New guidance on end-of-life care, replacing the controversial Liverpool Pathway, focuses on involving and supporting patients in their final days and hours.

Getting the priorities right in end-of-life care

Priorities for care of dying people

The role of nurses in end-of-life care

Delivering compassionate care

Author Pat Anderson is freelance writer and editor.


The Leadership Alliance for the Care of Dying People has drawn up five priorities for the care of dying people. The priorities replace the Liverpool Care Pathway, which was widely criticised for promoting a tick-box approach to the care of the dying.

The five priorities focus on: recognising that someone is dying; communicating sensitively with them and their family; involving them in decisions; supporting them and their family; and creating an individual plan of care that includes adequate nutrition and hydration.

The alliance has outlined the duties and responsibilities of nurses and other health professionals when caring for people at the end of their lives, with an emphasis on compassionate care.

Good care for dying people means looking at care from the perspective of the dying person and those important to them, and developing individualised plans. This is the view of the Leadership Alliance for the Care of Dying People (LACDP), a coalition of 21 national organisations including the Department of Health, Royal College of Nursing and the Nursing and Midwifery Council. The alliance aims to ensure that care for people in the last few days and hours of life is consistent and of a high quality.

In this article...

- Priorities for care of dying people
- The role of nurses in end-of-life care
- Delivering compassionate care

Staff must ensure the dying person is involved in treatment and care decisions.

5 key points

1. The Liverpool Care Pathway has been replaced by five priorities for care for dying people

2. The dying person and those important to them must be the focus of care

3. The dying person and their family must know which nurse is responsible for leading their care

4. Individualised care plans must prioritise comfort and dignity, and support people to eat and drink as long as they wish to

5. The person’s physical, emotional, cultural and religious needs must be assessed to create care plans

Recognising that someone is dying

The review of the Liverpool Care Pathway noted that many families and carers were “simply not told that their loved one was dying… conversations had not taken place, or doctors had used euphemisms such as ‘making comfortable’. In other cases, discussions… took place hurriedly and inappropriately”.

Priorities for Care of the Dying Person says that a person whose condition has deteriorated unexpectedly must be assessed by a doctor competent to judge whether this change in condition is irreversible or whether the person is likely to die within the next few hours or days. If reversing the change in condition is possible, consent to treatment should be sought and, if the doctor judges
Review

that the person is likely to die soon, she or he must clearly and sensitively communicate this to the dying person, if conscious. The same communication must take place with those important to the dying person, and the doctor may delegate this to another clinician who is competent to do this.

Sensitive communication
The second priority for care is that health and care staff must take time to talk with dying people and their families, listening and responding sensitively to their issues and concerns, and providing information.

All discussions should be in “simple, appropriate, straightforward language without using euphemisms” (LACPD 2014b). Staff must actively seek to communicate, not wait for the person or family to ask questions, and must listen to the views of the person and those important to them, not just provide information.

Difficult conversations “must not be avoided but must be carried out sensitively, recognising that communication is an ongoing process and not a one-off event” (LACPD 2014b).

Involving the dying person
The third priority for care is to ensure that the dying person, and those important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

Providing support
Meeting the support or information needs of the family and important others, as far as possible, is the fourth priority for care. Health professionals should:

» Regularly assess and address if possible the needs of families and those important to the dying person;
» Ensure families are welcomed to inpatient facilities and enabled to spend time with the dying person;
» Support family or important others in caring for the person who is dying if they wish to participate.

Health professionals should take family or important others’ observations and judgements into account as part of the ongoing discussion and planning of care, and explain decision-making processes for those who lack capacity to make decisions. They should explain what happens when a person is close to death, find out how family and important others wish to be supported when death is imminent, and ensure adequate support immediately after the person’s death.

Individual care plans
Priority five is described as “plan and do”, ensuring that an individual plan of care is agreed, coordinated and delivered with compassion.

Health professionals must offer dying people the opportunity to discuss, record and update their wishes and preferences — ideally starting early on in the person’s illness. Where a dying person has nominated a friend or family member to take part in care planning, they must be involved. The plan must take account of the views, beliefs and values of the person and must be agreed, communicated, adhered to and regularly reviewed.

Assessment should involve the person’s physical, emotional, psychological, spiritual, cultural and religious needs, and should be conducted with respect for personal privacy and dignity.

Important assessments of a patient’s condition, capacity to decide, and treatment and care needs must be conducted “openly” and family and important others should be provided with clear explanations. Practitioners must ensure that disagreements about the outcome of assessments are swiftly acknowledged and acted upon.

Two key criticisms made in the Liverpool Care Pathway review report (Neuberger, 2013) were that fluids were inappropriately withheld from dying patients and that painkillers or tranquilisers were sometimes given as a matter of course, rather than for symptom control.

Regarding food and drink, the alliance says health professionals should:

» Support the person to eat and drink as long as they wish to do so and there is no serious risk of harm, for example by choking;
» Respect a dying person’s informed choice to eat or drink, even if they are deemed at risk of aspiration;
» Pay attention to the dying person’s mouth care and other personal care needs.

All medications must have a clinical rationale, the starting dose, be regularly reviewed, and adjusted as needed for effect. The reason for any intervention, including the use of a syringe driver, must be explained, as must likely side-effects such as a reduction in consciousness.

Where specialist spiritual or religious support is required, health and care staff must ensure that the dying person and those important to them have ready access to information about chaplaincy or spiritual care provision.

Handovers must be accurate and timely so teams taking over care are aware of the person’s wishes and, if a dying person has to move between care settings, a clear emergency plan must be made and communicated.

Equal and sequential priorities
The alliance says that the priorities for care are all equally important, and that they follow on from each other to reflect what happens when a person is likely to die within days or hours.

Priorities of Care for the Dying Person (LACPD 2014b) provides prompts for practice; reference guides and posters for staff are available from NHS Improving Quality (2014). NT

BOX 1 THE FIVE PRIORITIES FOR CARE

- Recognising that someone is dying
- Communicating sensitively with them and others important to them
- Involving them and others important to them in decisions
- Providing support
- Creating an individualised plan of care and delivering it with compassion

The alliance says 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. To achieve this, clinical teams must give dying people and their families the names of the senior doctor responsible for treatment and care, and the name of the nurse responsible for leading care.

The starting point for communication must be that “all parties wish to act in the person’s best interests” and differences of opinion must be “discussed openly” (LACPD 2014b).

References
Leadership Alliance for the Care of Dying People (2014a) One Chance to Get it Right. tinyurl.com/one-chance-right
Leadership Alliance for the Care of Dying People (2014b) Priorities of Care for the Dying Person. tinyurl.com/priorities-of-care
NHS Improving Quality (2014) Care in the Last Days of Life. tinyurl.com/NHSIQ-last-days

Quick fact
21 Number of national bodies comprising the Leadership Alliance for the Care of Dying People

20 Nursing Times 06.08.14 / Vol 110 No 32/33 / www.nursingtimes.net