



Royal College
of Physicians



Care and support
through terminal illness

Hospital care in the last days to hours of life

A guide for patients, their
families and carers



About this guide

This guide is aimed at hospital patients nearing the end of their life and those who are important to them. It explains the essential care that you should expect to receive during the last few days and hours of your life, in order to make things as calm and peaceful as possible for you at this difficult time.



How to use this guide

The aim of this guide is to provide you with information on your care, and to let you know what good end-of-life care looks like across the country. The guide explains the five essential aspects of care for a person nearing the end of their life, and is designed to help you and those important to you (such as your family, friends and carers) understand and plan your care.

The guide also summarises what we have found in the *End of Life Care Audit – Dying in Hospital* – which monitors the care of patients coming to the end of their lives in hospitals in England.

The statistics included in this guide are taken from the audit report published in March 2016, which reports on the care of patients that died in hospital between 1 May and 31 May 2015.

The statistics are there to add context to the guide – we have included the essential elements of end-of-life care, and the statistics to show where this may not be happening across the country.

We strongly encourage you to ask questions of the hospital staff looking after you, and to discuss your treatment until you are happy that you understand what is being done and why.

Introduction

Once it is recognised that you are nearing the last few hours and days of your life, the care that you can expect to receive should be based on five essential aspects of care.



What are the essential aspects of care for someone nearing the end of their life?

This guide describes each of the five essential aspects of care and provides examples of the kind of care and treatment you should expect in relation to each of these. These five essential aspects of care are:

- > recognising that you may be about to die
- > communication with you and with the people who are important to you
- > involvement in decisions about your care
- > supporting the people who are important to you
- > planning and delivering care that is appropriate for you.

We also include some information from the latest *End of Life Care Audit – Dying in Hospital*, to show how well this care is generally delivered in hospitals across England.

Recognising that you may be about to die

When the possibility that you are nearing the end of your life is recognised by the hospital staff looking after you, this should be communicated clearly to you and those who are important to you.

The care that you receive from this point onwards should be in line with your needs and wishes, which the doctors and nurses should have discussed with you (or someone important to you) ahead of time – before it is recognised that you may be nearing the end of your life.

What if I don't want to be told that I'm about to die?

If you don't want to be told that you're nearing the end of your life, you (or someone important to you) should tell one of the hospital staff looking after you. They will then make a note of this in your record and make sure that your wishes are respected.

You may wish for the people who are important to you to be informed, even if you do not wish to be.

Less than 1% of patients in the 2015 audit had asked not to be told that they were nearing the end of life. While this is a small percentage, it still equates to about 60 patients in a single month who decided that they didn't want to be told they were dying.

If the hospital staff have recognised that I'm about to die, does this make it certain?

It can often be difficult to be certain that a person is dying; however the hospital staff looking after you are highly trained professionals, with many years combined experience of caring for patients who are nearing the end of life, and in recognising when someone is likely to die in the coming hours or days.

These healthcare professionals should regularly review your condition against a number of recommendations which help them to recognise when a person may be entering the final days of life, or if they may be deteriorating, stabilising or improving even temporarily. The recognition that a patient is about to die is usually the result of discussions involving several people including: senior doctors (consultants), other grades of doctors, nursing staff, and people that are important to you.

For more information about these recommendations, please visit www.nice.org.uk and search for the guideline on 'the care of dying adults in the last days of life'.

In the 2015 audit, it was recorded that a senior doctor (such as a consultant) was involved in recognising that a patient was about to die in about three-quarters of all cases. Other types of doctor were involved 71% of the time, while staff nurses were involved 32% of the time. In almost two-thirds of cases, the patient's friends and family were also involved in these discussions.

Communication with you and with the people who are important to you

The communication between hospital staff and yourself, and those who are important to you, should always be as sensitive as possible. You are entitled to open and honest communication with the hospital staff looking after you. They should speak to you in a way that is clear and understandable, using plain English as much as possible.



Will I (or the people who are important to me) be told ahead of time that I'm about to die?

Once the hospital staff looking after you have recognised that you are probably coming to the end of your life, they should make a record of this and make sure that you, and the people who are important to you, are made aware – unless you have requested otherwise.

Unfortunately, there are some circumstances when this won't be possible. For example, you may not be fully conscious or simply be too ill to communicate, or your family and friends may not be immediately contactable by the hospital staff.

In the 2015 audit, 93% of patients who did not die unexpectedly had it recognised in their medical notes that they were about to die. The hospital staff were then able to discuss this fact with the patients themselves in a quarter of these cases, and with the patient's friends and family in almost all (95%) cases.

While the frequency of discussion with the patients themselves may seem like a small proportion, it's important to remember that many patients would not have been able to take part in this discussion.

Involvement in decisions about your care

You, and those who are important to you, should be given the chance to be involved in decisions about the treatment and care that you receive while in hospital – and this should also be the case once it has been recognised that you are nearing the end of life.

These decisions will be about things like whether or not you want attempts made to resuscitate you after your heart stops beating ('CPR'), as well as other treatments specific to your individual needs. These decisions should take into account your current goals and wishes and whether you have any cultural, religious, social or spiritual preferences.

Communication with the hospital staff looking after you should be 'two-way'. Not only should staff provide you with information but they should also give you, and those important to you, the chance to speak, to input and to ask questions about your care. If you are ever unsure about what is being done or why, please ask a member of the hospital staff to explain things to you.

Will I (or the people who are important to me) be expected to help make decisions regarding my care?

You, and the people who are important to you, should be given the chance to input as much, or as little, as you like when it comes to making decisions about the care you receive and the way this is delivered.

In the 2015 audit, 94% of patients had a decision recorded in their medical notes as to whether or not attempts should be made to resuscitate them after their heart stops beating. This decision was recorded after discussions between a senior doctor and the patient's friends and family in 81% of eligible cases.

The audit shows that the patients themselves were also involved in making this decision 36% of the time. While this proportion may not seem very high, it is important to remember that not all patients would have been capable of taking part in these discussions.

Supporting the people who are important to you

The needs of the people who are important to you (eg family, friends and carers) should be considered by the hospital staff looking after you, respected and met as far as possible. These needs might include things like psychological support, spiritual or religious support, and help with more practical things such as overnight stays, parking facilities, and so on.

Another important aspect of this support involves, where possible, contacting the people who are important to you to let them know that you are about to die.

Will attempts be made to contact the people who are important to me when I am very near the end of life?

Hospital staff should make all reasonable attempts to contact the people who are important to you once it becomes apparent to them that you are very near the end of your life.

In the 2015 audit, it was recorded that 84% of the people important to the patient were successfully contacted and notified that the patient was about to die.

Will the needs of the people who are important to me be taken care of?

The hospital staff looking after you should ask the people who are important to you about their needs. If any needs are identified, they should then take reasonable measures to act on these and to make sure that the people important to you are supported during this difficult time.

Examples of such needs might include: access to counselling services, access to chaplaincy support (chaplains are NHS staff, qualified and employed to give spiritual, religious and pastoral care to patients and those important to them), or practical needs such as advice on overnight stay facilities, car parking, where to buy food, and so on.

In the 2015 audit there was evidence that the practical needs of the people important to the patient were assessed 88% of the time, and that those needs were acted on 95% of the time. Their psychological needs (the need to speak to a counsellor, for example) were assessed 71% of the time, and then acted on 97% of the time.

Unfortunately, there was no evidence that the spiritual, religious and cultural needs of the people important to the patient were assessed as often; 40% had their spiritual and religious needs assessed, and 28% had their cultural needs assessed.

If you, or the people that are important to you, have any such needs then please speak to a member of the hospital staff about these as early as possible.

Planning and delivering care that is appropriate for you

The hospital staff looking after you should create a personalised plan of care to match your needs during the last days and hours of your life. This care plan will involve food and drink, controlling any symptoms you may have (such as pain), and any psychological or spiritual support that you may need.



If I experience any pain, will this be controlled?

You, and the people important to you, should be given the opportunity to discuss with hospital staff the extent to which you want any pain, or any other symptoms you might have, to be controlled. They should discuss with you (or the people important to you) the benefits and harms of any medicines offered to you, as well as any preference you might have regarding how these medicines are taken.

In the 2015 audit, 79% of patients had evidence in their medical notes that their pain was controlled during the last 24 hours of life.

The audit also shows that almost three-quarters of patients had anticipatory drugs prescribed for the control of pain. Anticipatory drugs are prescribed by the doctor 'in advance', so that the patient's symptoms can be relieved promptly as they develop. These drugs will only be given if and when they are needed to help relieve symptoms.

Can I expect my needs for food and drink to be met?

The hospital staff looking after you should regularly assess your ability to eat and drink and discuss this with you and the people who are important to you. If you are physically unable to eat or drink, they may want to discuss other ‘clinical’ ways of providing you with food and drink – something known as ‘clinically assisted hydration’ (water eg a drip) and ‘clinically assisted nutrition’ (food eg receiving the nutrients that your body needs directly into your bloodstream – bypassing the usual process of eating and digestion). Again, any decisions made should include your input and/or the input of the people who are important to you.

If you *do* receive clinically assisted hydration or nutrition, this should be monitored regularly by the hospital staff looking after you, to look for changes in your symptoms, any signs of dehydration and for any evidence of benefit or harm. If any signs of harm (such as fluid overload) are discovered, or if you no longer wish to receive clinically assisted hydration or nutrition, then these should be reduced or stopped entirely.

In the 2015 audit, there was evidence that just over two-thirds of patients had an assessment of their ability to drink, while 61% of patients had an assessment of their ability to eat during the last 24 hours of life.

The audit also showed evidence that almost three-quarters of patients received an assessment for the need to have ‘clinically assisted hydration’ and that just over a third of patients received an assessment for the need to have ‘clinically assisted nutrition’.

Other information

About the *End of Life Care Audit – Dying in Hospital*

Funded by NHS England, Commissioned by the Healthcare Quality Improvement Partnership (HQIP) and managed by the Royal College of Physicians (RCP), the *End of Life Care Audit – Dying in Hospital* aims to improve the quality of care and services for patients who have reached the end of their life in hospitals in England.

The audit has two sections:

- 1 The **organisational** audit reviews the structure, policies and processes in acute NHS trusts. Hospitals in England are managed by acute trusts which ensure that hospitals provide high-quality healthcare. Acute trusts are also responsible for deciding how hospitals will develop, so that their services improve. In particular, the organisational audit looks at the number of staff employed and trained in end-of-life care; access to training for these staff; and access to advice outside of regular working hours (evenings and weekends).
- 2 The **clinical audit** reviews the medical notes of a sample of adult patients who died in each participating hospital during May 2015. The aim of this part of the audit is to compare the care that was delivered to each patient with the five recommended priorities of care outlined in this guide, to see how well these were met.

The *End of Life Care Audit – Dying in Hospital* has released an annual report describing the performance of hospitals at a national level. If you would like to read the full national audit report, please visit: **www.rcplondon.ac.uk/eolca**.

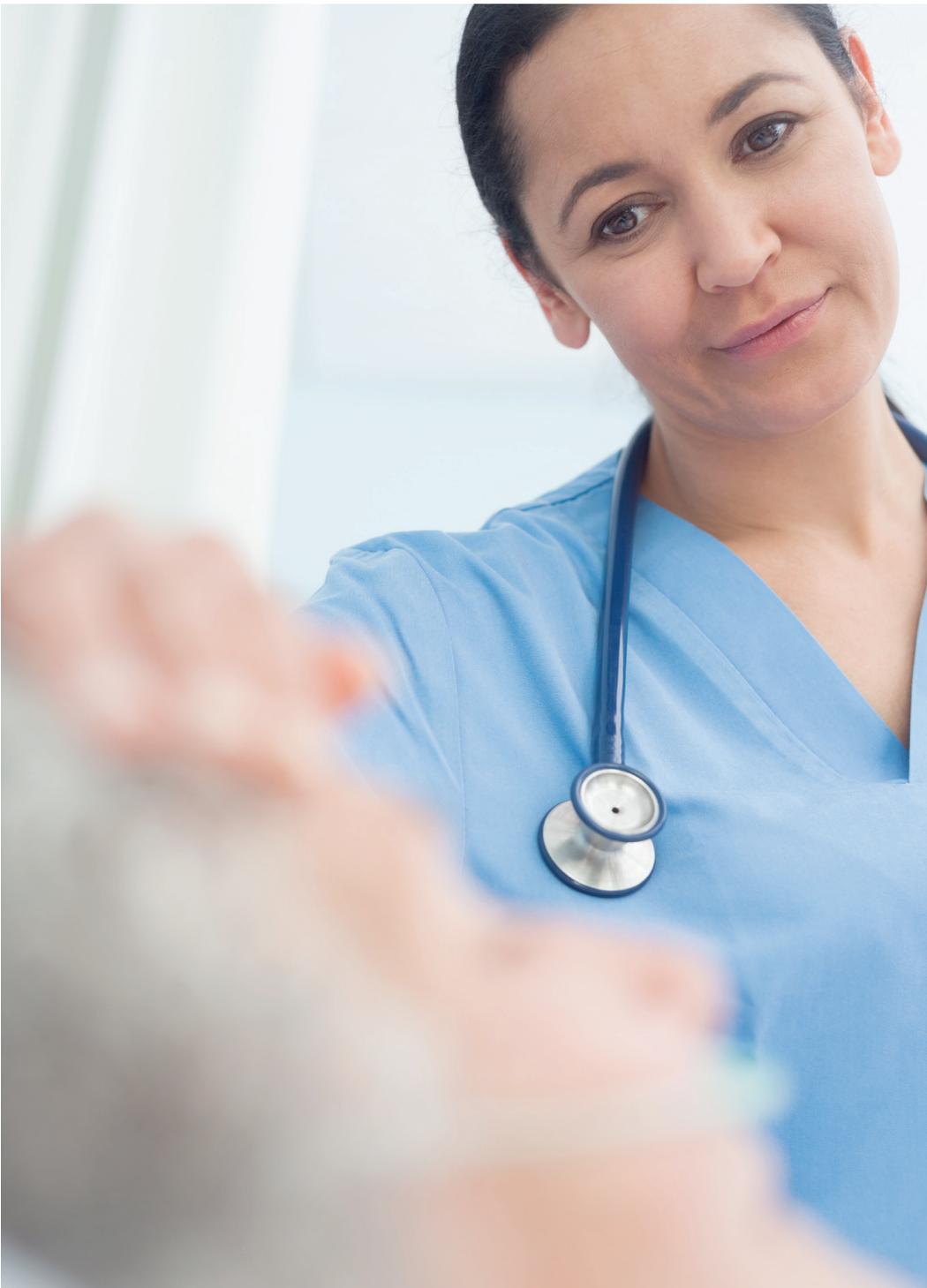
Each participating hospital site is also provided with an individualised report, which describes their performance and compares this to the overall national picture.

Please note: doctors and nurses looking after you in hospital will routinely record information on your care. This information is shared securely with the End of Life Care Audit – Dying in Hospital Team at the RCP for the purpose of carrying out the *End of Life Care Audit – Dying in Hospital*. The data shared and analysed is anonymous and it is not possible to identify individual patients from it.

What are the national guidelines for end-of-life care?

Since the 2015 *End of Life Care Audit – Dying in Hospital* took place, the National Institute for Health and Care Excellence (NICE) in partnership with the National Clinical Guideline Centre (NCGC), published a guideline on the care of dying adults in the last days of life. Find out more at www.nice.org.uk or www.ncgc.ac.uk.

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