

Priorities of Care for the Dying Person

**Duties and Responsibilities of
Health and Care Staff – with
prompts for practice**

Published June 2014 by the
Leadership Alliance for the Care of Dying People

About this document

This is Annex D (Priorities for Care of the Dying Person – Duties and Responsibilities of Health and Care Staff) from the document One Chance to Get it Right, but with additional prompts for practice for staff. There is also a handy reference guide and poster for staff, which are available on NHS IQ's website at www.nhsiq.nhs.uk/endoflifecare.

Prompts for Practice

1. Recognise

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.

Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc. **See page 5**

2. Communicate

Sensitive communication takes place between staff and the dying person, and those identified as important to them. **See page 7**

3. Involve

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. **See page 9**

4. Support

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible. **See page 11**

5. Plan & Do

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. **See page 13**

Introduction

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.¹ 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.

¹ 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.²

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.

² See also the 'reminder about the law on capacity' in the 'generic good practice reminders' section of this document, below.

Priority 1 - Recognise

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.

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 - Communicate

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 - Involve

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 - Support

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 - Plan & Do

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 Cardiopulmonary 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.³

References

- GMC 2010 guidance, Treatment and care towards the end of life: good practice in decision-making
www.gmc-uk.org/end_of_life.pdf_32486688.pdf
- Mental Capacity Act 2005 and the MCA Code of Practice (with accompanying guides for staff and members of the public)
www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act
- Standards of Conduct, Performance and Ethics, HCPC (2008: updated 2012 to reflect name change)
www.hcpc-uk.org/publications/standards/index.asp?id=38

³ 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



www.nhs.uk/endoflifecare