdf_44816170.pdf

Pages 1 to 6, sub-heading 1.4 *The scope of Intensive care medicine practice*, explains that Intensive Care Medicine specialists are expected to have medical expertise in end of life care.

Page 1 to 32, para 5.5.1 refers to the *Final FFICM MCQ (Fellowship of the Faculty of Intensive Care Medicine Multiple Choice Question examination)*. This examination consists of multiple choice questions which test factual knowledge in the areas of science applied to clinical practice which includes end of life care.

Pages 2 to 6, under the heading *Training progression grid*, trainees are expected to demonstrate their progression of competency in each curriculum domain throughout the stages of Intensive care medicine training. This includes Domain 8: *End of life Care*, where trainees are expected to demonstrate knowledge and skill competencies by:

- (8.1) managing the process of withholding or withdrawing treatment with the multi-disciplinary team;
- (8.2) Discussing end of life care with patients and their families/surrogates and members of the health care team;
- (8.3) Managing palliative care of the critically ill patient;
- (8.4) Performing brain-stem death testing;
- (8.5) Managing the physiological support of the organ donor; and
- (8.6) Managing donation following cardiac death.

Pages 4 to 43, under the heading *4.8 Management of respiratory and cardiac arrest in adult and children*, trainees must also be able to discuss the importance of respecting the wishes of patients regarding end of life decisions.

9. Paediatric palliative care medicine⁷¹

On page 53, trainees at Level 3 (specialty training years 6-8 or ST6-ST8) are expected where appropriate and at a negotiated time, to be able to raise and agree management of end of life issues with young people and their families and record conclusions in medical notes for them to gain effective skills in recognising and responding effectively.

On page 62, trainees at Level 3, are expected to acquire an awareness of religious and cultural diversity and beliefs in counselling children and families regarding end of life care as part of their responsibility to ensure an open minded approach to equality and diversity in the paediatric team.

On page 63, trainees at Level 3, must be able to demonstrate skills in ethical reasoning and decision-making in end of life care for their own patients and those referred in their advisory capacity, as part of their responsibility for ensuring an open minded approach to equality and diversity in the paediatric team.

On page 79, trainees at Level 3, must be able to convey and share effectively difficult or bad news, including end of life issues with children, young people, parents or carers and help them to understand any choices they have or decisions to be made about on-going management and this is part of trainees gaining effective skills in giving information and advice to young people and their families in common and complex cases.

⁷¹ See Paediatric Palliative Care Medicine curriculum statement online at: www.gmc-uk.org/Paediatric_Palliative_Medicine_NEW_curriculum_document_June_2010.pdf_55904192.pdf

On page 86, trainees must also be able to facilitate planning for end of life care as part of their gaining effective managerial skills in taking on a positive managerial role to support effective service provision.

On page 101, under the sub-heading *Emergencies*, trainees at Level 3 are expected to know the ethical considerations of managing palliative medicine emergencies at the end of life, particularly those relating to euthanasia, the principle of double effect and terminal sedation, and if necessary to contribute to clinical ethics committee debates on these subjects.

10. Medical oncology⁷²

On page 90, under the sub-heading *Psychosocial aspects of cancer related disease*, trainees are expected to acquire knowledge competence in issues relating to end of life care and death and trainees are assessed on this via specialty certificate examinations and case-based discussions.

On page 137, under the heading *Management of Teenagers and Young Adults (TYA) with Cancer* trainees are expected to be able to manage end of life issues with teenagers and young adults and their carers. Trainees are assessed on this competence via specialty certificate examinations and case-based discussions.

11. Respiratory medicine⁷³

On page 133, under the heading *Managing Long Term Conditions: Integrated Care and the Promotion of Self Care*, trainees are expected to gain knowledge competency in knowing and understanding the requirements for appropriate end of life care in chronic respiratory disease. Trainees are assessed on this via mini clinical evaluation exercises and case-based discussions.

12. Cardiology⁷⁴

On page 47, under the sub-heading *Infection Control* End of life care, Cardiology is listed as an element of training/learning.

On page 65, *End of life care in Cardiology*, Cardiology trainees are expected to attain and become competent in managing end of life care since many cardiac conditions e.g. heart failure, adult congenital heart disease and valvular heart disease enter an end of life phase. The focus on care should change from therapies designed to alter the natural history of the disease to those aimed at symptom control. Trainees are expected to demonstrate competence in the areas of knowledge, skills and behaviours and are assessed on these areas via an exam case-based discussions, and multi-source feedback.

On page 141, *Module 9: Training in Catheter Ablation for Ventricular Tachycardia (VT)*, trainees are expected to deal sensitively with end of life decisions in patients with Ventricular Tachycardia. Trainees are assessed on this via multi-source feedback and patient surveys.

⁷² See Medical Oncology curriculum statement online at: www.gmc-uk.org/education/medical_oncology.asp

⁷³ See Respiratory Medicine curriculum statement online at: www.gmc-uk.org/education/respiratory_medicine.asp

⁷⁴ See Cardiology curriculum statement online at: www.gmc-uk.org/education/cardiology.asp

13. Guidance – Prolonged disorders of consciousness – national clinical guidelines

Guidelines were also produced by the Royal College of Physicians in December 2013 and contain guidance (i.e. not just a simple checklist) around end of life care decisions for people who have a prolonged disorder of consciousness. It has the endorsement of the Association of Palliative Medicine.⁷⁵

Glossary of terms for Section B

ACCS – Acute Care Common Stem (core training option)

ACP – Advanced care planning

AIM – Acute internal medicine

BBT – Broad based training (core training option)

CbDs – Case-based discussions

CCT – Certificate of completion of training

CMT – Core Medical Training (core training option)

Final FFICM MCQ – Final Fellow of the Faculty of Intensive Care Medicine Multiple Choice Question examination

GIM – General (internal) medicine

GP – General practice/General practitioner

ICM – Intensive care medicine

Mini-CEX – Mini clinical evaluation exercise

MSF – Multi-source feedback

PS – Patient surveys

RCP – Royal College of Physicians

SCE – Specialty certificate examination

⁷⁵ See Royal College of Physicians website at:
www.rcplondon.ac.uk/sites/default/files/prolonged_disorders_of_consciousness_national_clinical_guidelines_0.pdf

Section C

Some additional training programmes and resources for end of life care

(Note: this is provided as examples only. It is not an exhaustive list. Much more education and training takes place locally and regionally.)

e-ELCA – e-learning for end of life care

e-ELCA is a library of e-learning sessions designed to enhance the training and education of all those involved in delivering end of life care to individuals who have been diagnosed with life limiting illnesses and are usually within the last 12 months of their life. It was developed to support the implementation of the 2008 End of Life Care Strategy.

It has a number of sessions that are on the Public Access website www.endoflifecareforall.com which are suitable for social care workers, administrative and clerical staff as well as volunteers and members of the public who may have an interest.

RCN resources

The RCN published, jointly with the RCGP, an End of Life Care Patient Charter.

The RCN also has a suite of documents entitled *Routes to Success*; a general overarching document, one aimed at acute hospitals and another aimed at care homes. These highlight the importance of decision-making, teamwork, communication, care planning and more.

Gold Standards Framework

The Gold Standards Framework (GSF) run quality improvement training programmes and validate accreditation in many settings, leading to the GSF Quality Hallmark Award. Training is delivered through workshops, distance learning, the GSF Virtual Learning Zone or from the GSF Regional Centres, with intrinsic evaluations assessing progress against national standards. GSF meets all national standards including, but not exclusively set by, the National Institute for Clinical Excellence, the Departments of Health, the Royal College of General Practitioners. The GSF has undertaken work on the commissioning of end of life care.

The GSF adopt a modular approach aimed at identifying the right patients, assessing their clinical and personal needs and planning coordinated care in line with their preferences. There are four modules: 1. Identify, 2. Assess, 3. Plan living Well, 4 Plan dying well. Each of the four modules has 3 outcomes which then turn into action plans. These also lead to accreditation in the case of care homes, primary care, community hospitals and in future acute hospitals, measured against key standards. The GSF summarise the standards as the five rights – right person, right care, right place, right time, every time.

Macmillan Cancer Support

Key resources developed by Macmillan include:

Foundations in Palliative Care: This is a facilitated learning programme, mainly designed for care-home staff, but applicable for other settings too. The main areas are:

- First Principles
- Communication
- Pain and Symptom Management
- Bereavement Care

Each module can be delivered separately if necessary, or as a complete programme. The programme supports participants to develop their skills in the workplace as they progress through each module.

Out of hours palliative care: <http://learnzone.org.uk/courses/course.php?id=35>:

For professionals involved in the delivery and coordination of out-of-hours (OOH) care. This modular course is based on the education section of a wider Macmillan Out-of-Hours Toolkit, which is currently under review. Users can dip in and out of the course topics according to relevance and personal preference. With particular relevance to End of Life Care, there are modules in the course including "Diagnosing dying", "End of life care", "The Liverpool Care Pathway" (written with the LCP in mind at that time, but still outlining important basic principles of End of Life Care), "Commonly used drugs in the Syringe Driver", "Palliative Care Emergencies", "Drug access in palliative care", and "Death verification".

Out of hours toolkit: <http://learnzone.org.uk/courses/course.php?id=64>:

Guidance and tools for sharing good practice in out-of-hours (OOH) care for cancer and palliative care patients. Within each chapter are sessions. Chapter 3 Session 1 covers "Symptom control and the end of life". Chapter 3 Session 2 covers "Session 2: Practical aspects of care at the end of life".

BMJ e-learning modules: Macmillan GPs have supported the development of e-learning modules for palliative care in the community and also palliative care during the out of hours period. The modules are targeted at GPs, GP trainees and hospital doctors. Links can be found here: http://learning.bmj.com/learning/module-intro/palliative-care-out-of-hours.html?moduleId=10025220&locale=en_GB (Palliative care during the out of hours period). http://learning.bmj.com/learning/module-intro/palliative-care-community.html?moduleId=5004331&searchTerm=%E2%80%9Cpalliative%20care%20in%20the%20community%E2%80%9D&page=1&locale=en_GB (Palliative care in the community).

Dying Matters: Macmillan is working in partnership with the National Council for Palliative Care to develop and deliver 'Dying Matters' communication skills training for GPs, as well as to train a number of GPs as facilitators so that they can deliver the course locally to other GPs. The training will increase the confidence and skills of GPs to initiate end of life conversations.

NHS Improving Quality

NHS IQ now holds a range of resources that were housed on the former National End of Life Care Programme website or that were links to other resources. Currently these are located under Domain 2 Long Term Conditions on the NHS IQ website. NHSIQ are particularly interested in identifying the practise of supported supervision and action learning models.

Resources:

1. EOLC core competences and updated docs:
www.endoflifecare.nhs.uk/education-training/core-competences.aspx
www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/developing-end-of-life-care-practice.aspx
2. Skills for care EoLC knowledge sets: www.skillsforcare.org.uk/endoflifecare/
3. Communications Skills training pages/reports: www.endoflifecare.nhs.uk/education-training/communication-skills.aspx
4. Training needs analysis tool programme website:
 - www.endoflifecare.nhs.uk/education-training/finding-the-right-direction-training.aspx
 - www.endoflifecare.nhs.uk/search-resources/resources-search/publications/end-of-life-care-facilitator-competency-framework-form.aspx
 - www.endoflifecare.nhs.uk/education-training/learning-resources-on-this-website.aspx
 - www.mylearningspace.me.uk/moodle/
 - www.endoflifecare.nhs.uk/education-and-training/learningresources2www.endoflifecare.nhs.uk/education-training/communication-skills/tnaquestionnaires.aspx
 - www.endoflifecare.nhs.uk/education-training/advance-care-planning.aspx
5. E-ELCA: www.endoflifecare.nhs.uk/education-training/e-elca.aspx
6. Skills for care care homes projects and training as shared by Anne Bagshaw www.skillsforcare.org.uk/areas/endoflifeinyh/eolyh_introduction.aspx
7. SaGE and Thyme training programme: www.endoflifecare.nhs.uk/search-resources/resources-search/case-studies/sage-thyme-foundation-level-workshop-communication-training-scheme.aspx
8. Finding the words: www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/finding-the-words.aspx
9. Routes to Success six steps care homes: www.endoflifecare.nhs.uk/assets/downloads/RtS_Care_Homes___Final__20100804.pdf
10. GSF framework training programmes: www.goldstandardsframework.org.uk/introduction-to-gsf-training-programmes
11. Connected communication skills training: www.royalmarsden.nhs.uk/education/school/courses/pages/connected.aspx

12. NCPC GP training Finding the 1 % resources:
 - www.ncpc.org.uk/event/gp-training-workshop-initiating-conversations-end-life-care-issues-0
 - <http://dyingmatters.org/gp>
 - http://dyingmatters.org/gp_page/dvd
 - http://dyingmatters.org/gp_page/signup
13. Macmillan Learn Zone <http://learnzone.org.uk/>
14. Macmillan Foundations in Palliative Care <http://be.macmillan.org.uk/be/s-206-learning-resources-and-courses.aspx>
15. NEOFPC Routes to success series:
www.endoflifecare.nhs.uk/search-resources/route-to-success-resources.aspx
16. Advance care planning it all adds up:
www.endoflifecare.nhs.uk/search-resources/resources-search/publications/acp-guide.aspx
17. Transform How to Guide:
www.nhs.uk/8203.aspx:- www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/transforming-end-of-life-care-in-acute-hospitals.aspx
18. QELCA training programme: www.stchristophers.org.uk/research/quality-end-of-life-care-for-all-qelca
19. www.endoflifecare.nhs.uk/education-training/learning-resources-other-websites.aspx
20. <http://dyingmatters.org/news/97>
 - Oxford learning Pathways-www.endoflifecare.nhs.uk/education-training/e-elca/oxford-learning-pathways.aspx
 - CLIP: www.endoflifecare.nhs.uk/education-training/learning-resources-other-websites.aspx
 - www.helpthehospices.org.uk/clip/intro.htm
 - www.skillsforhealth.org.uk/component/docman/doc_view/1273-end-of-life-pathways-final.html
 - www.helpthehospices.org.uk/our-services/international/resources/developing-services/education-and-training/
 - www.scie.org.uk/adults/endoflifecare/ideasforpractice/trainingforcaeworkers.asp

The following may also be a useful reference for GP end of life care training resources and is about to be circulated via the Dying Matters Finding the 1% campaign site which aims to support GPs in delivering high quality end of life care: <http://dyingmatters.org/gp>

Annex I:

Spiritual Care Assessment Tool Based on FICA approach

Spiritual Care Assessment Tool

The following assessment tool is included as an example of one approach to assessment of spiritual care needs.

FICA – originally devised by Dr. Christina Pulchalski MD

Suggested Questions.

These should be adapted to suit each person and revisited as patient circumstances change.

- | | |
|-----------------------------|---|
| Faith | What things do you believe in that give meaning /value to your life?
and/or: Do you consider yourself spiritual or religious?
and/or: What is your faith or belief? |
| Importance
& | In what ways are they important to your life?
and/or: What influence do they have on how you take care of yourself? |
| Influence | and/or: How are your beliefs/values influencing your behaviour during your illness?
and/or: In what ways do your beliefs/values help you in regaining your health/wellbeing? |
| Community | Is there a person or group of people who you love or who are very important to you?
and/or: How is this supportive to you?
and/or: Do you belong to a religious/cultural community? |
| Address | Is there anything we can do to help you while you are with us?
and/or: Would it help to talk to someone about these issues? |

An example of a Spiritual Assessment in a non-religious person

- F** Naturalist.
- I** Feels at one with nature. Each morning she sits on her patio looking out over the trees in the woods and feels 'centred and with purpose'.
- C** Close friends who share her values.
- A** After the discussion about belief, she will try to meditate, focusing on nature, on a daily basis to increase her peacefulness.

You can refer to the Chaplaincy Department at any time, but some specific situations may include:

- When one's own belief system prohibits involvement in the spiritual/religious/cultural care of the patient.
- When spiritual or religious/cultural issues seem particularly significant in the patient's suffering.
- When spiritual or religious/cultural beliefs or values seem to be particularly helpful or supportive for the patient.
- When spiritual or religious/cultural beliefs or values seem to be particularly unhelpful for the patient.
- When addressing the spiritual or religious/cultural needs of a patient exceeds your comfort level.
- When specific community spiritual or religious/cultural resources are needed.
- When you suspect spiritual or religious/cultural issues which the patient denies.
- When the patient or family have specific religious needs e.g. Confession, Holy Communion, Sacrament of the Sick, needs a prayer mat or private space to pray, sacred texts etc.
- When the patient's family seem to be experiencing spiritual/emotional pain or trauma.
- When members of staff seem to be in need of support.

Reference: Pulchalski C (1999) *Innovations in End-of-Life Care* November-December, Vol 1, No. 6. www2.edc.org/lastsacts/archives/archivesNov99/assesstool.asp

Annex J:

Report of rapid review on guidance on end of life care commissioned by the Leadership Alliance for the Care of Dying People

Report for Leadership Alliance for the Care of Dying People

Rapid Review

Vicki Morrey, October 2013

Contents

1. Introduction
2. Methods
3. Results
 - 3.1 Professional guidance and clinical practice
 - 3.2 Training and development resources
4. Discussion
5. Summary

1. Introduction

The recent independent review into the Liverpool Care Pathway (LCP) made a number of recommendations relating to key areas, including guidance, decision-making and training. A key recommendation was that the LCP should be phased out and that there should be a move away from the use of a 'pathway' of care in favour of developing individual 'care plans'.

The Leadership Alliance for the Care of Dying People, established in response to the findings of the Independent Review of the Liverpool Care pathway (LCP), commissioned a Rapid Review to provide an indication of the landscape of existing guidance and tools relating to the provision of end of life care. This Review focused on material relating to Professional Guidance and Clinical Practice. In particular, the Independent Review of the LCP identified the following key areas as requiring specific guidance and evidence based tools:

- care;
- prognosis and communicating prognosis;
- decision-making; and
- hydration and nutrition.

The Rapid Review focused on these aspects.

2. Method

Scope and Process

This exercise was restricted to material published from 2008 to date and primarily relating to the care of adults. There is some reference to children and young people where it was considered to be useful learning. The selection of 2008 as a cut-off date was guided by the publication date for England's first end of life care strategy. It also focused on guidance published within the UK. In addition, the websites of the World Health Organisation and the International Association of Hospice and Palliative Care were included. As a snapshot exercise, collating guidance from individual countries around the world was out of scope. This Review was carried out in October 2013.

Resources used and Search Strategies

This Review has been supported by the Help the Hospices Information Manager who undertook an extensive literature and database search. This was organised to include the scrutiny of eight literature databases, seven websites and all Royal Colleges. Key words included: "end of life", "terminal", "guidelines or guidance", "last days or last hours", "pathway or care pathway" Restrictions and filters applied. Where given, links were followed to articles citing original work. A significant amount of relevant material resulted from the Search Strategy and is reviewed under the agreed specified topic headings.

Literature databases

1. NHS Evidence. Search: ("end of life" OR terminal* OR "last hours" OR "last days") [Filters applied - Guideline = n752, Care pathways = n26, before date restrictions applied]
2. PubMed. Search: ("Guideline" [Publication Type] OR "Critical Pathway" [Mesh] OR guidance[tw] OR guide*[tw]) AND ("Terminal Care"[Mesh] OR "end of life"[tw] OR "last days"[tw] OR "last hours"[tw]) English language only.
3. CINAHL. Search: See appendix A
4. Embase. Search: See appendix A
5. The Knowledge Network. Search: ("last days" OR "last hours" OR "end of life" OR terminal*) Filter: Evidence & guidance = n279
6. WHOLIS (World Health Organization library catalogue)
7. RCGP Library. Search: care pathways[su] OR "end of life"
8. RCPL Library. Search: "end of life" OR pathway

Websites

1. National End of Life Care Programme website; publications search [Filter applied - care pathway: last days of life]
2. ehospice. Search: guidance OR guidelines
3. Healthcare Improvement Scotland. Publications search – Filter on "clinical topic" : palliative care
4. International Journal of Care Pathways. Search: "end of life" OR "last days of life" OR "last hours of life"
5. National Clinical Guidelines Centre
6. National Council for Palliative Care – online library. "Hand search".
7. Scottish Intercollegiate Guidelines Network

Royal Colleges websites

1. College of Emergency Medicine. (Sections checked: College guidelines; Clinical guidelines; Clinical Standards)
2. Royal College of Anaesthetists (Sections checked: Publications; Clinical standards, safety & quality)
3. Royal College of General Practitioners. (Sections checked: Clinical resources)
4. Royal College of Nursing See Page 46 of LCP Review
5. Royal College of Obstetrics & Gynaecology (Section checked: Guidance/ Search: end of life)
6. Royal College of Paediatrics and Child Health
7. Royal College of Pathologists (Search: end of life)

8. Royal College of Physicians of Edinburgh (Sections checked: Publications; Policy; Standards)
9. Royal College of Physicians of London. (Section checked: Resources – clinical guidelines)
10. Royal College of Physicians and Surgeons of Glasgow. Search: end of life
11. Royal College of Psychiatrists. Search: “end of life”
12. Royal College of Radiologists. (Section searched: Clinical oncology: publications & guidance; Clinical radiology: Standards)
13. Royal College of Surgeons of England. (Sections searched: Clinical standards & policies)

Colleges not checked: Royal College of Ophthalmologists

Where given, links were followed to articles citing the original work. All links checked October 2013.

3. Results

3.1 Professional guidance and clinical practice

The results of the search are organised into the categories of Professional Guidance and Clinical Practice. The agreed themes of care, communicating prognosis, decision-making and hydration and nutrition are used to organise the findings and are collated together in Tables 1 & 2, which align the themes with the relevant publications.

Professional Guidance

The specification indicated that professional guidance should include reference to:

- communication and shared decision-making between professionals and patients/families and between different professional;
- communication of information to support coordination of care, including facilitating accurate handover;
- Mental Capacity Act with respect to care in the last days of life; and
- guides and alerts that reflect common principles of good palliative care.

It is assumed that professional guidance may be acquired via two principle routes:

That which is produced by specific professional bodies

That which is produced generically and applied to professional practice

The findings refer to both sources and are grouped under each of the above categories.

Guidance produced by professional bodies:

- The General Medical Council *Treatment and care towards the end of life: good practice in decision making 2010*
- The Royal College of General Practitioners and Royal College of Nursing *Matters of life and death: helping people to live well until they die: general practice guidance for implementing the RCGP/RCN End of Life Care Patient Charter 2012*
- College of Emergency Medicine *End of life care for adults in the emergency department 2012*

Guidance to support professional practice:

- Gold Standards Framework (GSF)
- AMBER care bundle
- NCPC Publications on Mental Capacity Act
- National End of Life Care Programme publication, *Capacity, care planning and advance care planning in life limiting illness*
- National End of Life Care Programme Co-ordination and Implementation Guidance

Table 1 Guidance on professional practice

Topic	Guidance
<ul style="list-style-type: none"> Communication and shared decision-making between professionals and patients/families and between different professionals. 	<p>The General Medical Council's <i>Treatment and care towards the end of life: good practice in decision making 2010</i></p> <p>The Royal College of General Practitioners and Royal College of Nursing's <i>Matters of life and death: helping people to live well until they die: general practice guidance for implementing the RCGPIRCN End of Life Care Patient Charter 2012</i></p> <p>College of Emergency Medicine <i>End of life care for adults in the emergency department 2012</i></p>
<ul style="list-style-type: none"> Communication of information to support coordination of care, including facilitating accurate handover. 	<p>AMBER care bundle</p> <p>Gold Standards Framework (GSF)</p> <p>College of Emergency Medicine <i>End of life care for adults in the emergency department 2012</i></p>
<ul style="list-style-type: none"> Mental Capacity Act with respect to care in the last days of life. 	<p>National End of Life Care Programme publication <i>Capacity, care planning and advance care planning in life limiting illness</i></p> <p>National End of Life Care Programme <i>Co-ordination and Implementation Guidance</i></p> <p>NCPC Publications on Mental Capacity Act</p>
<ul style="list-style-type: none"> Guides and alerts that reflect common principles of good palliative care 	<p>The General Medical Council <i>Treatment and care towards the end of life: good practice in decision making, 2010</i></p> <p>Gold Standards Framework (GSF)</p>

Clinical Practice

The specification indicated that guidance for clinical practice should include reference to:

- diagnosing dying, including prognostication for last days of life, managing uncertain recovery, withdrawal of active treatment, etc;
- managing issues relating to hydration and nutrition;
- technical guidance specific to disease groups can be
- personalised care in last days of life.

Existing guidance relating to these topics are set out in Table 2. In addition, there are NICE Pathways (e.g. dementia) and a NICE Quality Standard for End of Life Care.

Table 2 Guidance relating to specific aspects of clinical practice

Topic	Guidance
<ul style="list-style-type: none"> • Diagnosing dying, including prognostication for last days of life, managing uncertain recovery, withdrawal of active treatment, etc. 	GSF – includes prognostic indicator College of Emergency Medicine. <i>End of life care for adults in the emergency department</i> (Best Practice Guidance 2012) EAPC recommended framework for sedation in palliative care
<ul style="list-style-type: none"> • Managing issues relating to hydration and nutrition 	Royal College of Physicians and British Society of Gastroenterology <i>Oral feeding difficulties and dilemmas: a guide to practical care, particularly towards the end of life</i> 2010 NCPC & APM <i>Artificial Nutrition and Hydration: Guidance in end of life care for adults</i> (pre 2008 but useful in context of Mental Capacity Act)
<ul style="list-style-type: none"> • Technical guidance specific to disease groups 	Diabetes UK <i>End of life diabetes care: clinical care recommendations</i> 2012 NHS Improvement <i>End of life care in heart failure: a framework for implementation</i> 2010 British Heart Foundation, Marie Curie Cancer Care, NHS Greater Glasgow and Clyde <i>Caring Together</i> NCPC <i>Improving end of life care in neurological conditions: a framework for implementation</i> 2010

	<p>NCPC <i>Parkinson's and the last days of life: consensus statement on the management of symptoms for people with Parkinson's and related conditions in the last days of life 2011</i></p> <p>NCPC, National End of Life Care Programme, Neurological Alliance: <i>End of life care in long term neurological conditions: A framework for implementation 2011</i></p> <p>National End of Life Care Programme <i>End of life care in advanced kidney disease: a framework for implementation 2009</i></p> <p>NCPC <i>Out of the shadows: End of life care for people with dementia 2009 (references the Pan Birmingham Palliative Care Network's Supportive Care Pathway)</i></p>
<ul style="list-style-type: none"> Personalised care in last days of life 	<p>GSF – includes prognostic indicator</p> <p>AMBER Care Bundle</p>

Additional UK Resources

It is recognised that a key concern reflected in the LCP Review is that of both quality and equity of care in all end of life care settings. The use of a single tool under a blanket approach to implementation has resulted in problems of misunderstanding and misapplication. A number of other resources to support the adoption of good practice across all settings have been produced and made available for health and social care professionals.

These are reflected in the work of the National End of Life Care programme, developments in other UK countries, children and young people's sector and Care Homes. These have all made a useful contribution to the development of helpful resources to improve end of life care in a given setting. Details of these resources and approaches are indicated below.

(i) Route to Success Series

The national End of Life Care Programme has been pro-active in both developing and promoting a variety of helpful guides and resources. Key among them is their Route to Success series detailed below.

The aim of The Route to Success series is to provide health and social care staff with simple guides to support the implementation of the End of Life Care Pathway. The series covers the topics detailed below:

By setting:

- Acute hospitals
- Acute hospitals 'how to' guide
- Care homes
- Prisons
- Ambulance
- Environment of care

By professional group:

- Occupational therapy
- Social workers
- Nursing Domiciliary care

By individual group:

- Homeless people
- Lesbian, gay bisexual and transgender people
- People with learning disabilities

Several publications in this series have been evaluated and a range of support sheets have also been produced to accompany the series

(ii) Resources in Scotland

The Dignity Care Pathway developed by the University of Dundee with Community nurses in Tayside. While recognising the difficulty with the term 'pathway' this tool appears to be significantly different in approach. It is based on the Chochinov theoretical model of dignity care. It has four sections: a manual, a Patient Dignity Inventory, reflective questions, and care actions. Used by community nurses it was reported to have helped them identify when patients were at the end of life, identified patients' key concerns, and aided nurses in providing holistic end-of-life care.

(iii) Resources in Wales

Wales did not adopt the LCP and introduced its own approach to end of life care. The latest version of this is *The All Wales Integrated Care Priorities*. The approach aims to improve care for dying patients in Wales by promoting the delivery of best practice care, facilitated by a care priorities approach.

Care is agreed and delivered using a three step approach as detailed below:

- *Step One:* Is it agreed by the family/carers and the professional team caring for the patient that the patient is dying, all reversible causes have been excluded and death is now imminent?

The professionals involved in this decision-making process should be a senior nurse and a General Practitioner or a Medical Consultant. Do not proceed to Step Two if there are any doubts expressed by the family/ carers or by the professionals giving care regarding the diagnoses of any reversible causes.

- *Step Two:* What are the priorities at this time for the patient and their family/carers?
- *Step Three:* What can the doctors and nurses caring for the patient do to make the patient comfortable, alleviate any pain or distress and allay any fears and concerns of the family/carers?

As ever, each professional has a personal responsibility to be vigilant to the patients changing condition, diligently review the situation and respond appropriately to address need. When caring for the dying, this extends to being particularly sensitive and accommodating to the needs of the close family and carers.

This model is well established in Wales and patients in Wales do not appear to have been affected by the issues relating to the LCP in England.

(iv) Babies, Children and Young Adults

Together for Short Lives has produced comprehensive guidance in the publication *A Guide to end of life care of children and young people before death, at the time of death and after death 2012*.

British Association of Perinatal Medicine *Palliative care (supportive and end of life care): a framework for clinical practice in perinatal medicine 2010*

ACT *A care pathway to support extubation within a children's palliative care framework 2011*

Together for Short Lives *A core care pathway for children with life limiting and life threatening illnesses 2013*

(v) Care Home Support

Some guidance and education tools have been developed specifically for use in care homes. The national End of Life Care Programme publication *Route To Success in End of Life Care* for the care home setting led to the successful development of the 6 Steps Programme. This was originally developed in the North West as a programme of learning for care homes. It has since been widely adopted and amended for use in other settings. It contains the core principles of approaches to end of life care and aims to build confidence and skills among health and social care professionals.

NCPC produced the *Care to Learn Pack* a similar structured approach to end of life care in Care Homes.

3.2 Training and Development Resources

Resources and Search Strategy

In order to ensure all relevant material was captured, the search scope was extended to include training and development resources. This search revealed that guidance on end of life care is produced in a variety of mediums and captured under various headings. Some useful products and programmes containing helpful approaches to end of life care practice emerged under the category of Education.

The National End of Life Care Programme's website provided the majority of information with further support of the Help the Hospices Information Manager. The search revealed an extensive amount of material from an impressive array of source providers and is detailed below.

Search Results

Advance Decisions to Refuse Treatment Training Programme - The ADRT Training Programme produces training and guidance for health and social care.

Lessons Learned - Lessons Learned is an interactive e-learning programme from Macmillan Cancer Support designed to address the experience of patients and their carers when facing end of life issues. You will need to register to use the site, but there is no charge.

'be.macmillan' learning resources and courses – These are a selection of learning programmes to improve knowledge of all aspects of palliative care. Including a CD explaining how to manage breathlessness in patients.

Current Learning in Palliative Care (CLIP) - A collection of 15 minute, online tutorials, developed by Help the Hospices from *Helping the Patient with Advanced Disease: a Workbook*, Regnard C, ed. Radcliffe Medical Press 2004.

With Respect training materials from the Dignity in Care Network website
Hosted by the Dignity in Care Network, two collections of dignity-specific training resources designed for health and social care staff providing care for a) residents of care homes, or b) for people living in their own homes.

Evaluation Toolkit - An evidence-based framework for assessing the outcomes of end of life care learning event and changes in confidence and competence.

Common Core Competences for End of Life Care (DH 2009) covers all four competence areas and the overarching values and knowledge. The toolkit is available on the East Midlands Cancer Network website.

NHS Local - end of life - A collection of resources related to end of life care, including videos submitted by members of the public listing 5 things they want to do before they die. www.nhslocal.nhs.uk/page/end-life

New end of life care education and training strategy - South East London Cancer Network and Marie Curie Cancer Care have developed a comprehensive end of life care education and training strategy.

Skills for Care - Working in consultation with carers', employers and service users, Skills for Care aims to modernise adult social care in England by ensuring qualifications and standards continually adapt to meet the changing needs of people who use care services.

Social Care Institute for Excellence (SCIE) - SCIE improves the lives of people who use care services by sharing knowledge about what works. Their website includes a growing number of end of life care learning resources.

Skills for Health - Skills for Health is the UK's health sector skills council. It helps the whole sector develop solutions to deliver a skilled and flexible workforce in order to improve health and health care.

The Center to Advance Palliative Care (CAPC) website - US resource offering palliative care tools, training and technical assistance.

Communication Skills Training Materials

Connected - Connected is the national communication skills programme for the NHS.

Living and Dying with COPD - An educational package including short film clips of professionals about Advance Decisions to Refuse Treatment.

Mental Capacity Act E-Learning Site - These short narrated presentations introduce practitioners to the Mental Capacity Act and explain its impact on palliative care.

Mental Capacity Act training materials - The Department of Health, in partnership with the Welsh Assembly Government and the Social Care Institute for Excellence, published five sets of training materials to support the implementation of the Mental Capacity Act 2005. These include the Mental Capacity Act Core Training Set, which provides in-depth information and guidance on what the MCA means to people working in health and social care. This was developed by the University of Central Lancashire and the Social Care Workforce Research Unit at King's College, London.

Other education and training resources

Self Care resources on www.selfmanagement.co.uk - A library of self-care resources, from Department of Health guidance papers to online toolkits to help patients directly or those caring for people living with long term health conditions.

Walk a mile in my shoes - scrutiny of dignity and respect for individuals in health and social care services: a guide - Designed to assist Overview and Scrutiny Committees to raise awareness and understanding of dignity and respect for individuals who are receiving health and social care services. It is evident that there is a significant amount of material available in the form of training resources to provide good quality guidance on end of life care practice. Significantly, Specialist Palliative Care staff usually provide most of this level of training, especially that relating to communication skills. Additional results and a brief commentary on the resources identified is detailed below:

e-ELCA (End of Life Care for All)

Commissioned by the Department of Health and delivered by e-Learning for Healthcare in partnership with the Association for Palliative Medicine of Great Britain and Ireland, e-ELCA supports the implementation of the Department of Health's national End of Life Care Strategy. e-ELCA aims to enhance the education and training of everyone involved in delivering end of life care, so people at the end of their lives can receive well-informed, high quality care delivered by confident and competent staff and volunteers, across health and social care, wherever they happen to be. Over 150 interactive sessions of e-learning are available covering: Advance care planning Assessment Communications skills Symptom management, comfort and wellbeing Social care Bereavement Spirituality Integrating learning.

Common Core Competencies and Principles for Health and Social Care Workers working with Adults at the end of life

Published jointly between National End of Life Care Programme, Skills for Health, Skills for Care and the Department of Health. The principles and competences outlined in this document form a common foundation for everyone whose work includes care and support for people nearing and reaching the end of their lives, whether their primary

involvement is health or social care and support-related. The core competences and principles cover:

- communication skills;
- assessment;
- advance care planning; and
- symptom management, comfort and well-being.

Thinking and Planning Ahead: learning from each other.

Available from the National End of Life Care Programme

A volunteer training programme about Advance Care Planning designed to help people:

- understand what advance care planning is and how to do it; and
- assist others with advance care planning.

Sage and Thyme

Communication training tool. This model was developed by clinical staff at the University Hospital of South Manchester NHS Foundation Trust (UHSM) and a patient in 2006. It was designed to train all grades of staff how to listen and respond to patients/clients or carers who are distressed or concerned. It places published research evidence about effective communication skills within a memorable structure for clinical practice.

Lessons Learned

Lessons Learned is an interactive e-learning programme from Macmillan Cancer Support designed to address the experience of patients and their carers when facing end of life issues. It was developed with St Margaret's Hospice, Somerset, NHS Somerset and Yeovil District Hospital NHS Trust. Topics covered include:

- anticipatory care;
- partnership resolution to complaints – to lead to improved practice which can be replicated in other settings;
- the challenges of different clinical care settings;
- the importance of philosophy, attitude and environment;
- identify issues important to carers;
- the challenges of integration of services; and
- provides examples of good practice.

Current Learning in Palliative Care (CLIP)

A collection of 15 minute, online tutorials, developed by Help the Hospices from *Helping the Patient with Advanced Disease: a Workbook*, Regnard C, ed. Radcliffe Medical Press 2004. CLIP consists of worksheets for self-learning which can be applied to:

- individual learning;
- group learning (small and large);
- with tutor support;
- lecture theatre settings; and
- online.

Has a focus on the last days/hours and covers adjustments, managing distress and the time around the death.

National Dignity Council 'With Respect'

Hosted by the Dignity in Care Network, two collections of dignity-specific training resources designed for health and social care staff providing care for a) residents of care homes, or b) for people living in their own homes. This is helpful with relevant generic references, but not specific to end of life care.

Evaluation Toolkit - An evidence-based framework for assessing:

- the outcomes of end of life care learning
- changes in confidence and competence: The tool is linked to the Common Core Competencies for end of life (DH 2009), covers all four competence areas and the overarching values and knowledge. The toolkit was developed by the East Midlands Cancer Network and is now available on the National End of Life Care Intelligence Network e-learning hub – my learning space.

NHS Local - end of life

A collection of resources related to end of life care, including videos submitted by members of the public listing 5 things they want to do before they die.

New end of life care education and training strategy

South East London Cancer Network and Marie Curie Cancer Care have developed a comprehensive end of life care education and training strategy.

NHS East of England.

ABC end of life care programme. An online programme.

North East of England Regional Skills Development Group & Skills for Health.

End of life care: learning and development pathway.

Living and Dying with COPD

An educational package including short film clips of patients' and carers' stories and views on diagnosis and end of life dialogue and an 'expert panel' discussion on ways to approach these issues with tips on how to improve the consultation. Recommended for use by a facilitator as part of an educational package on communication skills, or COPD care.

Royal College of Physicians, National End of Life Care Programme, Association for Palliative Medicine of Great Britain and Ireland.

Improving end-of-life care: professional development for physicians: report of a working party. London: RCP, 2012.

NHS Education for Scotland.

Palliative care in practice: end of life care. [online]

Princess Alice Hospice, Esher

European certificate in essential palliative care. [online]

British Lung Foundation

Coping with the final stages of chronic lung disease

Advance Decisions to Refuse Treatment Training Programme

The ADRT Training Programme produces training and guidance for health and social care professionals about Advance Decisions to Refuse Treatment.

Mental Capacity Act E-Learning Site

These short narrated presentations introduce practitioners to the Mental Capacity Act and explain its impact on palliative care.

Mental Capacity Act training materials

The Department of Health, in partnership with the Welsh Assembly Government and the Social Care Institute for Excellence, published five sets of training materials to support the implementation of the Mental Capacity Act 2005.

These include the Mental Capacity Act Core Training Set, which provides in-depth information and guidance on what the MCA means to people working in health and social care. This was developed by the University of Central Lancashire and the Social Care Workforce Research Unit at King's College, London

In discussing the scope of this paper it was noted that it would be useful to include examples of good practice and how the learning from these could be utilised going forward. These are detailed below:

Examples of Good Practice

There are numerous examples of good practice driven by the National End of Life Care Strategy and arising from work undertaken by a number of organisations, including:

- cancer networks;
- workforce deaneries;
- care home organisations;
- PCT/CCG's;
- local consortia – e.g. hospice, hospital, community collaborations;
- clinical networks; and
- National End of Life Care Intelligence Network.

It is notable that the defining characteristics of the above include:

- a structured approach by a designated organisation, e.g. a cancer network, working to a specific brief to bring about positive improvement;
- the engagement of expert practitioners, such as hospices and specialist palliative care teams, in the production of protocols, guidance and practice aids;
- joint collaboration between providers; and
- a systematic approach to deliver on a locally agreed strategy for end of life care.

These areas of good practice provide useful learning and serve to demonstrate that the application of available guidance under the support of expert practitioners can be effective in achieving positive outcomes. It is apparent that the implementation of the LCP was not necessarily supported by expert practitioners in all cases or was part of

a systematic approach to changes in practice. The joint development of a local plan for end of life care and the subsequent supported implementation appear to be key elements to improved practice and outcomes.

4. Discussion

The searches undertaken have revealed there to be an extensive amount of available material for both guidance and training and development. With only one or two exceptions (namely end of life care guidance available from the Social Care Institute for Excellence, and NCPC and APM Artificial Nutrition and Hydration guidance) all material is recent and clearly has the End of Life Care Strategy as the point of reference. For ease the review will be discussed under the headings of credibility, accessibility and ease of application.

A. Guidance for Professionals and to support Clinical Practice

Credibility

Please note that for the purposes of this report the credibility of material is determined by the source references, design and content. No attempt has been made to evaluate each piece of work, published guidance or tools.

Professional guidance and guidance related to clinical practice have been produced by various professional bodies and cite established experts and authentic research. Where non-palliative care organisations have produced guidance there is acknowledgement of support from specialist organisations, for example NCPC and the National End of Life Care Programme and references to accepted published material such as the GMC's *Treatment and Care towards the end of life (2010)*.

Guidance has been produced for a number of diverse settings and contexts, including emergency medicine, gastroenterology, people with learning disabilities, neurological conditions, heart failure, respiratory disease, dementia and diabetes. On examination there is a high level of consistency in the approaches adopted in the guidance in terms of the principles of good management in end of life care. Specific guidance relating to nursing is produced as a combined document between the Royal College of General Practitioners and the Royal College of Nursing. It would be beneficial to strengthen nursing specific guidance.

Communication between professionals and with the family, assessment, co-ordination of care and symptom management are all apparent in the published guidance contained in tables 1 and 2.

It can be concluded that there is a considerable quantity of professional and clinical end of life care guidance available. It may also be concluded that it is consistent in content, reliably informed with credible points of reference.

Accessibility

For guidance to be relevant it needs to be readily accessible. As the guidance available has been produced by a variety of sources there are several points by which relevant guidance can be accessed. These include; direct distribution from specific professional bodies, National End of Life Care Programme, National Council for Palliative Care and Help the Hospices. Accessibility is likely to be variable at local level and heavily dependent on the quality of local NHS organisation or network communications and websites.

Non-NHS organisations such as care homes, care agencies, private hospitals and charities providing care services are largely reliant on promotion and marketing to raise awareness and signpost to sources of guidance and support.

The National End of Life Care Programme has been an important development in relation to increasing the accessibility of resources as it appears to have provided a central point of comprehensive information, including details and links to a broad range of resource material. In the absence of the National End of Life Care Programme consideration needs to be given to ensuring awareness of and access to available guidance in the future.

It may be concluded that resources should be widely promoted, readily available and easily accessible. There may be merit in establishing an 'official' register of credible resources.

Ease of application

It may be argued that ease of application of guidance materials to practice may be enhanced by consistency in style, language and presentation. There are wide variations in the style and presentation of the various resources on guidance. They range from comprehensive, detailed reference documents to more practical implementation frameworks. This may present some barriers to use in certain settings or lead to variations in interpretation within a given area. Some aspects of care have the benefit of specific individual guidance, including:

- Withdrawal of hydration and nutrition
- Communication
- Advance care planning
- Neurological conditions
- Advanced kidney disease
- Advanced heart failure
- Advance respiratory disease
- Diabetes
- Sedation
- Symptom management

Guidance in the form of a tool is available via practical frameworks for practice such as the Gold Standards Framework and the AMBER care bundle. Each individual guidance publication is independent and, as such, there are no common approaches of style and format. While there is consistency of content there is diversity in ease of reading and ready application to patient situations. In the absence of the LCP it would be worth rationalising the source documents in presentation and adaptability. Reliable guidance is certainly available but the challenge could be ensuring its ready transfer to patient care planning.

It can be concluded that while there is widespread consistency in the content of the various guidance documents, there is wide variation in style, presentation and format. This could pose challenges when applying the guidance to patient care planning.

Training and Development

The search revealed there is a considerable amount of training materials in circulation. In addition the search highlighted several areas of local practice developments and training packages. Many of these have been driven by the Cancer Networks' response to the End of Life Care Strategy.

There are numerous examples of collaboration between hospices, hospitals, community, and academic centres working together to develop models of good end of life care alongside the production of training modules. It is strongly evident that specialist palliative care practitioners see the education and development of professional colleagues as integral to their role. It is understood that alongside the delivery of formal training and development sessions many palliative care clinicians provide free informal training for their non-specialist colleagues on a regular basis.

Learning materials have been produced by the major organisations which have end of life care as their main focus. These include; Macmillan Cancer Support, Marie Curie Cancer Care, Help the Hospices and the National Council for Palliative Care. This supports the understanding that as a specialism, palliative care takes seriously the responsibility to equip professional colleagues with the knowledge and skills to provide appropriate end of life care. The European Certificate in Essential Palliative Care, developed by Princess Alice Hospice is an excellent example of a local centre of excellence developing a learning tool as a means of sharing the knowledge, skills and expertise which underpin their practice with a wider audience.

Communication skills training has received a high priority and emphasis. This is evident both from a statutory perspective with the national Connections communication programme and by its inclusion in most locally developed training programmes. Commissioning priorities and Peer Review have also fostered a strategic approach to end of life care education and training. It is worth noting that as there is a commercial value attached to training it is entirely possible that there are more training materials being used by generic trainers in health and social care than have been identified. It is clear that end of life care education and training materials are plentiful and many originate from credible and reliable sources. As such they can command a reassuring level of confidence.

There remains the issue of workforce development and access to training. Anecdotally it appears that there are predictable constraints on funding and release of staff to attend further education and development. This may be a significant factor in the future if an adequate understanding of end of life care issues will be required by clinicians in order to develop appropriate individual care plans.

The training and development of generalist practitioners is taken seriously by specialist palliative care professionals and considered an integral part of their role. There is a large amount of education and training material available. The major organisations with a focus on end of life care have all produced learning packages. Most end of life care education is delivered by SPC practitioners, often at no cost. Constraints on budgets appear to be affecting the ability for staff to access training and development activities.

5. Summary

The Leadership Alliance for the Care of Dying People is considering how to advise health and care staff about what needs to occur in place of the LCP. It is well documented that there remains high levels of dissatisfaction in many cases with people's experience of end of life care. This is not only related to experience of the LCP and it is important to gain a better understanding of the reasons for this before making further proposals and recommendations. The recommendations of the Independent Review include adopting an individual end of life care plan rather than following a set pathway. Such a move would rely on the existence of a sufficient standard of guidance and the availability of appropriate education and training. It is necessary to understand to what extent these already exist and whether they are adequate for the intended purpose. In relation to guidance the Rapid Review has:

- Provided evidence of the extent of provision of guidance for professionals and clinical practice
- Established the reliability of quality
- Established there are high levels of consistency among the guidance
- Established the credibility of the authors and points of reference

In relation to the availability of training and development the Rapid Review has:

- Provided evidence of the extent of provision
- Identified the major contribution by specialist palliative care practitioners in the development and delivery of education and training
- Identified the important contribution of charitable organisations in the provision of materials and training
- Confirmed the quality and reliability of training materials
- Raised an alert on the constraints impeding staff access to training and development

It is important to note that the scope of this paper does not allow for a detailed evaluation of the material identified. Reliance of quality and credibility is qualified by the reputation and credentials of the authors and publishers and the extent of its use and application.

It is important for the Leadership Alliance to better understand the balance between what already exists and how it is practically implemented. The important question to address is *"Is the gap a lack of available quality guidance or lack of application and poor practice?"*

The results of this snapshot review would suggest that there is good quality, accessible material readily available. Furthermore it is evident that there are expert practitioners supporting the education and learning of professional colleagues.

It was noted that, although consistent in content, the various guidance is presented in very different styles and format. This may prove to be problematic if the application

of guidance to individual care plans is to be recommended. It is suggested that there might be benefit, going forward in an agreed format making the content clearer and its application easier.

The previous National End of Life Care Programme was particularly valuable in providing a central contact point for all reliable, “accredited” information and resources.

This Review has established the existence of relevant guidance. It has also identified the varying forms and styles of presentation which may prove challenging if it is to have maximum impact on practice.

There is evidence of an extensive range of education and training materials. These are a combination of formal and informal modules and packages. Highly rated programmes of learning are attributed to leading charitable organisations with a focus on end of life care. Communication skills training features highly and several courses and modules of learning are available. It should be noted that formal academic programmes of learning such as undergraduate curricula, diplomas, degrees and postgraduate courses are not included but are addressed in a separate exercise.

The delivery of education on end of life care is heavily dependent on the contribution of specialist palliative care practitioners, often provided free of charge. There is a widespread shared understanding that formal and informal education of non-specialist colleagues is integral to the role of a specialist practitioner.

The challenge for the future lies in bringing together in an accessible format the wealth of high quality resources and tools, aligning them to any newly developed principles of practice and enabling their ease of application to individual care planning.

Appendix A: Additional Search Strategies

CINAHL

1. CINAHL; exp PRACTICE GUIDELINES/; 30703 results.
2. CINAHL; exp CRITICAL PATH/; 3079 results.
4. CINAHL; exp HOSPICES/ OR exp HOSPICE AND PALLIATIVE NURSING/ OR exp HOSPICE CARE/; 9781 results.
5. CINAHL; exp PALLIATIVE CARE/ OR exp TERMINAL CARE/; 33954 results.
6. CINAHL; exp TERMINALLY ILL PATIENTS/; 7049 results.
7. CINAHL; "last hours" .ti,ab; 44 results.
8. CINAHL; "last days" .ti,ab; 165 results.
9. CINAHL; "end of life" .ti,ab; 8308 results.
10. CINAHL; terminal* .ti,ab; 8221 results.
14. CINAHL; exp PROFESSIONAL PRACTICE, EVIDENCE-BASED/ [Limit to: Publication Year 2008-2013 and (Language English)]; 18405 results.
15. CINAHL; pathway.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 5592 results.
16. CINAHL; guidance.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 6041 results.
17. CINAHL; guideline* .ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 18764 results.
18. CINAHL; palliative.ti,ab [Limit to: Publication Year 2008-2013 and (Language English)]; 6512 results.
19. CINAHL; 1 OR 2 OR 14 OR 15 OR 16 OR 17 [Limit to: Publication Year 2008-2013 and (Language English)]; 54575 results.
20. CINAHL; 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 18 [Limit to: Publication Year 2008-2013 and (Language English)]; 19015 results.
21. CINAHL; 19 AND 20 [Limit to: Publication Year 2008-2013 and (Language English)]; 1490 results.

Embase

1. EMBASE; exp TERMINAL CARE/; 45189 results.
10. EMBASE; exp CLINICAL PATHWAY/ [Limit to: Publication Year 2008-2013]; 2052 results.
12. EMBASE; exp PRACTICE GUIDELINE/ [Limit to: Publication Year 2008-2013]; 118753 results.
13. EMBASE; 10 OR 12 [Limit to: Publication Year 2008-2013]; 118753 results.
14. EMBASE; 1 AND 13 [Limit to: Publication Year 2008-2013]; 837 results.
15. EMBASE; 14 [Limit to: Human and (Languages English) and Publication Year 2008-2013]; 682 results.

Annex K:

Terms of Reference and Membership of the LACDP Clinical Advisory Group

Terms of Reference

1. To consider the Independent Review of the Liverpool Care Pathway recommendations within the theme of 'clinical practice' and how these should/could influence practice; and advise the Leadership Alliance on taking these recommendations forward. In doing this, the Group will consider care in the last days of hours wherever that care takes place, including social care settings. As appropriate, the Group's advice will cover care for children in the last days and hours of life, as well as adults.
2. To oversee and facilitate a set of workshops to gather views and ideas from service users, clinicians and carers across the country about good practice in caring for somebody in the last days and hours of life, and how this can be achieved.
3. To draft appropriate advice on care in the last days and hours of life, for clinicians, managers and leaders, and information for the public if necessary. In the light of further consideration, the Group will advise the Leadership Alliance on the exact scope and nature of the advice it proposes to develop and secure the Alliance's agreement to the final specification for the work. In taking forward this work, the Group will consider care in the last days of hours wherever that care takes place, including social care settings. As appropriate, the Group's advice will cover care for children in the last days and hours of life, as well as adults.
4. To liaise closely with the Guidance, Education and Training Group (GETAG) on mutually relevant issues.

Membership List

Dr Bee Wee (Chair)	National Clinical Director, End of Life Care - NHS England
Candice Pellett	Senior Case Manager District Nurse; CPT, Queen's Nurse - Lincolnshire Community Health Services
Dr David Brooks	President - Association for Palliative Medicine of Great Britain and Ireland
Claire Henry (to March 2014)	NHSIQ
Carole Mula	Nurse Consultant - National Nurse Consultant Group (Palliative Care)
Irene Carey	Clinical Lead - AMBER care bundle work – decision-making in uncertain recovery

Sheilah Blackwell	Nurse Consultant - National Nurse Consultant Group (Palliative Care)
Ann Farenden	National Professional Advisor, Regulatory Development - CQC
Dr Matt Carey	Specialty trainee in general medicine - Health Education Thames Valley
Dr Martin Vernon	Clinical Director - University Hospital South Manchester NHS Foundation Trust, and British Geriatric Society
Jo Hockley	Nurse Consultant - St Christopher's Hospice
Susan Swientozielskyj	Head of Long Term Conditions Nursing Directorate – NHS England
Heather Richardson	Clinical Lead – Help the Hospices
Bill Noble	Medical Director – Marie Curie
Rosie Loftus	Joint Chief Medical Officer - Macmillan Cancer Support
Kevin Stewart	Head - National Care of the Dying in Hospitals Audit
Steve Barnard	Head of Clinical Governance - North West Ambulance Service NHS Trust
Sharon Blackburn	Sharon Blackburn RGN RMN, Policy & Communications Director - National Care Forum
Dr Leann Johnson	Clinical Fellow to Mike Durkin (Domain 5) in NHS England.
Tony Bonser	Lay representative
Anne McFarlane OBE	Lay representative
Natalie Laine	Lay representative
Helen Findlay	Lay representative
Elizabeth Lloyd-Dehler	Lay representative

Annex L:

Terms of Reference and Membership of the LACDP Guidance, Education and Training Advisory Group

Terms of Reference

The Guidance, Education and Training Advisory Group will provide advice to the Leadership Alliance for the Care of Dying People and its individual members particularly on actions that can be taken to improve education, training and advice in relation to the care of people in the last days and hours of life.

Membership List

Bee Wee (Chair)	NHS England
Sue Swientozielskyj	NHS England
Jacqueline Naylor	Department of Health
Sue Ambler	Health Education England
Peter Nightingale	RCGP/Marie Curie
Chris Bell	Nursing and Midwifery Council
Rob George	Association for Palliative Medicine
Katherine Hopkins	National Nurse Consultant Group (Palliative Care)
Mark Dexter	General Medical Council
Winnie Wade	Royal College of Physicians
Maaïke Vandeweghe	Care home sector
Anita Hayes	NHSIQ
Stephen Richards	Director of Professional Engagement, Macmillan Cancer Support

Vicki Morrey	Rapid review on existing guidance for end of life care commissioned by the Leadership Alliance
Penny McNamara	Sue Ryder
Kate Birrell	CQC
Damian Day	General Pharmaceutical Council
Gail Eva	University College Hospital
Keri Thomas	Coordinator for Primary Care & Acute Hospitals: Gold Standards Framework
Alistair Henderson CE	Academy of Royal Medical Colleges
Stephanie Aiken	Royal College of Nursing (RCN)
Chris Farnham	Chair of the APM Education Committee
Steve Barnard	North West Ambulance Service NHS Trust

