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Leadership Alliance for the Care of Dying People

Engagement with patients, families, carers and professionals.

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Leadership Alliance for the Care of Dying People

Engagement with patients, families, carers and professionals: Proposed advice for health and social care practitioners involved in looking after people in the last days of life

The Leadership Alliance for the Care of Dying People was set up to lead and provide a focus for improving the care for this group of people and their families and carers following the publication of the ‘More Care Less Pathway’ report by the independent review of the Liverpool Care Pathway in July 2013.

The alliance is chaired by NHS England and its members are as detailed below.

Care Quality Commission (CQC)	NICE (National Institute for Health and Care Excellence)
College of Health Care Chaplains (CHCC)	NHS England
Department of Health (DH)	NHS Trust Development Authority (NTDA)
General Medical Council (GMC)	NHS Improving Quality (NHS IQ)
General Pharmaceutical Council	Nursing and Midwifery Council (NMC)
Health and Care Professions Council (HCPC)	Public Health England (PHE)
Health Education England (HEE)	Royal College of GPs
Macmillan Cancer Support*	Royal College of Nursing (RCN)
Marie Curie Cancer Care*	Royal College of Physicians (RCP)
National Institute for Health Research (NIHR)	Sue Ryder Care*

*Note: Marie Curie Cancer Care is also representing Help the Hospices and the National Council for Palliative Care. Sue Ryder is also representing the National Care Forum (NCF) and the Voluntary Organisations Disability Group. Macmillan Cancer Support is also representing the Richmond Group of charities.

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Introduction

In July 2013, the Independent Review of the Liverpool Care Pathway published its report ‘More Care Less Pathway’. In response to its recommendations, the Leadership Alliance for the Care of Dying People was set up to lead and provide a focus for improving the care for this group of people and their families.

This document has been drafted to engage with patients, families and carers, professionals and interested organisations in our proposals for the care of people in the last days of life in the light of the report ‘More Care Less Pathway’. These proposals are only one part of a programme of work which is being carried out to address the report’s recommendations. It relates to the recommendations that focus on clinical practice (see Annex A), including the recommendation that “the use of the LCP should be replaced within the next six to 12 months by an end of life care plan for each patient”. Other parts of the programme of work, including those on education and training, will be reported later this year.

Throughout this document, the term ‘families and carers’ is used to refer to families, close friends and loved ones of the person who is approaching the last days of life. The term ‘professional’ is used to refer to any staff in health and social care employed to look after these people. A glossary is available in Annex B to explain some of the terms used in this document.

The proposals set out here are directed at health and social care practitioners, and have been drafted with advice from some professionals, families and carers. We now wish to engage more widely with patients, families and carers, professionals and organisations with an interest in the care of dying people, covering the nine characteristics given protection under the Equality Act 2010 (see glossary – Annex B). We seek your feedback on these proposals and your help to improve them. This can be done either by signing up to attend one of 12 workshops being run across the country (October/November 2013) or by submitting a response to the questions set out towards the end of this document. Further details are available from the NHS England website: http://www.england.nhs.uk/ourwork/qual-clin-lead/lac/

The engagement period for this work ends on 31 January 2014. Formal clinical advice will be issued by the Leadership Alliance for the Care of Dying People in February 2014, taking into account the feedback we receive, and examined with regard to the nine characteristics given protection under the Equality Act 2010. Any risks that emerge from an assessment of the potential impact on these nine protected characteristics will be outlined and a plan will be produced to manage the risks. The formal clinical advice will also inform inspection frameworks used by the regulators of professionals and health and social care organisations, and will also be useful to those organisations involved in commissioning, setting standards and promoting education and training (including the royal colleges). We will then produce a lay version for patients, and their families and carers, which will focus on what they should expect and what they should do if they feel the care is not meeting those expectations.

The proposal

Care of all patients must be set in line with a culture of professional care which is safe and effective, and which puts the person, his/her experience of care, and that of his/her family and carers, at the heart of everything we do. Setting the foundation for achieving good care in the last days to hours of life should start earlier in the process of care. It should begin when the person's life expectancy is known, or expected, to be limited (or shortened) by his/her condition(s). Ideally these conversations should start well before the last days of life. The principles of palliative care (see glossary – Annex B) remain central to the care of people with progressive, life-limiting conditions until they die - and after they have died, for their families and carers.

<u>We propose that:</u>

1. Anybody who has a progressive life-limiting illness should be offered the opportunity to develop, document, review and update a Personal Palliative Care Plan. This should be developed over a period of time (especially when gradual deterioration occurs on a monthly or weekly basis), in response to the person's wishes and readiness to discuss these matters. Such a plan could include:
    a. current and future preferences about care and treatment
    b. the goals and outcomes of care and treatment which are most important to that person
    c. their current wishes about cardiopulmonary resuscitation and other potentially life-sustaining interventions, e.g. the administration of food and fluids through medical means (drips and tubes) and hospital admissions for intravenous antibiotics
    d. the limits to treatment with which that person is currently agreeable, especially when emergencies arise (note: treatment can legally be refused but not demanded)
    e. future wishes with respect to care in the last days of life, and care after death

2. Care of people in the last days of life must seek to achieve the outcomes set out in Table 1 below, supported by the guiding principles set alongside each outcome. Some of these outcomes apply when a person is thought to be dying within the next few hours or days, whereas others are important even before

then. We have taken the decision not to produce measurable standards as these already exist, or are being developed by the National Institute for Health and Care Excellence (NICE) and by the regulatory bodies.

3. The outcomes and principles set out in Table 1 should be used to guide the care of dying people while the Liverpool Care Pathway is phased out and its use discontinued by 15 July 2014. This does not preclude organisations from using specific tools, templates or documentation which they have developed for the care of people in the last days of life. Whatever is used, these organisations must continue to support practice with strong leadership, continuing education and training, and quality assurance processes in keeping with the outcomes and principles we have outlined in Table 1.
4. The discomfort that lies in conversations about dying and care in the last days of life must be acknowledged, especially for professionals who have these conversations infrequently and for the person and his/her family who face such a life-changing event. There should be a recognition that whilst some tasks of caring for dying people can, with adequate training and supervision, be reasonably straightforward, other aspects of care will be more difficult, such as the need to cope with uncertainty in diagnosing dying and how to communicate this to individuals. Professionals do not always have answers to questions that are asked. Local leadership should ensure that there are adequate mechanisms for supporting staff in sharing, discussing and finding ways to manage, respond to and learn from these challenges. This should include access to senior staff and specialist support when needed.
5. The quality of care of dying people should be demonstrated through local quality assurance processes, participation in national audits and inspections, and by exploring the experience of the dying person and those closest to them.

Table 1 **Outcomes and guiding principles for care in the last days of life, and what this means for people approaching the last days of life and their families and carers**

Outcome	**Guiding principles for professionals**	**What this means for people approaching the last days of life and their families and carers**
A. People who have a progressive, life-limiting illness have been offered the opportunity to develop, document, review and update a personalised palliative care plan at different stages in their illness or condition.	1. People who have a progressive, life-limiting illness should be encouraged to discuss and document their wishes and preferences to guide decision-making, and opportunity should be provided for them to review and update this regularly, or as circumstances change. 2. People should be encouraged to identify individuals whom they would like professionals to involve in decision-making about their care if they themselves are unable to fully participate in such decisions However there are legal limits of decision-making by other people on behalf of the dying person. 3. People should be encouraged to identify individuals with whom they would be happy for information about their care to be shared.	You should be offered the opportunity to discuss your wishes and preferences about your care and treatment, and to put this in writing as a personal palliative care plan. It is entirely up to you whether or not you wish to do this – you should not feel forced to do so. But such a plan can be shared amongst those caring for you, saving you the need to explain your wishes over and over again. If you feel too unwell to actively participate in discussions about your care in the future, this plan would make it easier for those caring for you to take your views into account when decisions are being made. Ideally you should review the plan from time to time, so that it remains in line with your views if these change. You can name individuals whom you would like your doctors, nurses and other professionals to consult if you are

		unable to make your own decisions. Unless you have appointed somebody to be your Lasting Power of Attorney for health and welfare (see glossary - Annex B), they cannot legally make decisions on your behalf but they can, and should, receive explanations and be involved in the discussions (unless you had previously stated otherwise). A specific treatment can be legally refused (at the time, or in advance by you) but specific treatments cannot be demanded. If there are individuals with whom you would be happy for your doctors, nurses and other professionals to share information about your care and treatment, you can include their names in this plan.

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
B. People, including those thought to be in their last days of life, whose condition changes, are identified in a timely way, receive good care that is reassessed at least daily (or more frequently as their condition requires), receive timely appropriate medication and have their emotional, psychological, social and spiritual needs addressed.	1. People whose condition changes must be identified, promptly reassessed, pre-existing care and treatment plans consulted, and care and treatment goals re-evaluated. This must be done in consultation with the person (where possible), their families and carers (where present or contactable) and other members of the team who may have information to contribute. It must take into account the specific features of their underlying condition(s). If it is clear that attempting to reverse the person's condition is possible and in keeping with their wishes, treatment should focus on maintaining life and wellbeing. If the person's change in condition is not reversible and he/she is likely to die within the next few days, the focus of treatment and care should move towards palliation and preserving the individual's comfort and dignity. 2. In hospital, people who have been identified as likely to die within the next few days, must be assessed by appropriately trained doctors at least daily, monitored by appropriately trained registered nurses regularly (at least four hourly) and have their needs addressed as they arise. This must be integrated into regular day to day clinical practices on the ward. 3. At home, people who have been identified as likely to die within the next few days, must be assessed by an appropriately trained doctor or nurse at least daily, and steps taken to ensure that individuals	If your condition changes, you should be promptly assessed. Treatment decisions require a balance to be struck between how likely you are to benefit from the treatment, what side effects that treatment might cause and how burdensome that treatment might be, given how you are at the time. You should be involved in making these decisions unless you do not wish to, or are not able to, do so at the time. If that is the case, your doctors should act in your best interests (see glossary – Annex B), taking into account the balance described above, as well as any wish you have previously expressed and what your family and carers know would have been your wish. Even if your family and carers do not know what your wish would be, unless you have forbidden this, they should still be given the opportunity to participate in the discussion about what should happen next even though they cannot legally give consent on your behalf. If you have nominated one of them to be your Lasting Power of Attorney for

	who are with the person at home know how to check the person’s comfort levels, address their immediate needs, and when and how to seek professional help. 4. In care homes and other institutions, people who have been identified as likely to die in the next few days, must be assessed by an appropriately trained doctor or nurse at least daily, and steps taken to ensure that staff who are looking after the person know how to ‘monitor’ the person and his/her comfort levels, address their immediate needs, and when and how to seek additional professional help. 5. The care of the dying person must be personalised, reflect individual needs and preferences, and have attention paid to assessing and addressing physical (including symptoms, hydration and nutrition, and skin and mouth care), emotional, psychological, social and spiritual needs of that individual, as well as his/her personal care needs and sense of dignity. 6. The dying person should be supported to eat and drink as long as he/she is able, and wishes, to do so. If he/she is unable to swallow, decisions about the use of clinically assisted hydration and nutrition should be taken in the person’s best interests (see glossary – Annex B), in consultation with any known prior wishes, and in consultation with the person’s family and carers and other members of the team. All decisions should be made in line with the principles within the GMC guidance: http://www.gmc-	health and welfare decisions (see glossary – Annex B), that individual will have a greater role in deciding about your care. If you are thought to be likely to die within the next few days, the goal of care and treatment should be to maximise your comfort and dignity. This means paying specific attention to your physical, emotional, psychological, social and spiritual needs, as well as that of your family, and carers. You should be assessed regularly. The frequency of such assessments depends on where you are at the time, for example at home, in hospital, in a hospice or a care home, etc. An assessment to adjust your regular medicines should take place at least once a day. You should have frequent and regular checks on your comfort level so that action can be taken where necessary. If you are in hospital, hospice or a care home or other institution, nurses or care home staff should carry these checks out at least every four hours. If you are at home, although nurses and social care staff may call in regularly, it is more likely that your family and carers will be

	k.org/guidance/ethical_guidance/end_of_life_care.asp. 7. People who are likely to die within the next few days should have medicines prescribed in anticipation of common symptoms that may arise and arrangements made for securing such medicines and any equipment needed for administering these so that timely symptom control can occur at any time of day or night. 8. All medications used in the palliative care of the person, including sedative medications, must be targeted at specific symptoms, used in the smallest dose that works, for the shortest time that is necessary, and their use regularly reviewed and adjusted as necessary. 9. The reason for any intervention, including the use of a syringe driver, should be explained to the dying person (if possible) and his/her family and carers. If the dying person is unable to consent, reasonable efforts must be made to discuss the purpose of these interventions with his/her family and carers, but if they are not present nor readily contactable, this should not delay starting the intervention where this is clearly in the person's best interests. 10. Access to pressure-relieving equipment and other aids to improve the person's comfort and dignity must be provided in a timely way.	keeping an eye on your comfort level. It is important that professionals show them how to do this, what to do to make you more comfortable, and when and how to seek professional help when they need it. If you are able to swallow safely, and wish to eat or drink, you should be encouraged and helped to do so. In the last hours or days of life, dying people often do not have a desire to drink but just need to wet their mouths to prevent dryness. A decision to give fluids through drips and tubes needs to be weighed up at the time by the doctors and nurses looking after you. They will be informed by your own preferences in making decisions. They should share making this decision with you (if you are able to join in), consult with your family and carers and take into account views that you may have previously expressed. If you need medicines to help with your symptoms (such as pain or nausea), you should receive these promptly. These should be prescribed and given by doctors and nurses who are appropriately trained, and who will use the smallest dose that works for your

	11. All aspects of assessment, care and treatment must be carried out by staff who are competent to do so and who remain up-to-date in their knowledge and skills of palliative care, including doctors, nurses, therapists, social care workers and spiritual care advisors.	symptoms, only for as long as you need it. They will regularly review how the medicines work for you and adjust things accordingly. If you need a 'syringe driver' (a small machine that allow your medicines to be given continuously under the skin rather than injected every four hours), your doctor and nurse should explain its purpose and check that you are willing to have it. They should also explain this to your family and carers so that they understand its purpose. However, it is important that your doctors and nurses act in your best interests and promote your comfort at all times, so if your family or carer is not around, or is not readily contactable, they should go ahead and provide you with what you need for relief of your symptoms, unless you have previously said that you do not wish to receive them. Additional prescriptions for medicines for symptoms that commonly occur should be pre-written to avoid delay. If you are at home, these medicines may even be ordered in advance and kept in your home so that they are readily available if and when you need them.

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
C. Regular, pro-active and responsive communication takes place between professionals and the person who is approaching the last days of their life and their family and carer. The content and outcomes of these discussions are clearly documented and shared with others involved in this person's care.	1. The content and outcome of discussions with individuals and their family and carers should be clearly documented. This information should be easily accessible and understood by other professionals within and beyond the immediate team involved in caring for this person. This includes conversations that have taken place about prognosis, treatment goals and care plans at each point in time, and particular concerns that the person and/or family and carers have expressed. 2. The starting point of communication between professionals and the family and carers of the person who is approaching the last days of life must be that all parties wish to act in the person's best interests. Differences in opinion about how this is achieved should be discussed openly and alternatives, including a second opinion, actively sought if there is a continuing difference of opinion or if additional reassurance would be helpful. 3. Doctors, nurses and other professionals need to become proficient in the skills of shared decision making, and to understand the difference between explaining to the person and his/her family and carers what is going on at any point in time, seeking the person's consent for specific interventions or actions, and consulting the person's family and carers about the most suitable course of action where the person is unable to participate in the decision-making at the time. They	There should be regular communication between the professionals looking after you and your family and carers. When there is a change in your condition or there is progress to report on how you are responding to any treatment or type of care, professionals should pro-actively seek to discuss this with you and, with your permission, your family and carers. Normally, professionals are bound by their code of confidentiality to discuss your health and care information only with you and anybody you wish to involve. When you are very ill, particularly in the last days of life, you may not be able to give express permission about this. Professionals recognise that your family and carers will want, and need, to know how you are and what is going on, so it is particularly helpful if you are able to indicate in advance which of your family and carers you would like to be involved in discussions. It is also helpful if you are willing to allow professionals to share with other

	must understand their duty to take into account any prior wishes the dying person has expressed, to involve the person’s Lasting Power of Attorney (LPA) for health and welfare decisions if there is a nominated LPA and to involve an Independent Mental Capacity Advocate (see glossary – Annex B) if the person does not have family or friends or there is a disagreement about a person’s best interests. 4. Professionals should recognise that accurate and timely handover between professionals and teams is particularly important in the care of a person whose condition is changing or fluctuating, regardless of whether the anticipated outcome is recovery or death. Professionals/teams taking over care must receive all necessary information to enable them to make timely, sensible decisions if the situation changes further.	professionals the necessary information about your care and preferences, both verbally and in writing, so that decisions about your care can be as informed and timely as possible, especially if you are unable to participate in these discussions yourself. Sometimes professionals and your family and carers may have a difference in opinion about what should be done (or not done). In that situation, it is helpful for all parties to remember that they all usually want what is best for you – they may simply disagree on how best to achieve this. They should discuss this openly and if they still can’t agree, they might want to take time to think about it then meet again, or to seek a second opinion. In some cases, it may be appropriate for someone to act as your independent advocate to assist in making decisions.

Outcome	**Guiding principles for professionals**	**What this means for people approaching the last days of life and their families and carers**
D. There are arrangements in place, with which the individual is in agreement, to share key information about his/her care, treatment and preferences between professionals, service providers and others relevant to the person's care.	1. There must be clear arrangements for sharing key information about the individual's care, treatment and preferences (with the person's agreement) between professionals, service providers and others relevant to the person's care. 2. Any local arrangement for shared care folders must include provisions for safeguarding the person's confidentiality and managing potential risks caused by multiple sets of documentation. 3. For people who do not wish to have information about their care, treatment and preferences shared with other professionals pre-emptively, the pros and cons of doing so must be explained and arrangements made that the person is comfortable with, e.g. putting limitations on information sharing, holding key information in one place at home, etc. 4. There should be adequate care planning information held by the person to ensure safe and appropriate clinical decisions are made regarding the individual's care and treatment, taking into account his/her prior wishes, in the event that he/she is unable to participate actively in the discussion at the time. 5. Information folders or diaries shared between patients, families and carers, and professionals may enhance communication.	There should be clear arrangements made, with your permission, to share key information about your care, treatment and preferences with other professionals, service providers (such as hospitals, ambulance services, GP deputising services, etc.) and others who might be involved in your care. If you are not sure that you want your information to be shared, your doctor or nurse should discuss this with you. Together you can work out a way to make information available to those who need this to make good decisions on your behalf (if you are unable to participate), in a way that is comfortable for you and keeps you in control of things. In some situations, you and your family and carers may wish to keep a shared information folder or diary so that you can share certain information with professionals looking after you when necessary.

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
E. Local governance arrangements are explicit about the role of 'senior responsible clinicians', delegation arrangements when the person's usual GP or consultant is not on duty, information sharing arrangements to enable timely decision-making, and how people who are approaching their last days of life, and their families and carers know who are their 'senior responsible clinician' and nurse responsible for leading their nursing care.	1. There needs to be a distinction made between decisions that need to be made by doctors and nurses on-the-spot to ensure the person's comfort and safety, and those that can wait for review by a senior responsible clinician who has gathered the necessary information to inform his/her clinical judgement. 2. In hospitals and hospices, the senior responsible clinician is the person's named medical consultant during their rostered hours. Outside of that period, this responsibility is taken on by the senior responsible clinician for that clinical area/ward, as designated by local clinical governance and rostering arrangements. The person's named consultant has a duty to ensure that adequate information is available to the covering senior responsible clinician to support decision-making. 3. At home or in care homes, the person's registered GP is the senior responsible clinician during surgery hours. Outside of that period, this is delegated to the GP's deputising service. The person's registered GP has a duty to ensure that the deputising service has been provided with, or has access to, adequate information to support decision-making. 4. The person's 'senior responsible clinician' and any doctor who deputises for him/her, whether in hospital or in the community, has a duty to consult specialists in palliative care when the patient's	You should have a clearly designated 'senior responsible clinician' and registered nurse responsible for your care. They should ensure that you are involved in decisions about your care wherever possible, and that decisions are made in a timely way. If you are in hospital or a hospice, the 'senior responsible clinician' is your named consultant. When he/she is not available, this responsibility should be delegated to another suitably senior doctor so that decisions for your care are not unduly delayed. You and your family should be made aware that this is the case and the name of the alternative senior responsible clinician made known to you. If you are at home or in a care home, the 'senior responsible clinician' is your registered GP. Outside surgery hours, this is delegated to the GP's out of hours (deputising) service. Some decisions may be delayed until your normal 'senior responsible clinician' is available. At other times, it is

	complex needs warrant it. 5. The dying person and his/her family and carers should know who is the registered nurse responsible for leading the nursing care of that individual at any one time. This nurse is responsible for communicating effectively with the family, checking their understanding and ensuring that any emerging concerns are addressed.	important that the doctor caring for you is able to take action in a timely way so that your needs are addressed. He/she relies on information that your normal 'senior responsible clinician' should have made available. Equally, he/she has a duty to seek specialist advice if your needs are complex and are beyond the limits of his/her competence. If you are concerned that the decision being made is not right, you may request a second opinion from another senior or more specialist doctor. The nurse responsible for leading your nursing care should communicate with you and your family and carers, explain things to you and make sure that any concern you may have is dealt with.

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
F. People who are approaching their last days of life, and their families and carers, receive the benefit of specialist palliative care (see glossary – Annex B) advice and support in a timely manner.	1. People approaching the last days of their life, their family and carers, and professionals caring for them should have timely access to specialist palliative care advice and support.	When you and your family and carers need the skills and expertise of specialists in palliative care, you should be able to receive this in a timely way. At the very least, those professionals who are looking after you, who might not be specialists in palliative care themselves, should be able to seek telephone advice from specialists on your behalf.
G. Families and carers feel supported, including knowing how to seek urgent help when this is needed for the dying person whatever time of day or night, and having their own needs addressed or signposted to sources of help and support.	1. People who are approaching their last days of life, and their families and carers, must be 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. 2. Families and carers should have their own needs regularly assessed, and either addressed directly or signposted to suitable sources of help and support. 3. Families and carers should be welcomed and enabled to spend with the dying person, whatever time they and the dying person wishes. 4. Families and carers, if they wish, should be coached in comfort measures to enhance their resilience and confidence in caring.	You and your family and carers should be told how to seek help urgently if you need it, including who to ring, what number(s) to use at any time of day or night and what key information you should provide so that you receive the most suitable help. Your family and carers should have their own needs assessed and addressed. If professionals looking after you cannot help your family and carers themselves, they should give your family and carers information about how to seek help for themselves. You and your family and carers should be able to spend as much time together as you both wish.

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
H. People who are approaching their last days of life, and their families and carers, experience ambulance transfer that is timely and takes place in a way that prioritises the person’s comfort and preferences, and that staff conducting the transfer know what to do if the situation changes unexpectedly.	1. When a dying person needs to be transferred by ambulance from one setting to another, the transfer should take place in a way that maximises the person’s comfort, and there must be a clear and effective emergency plan in place so that ambulance staff know what action needs to be taken that is appropriate to the person’s needs and preferences, if that person’s condition changes unexpectedly. 2. Ambulance and community services should be fully involved in the development and implementation of arrangements for rapid discharge from hospitals or between care settings.	If you need to be transferred from one place to another by ambulance, this should take place in such a way that you are kept as comfortable as possible. Ambulance staff should know what to do if your condition changes unexpectedly, ideally informed by an emergency plan that has been agreed with you and/or your family and carers (if you are unable to participate in discussions) in advance.
I. People approaching their last days of life and their family and carers experience care after death that is respectful to the deceased person, supportive of the family and carers and considerate of others who know the person well.	1. When a person has died, his/her body must be cared for in a way that is respectful of the deceased person and the process of verifying and certifying the death carried out in a way that is supportive of the person’s family and mindful of their recent bereavement. 2. When a person has died, the responsible clinical team has a duty to assess the wellbeing of the bereaved family and carers and ensure that adequate support is available according to their needs. 3. When a person has died in hospital or a care home, attention should be paid to the impact that this could have on other people, residents and staff who may have come to know the deceased person well.	You should be confident that when you die, your body will be treated with respect and in accordance with wishes you may have expressed beforehand, and any cultural and faith requirements that you may have. Your family and carers should be treated with respect and sensitivity. Professionals should be mindful of their recent loss and have a duty to make sure that they have adequate support. This also applies to those who have been around you, and got to know you, if you were in a care home, hospice or hospital for some time.

	4. There must be collaborative working between organisations and agencies to minimise bureaucracy surrounding the management of expected deaths.	

Outcome	Guiding principles for professionals	What this means for people approaching the last days of life and their families and carers
J. Professionals are competent in the specific requirements for excellent care in the last days of life, and these skills are embedded within a high standard of professionalism.	1. Professionals caring for people approaching their last days of life must be able to demonstrate competence in their approach to, and assessment and management of, dying people, and be able to communicate with them, their families and other team members at a level that is commensurate with that staff member’s role and level of responsibility. 2. Professionals caring for people in the last days of life know the limits of their own competence, with respect to both palliative care and the underlying condition, and know how to seek further help when necessary. 3. There is a clear culture of expectation of the highest possible standard of professionalism, including respect, compassion, kindness and attention to detail in the care of all people who are approaching their last days of life.	You should be able to expect that the professionals who look after you have the skills they need to assess and address your needs and are effective in communicating with you, your family and carers and others involved in your care. They should know when and how to seek help when they need it. They should work in a culture which expects them to have high standards of professionalism, including being respectful, kind and compassionate, and paying attention to detail when looking after you and your family and carers.

Questions for engagement/feedback:

1. Do you agree with the proposed outcomes?
   If not, how can they be improved?

2. Are the guiding principles right and sufficient to achieve the particular outcomes?
   If not, how can they be improved?

3. Do you agree that anyone who has a progressive life-limiting condition should be offered opportunity to develop, document, review and update a personalised palliative care plan, rather than a plan that focuses only on the last days of life?

4. If you agree with the proposal to offer a personalised palliative care plan, do you agree with calling it a ‘Personal Palliative Care Plan’?
   If not, what should it be called?

5. If personalised palliative care plans are to be introduced, it raises a question of how and where this should be kept. If it is kept in the person’s home, he/she would be able to look after it more easily. However, it may delay the ability of health and social care professionals (such as a doctor, nurse or ambulance staff) to take appropriate action on behalf of the person if the professional is not able to easily get hold of the information when needed. Do you have any ideas for how to find an answer to this practical question?

6. Do you have any other ideas or suggestions for how we can improve care for people in the last days of life?

Annex A

Recommendation 3	The name "Liverpool Care Pathway" should be abandoned and within the area of end of life care, the term "pathway" should be avoided. An "end of life care plan" should be sufficient for both professionals and lay people.
Recommendation 14	Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any ‘out of hours’ period. Unless it is unavoidable, urgent and clearly in the patient’s best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician, in consultation with the healthcare team. The practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith.
Recommendation 20	There should be a duty on all staff to ensure that patients who are able to eat and drink should be supported to do so.
Recommendation 23	Before a syringe driver is commenced, this must be discussed as far as possible with the patient and their relatives or carers; and the reasoning documented.
Recommendation 26	A named consultant or GP respectively should take overall responsibility for the care of patients who are dying in hospital or the community.
Recommendation 27	The name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will also be responsible for communicating effectively with the family, checking their understanding and ensuring that any emerging concerns are addressed.
Recommendation 29	Guidance should specify that the senior clinician writes in the patient’s notes a record of the face-to-face conversation in which the end-of-life care plan was first discussed with the patient’s relatives or carers. The record of the conversation must include that: the clinician explained that the patient is dying and when and how death might be expected to occur; if the family or carers do not accept that the patient is dying, that the clinician has explained the basis for their judgement to the contrary; and that relatives or carers had the opportunity to ask questions.
Recommendation 30	A shared folder, kept at the hospital bedside and designed for communication between patients, relatives and the staff should be introduced, supported by training for staff on how to use it.
Recommendation 31	There should be better integration in the community between the LCP or similar documentation and the existing system of shared care folders, so that the care provided by relatives and carers (professional or otherwise) is noted, and their contribution is incorporated into documentation.
Recommendation 38	Use of the Liverpool Care Pathway should be replaced within the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.

Annex B Glossary

Advance Care Planning (ACP)	Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, to set on record: choices about their care and treatment and / or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family and carers) in the event that they lose capacity to decide once their illness progresses.
Advance Decision to Refuse Treatment (ADRT)	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 2005 (England and Wales). Specific rules apply to advance decisions to refuse life-sustaining treatment.
Best interests	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 standard minimum steps to follow when working out someone's best interests. 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: • 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	Public authorities must have due regard to the need to eliminate unlawful 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 general 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).
Independent Mental Capacity	If a person who lacks capacity has no close family or friends and has not recorded any choices

Advocate (IMCA)	about their care and treatment or made an advance decision to refuse treatment in advance of losing capacity, then an *Independent Mental Capacity Advocate* (IMCA) should 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.
Lasting Power of Attorney (LPA)	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 health and welfare; (b) for property and affairs.
Mental capacity	Mental capacity is the ability to make a decision. 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: • 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?
Palliative care	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: • 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
Specialist palliative care	People who may benefit from specialist palliative care are those whose physical or psychological symptoms, emotional, social or spiritual needs are complex and cannot be adequately managed by professionals who have not had specialist training in palliative care. The goal of specialist palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of specialist palliative care are applicable earlier in the course of the illness (or condition) in conjunction with other treatments. It is provided by physicians, nurses, occupational therapists, physiotherapists and other therapists, social workers and chaplains who have been trained, and have specialist skills, in palliative care.