Dignity on the Ward

Dying

A guide for hospital staff

In association with

Royal College of Nursing
Background to the project

This pocket guide was developed for Help the Aged by Sheila Payne, Katherine Froggatt and Jo Hockley as part of a project commissioned by the Help the Aged Dignity on the Ward campaign, which began in 1999.

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Contents

Introduction 3
Transitions into dying 4
Care of the dying 9
Death as a process 14
Working with dying people and their families 17
References 19
'I think my mum is dying, or it is the beginning of the end. My mum is 89. I just want her to have a quiet, peaceful, pain-free, dignified death – that’s what I want for my mum. They said there had been a very severe bleed and they were not expecting her to recover. It was handled very calmly and very sensitively.'

Daughter talking about her mother dying following a stroke
Introduction

Many older adults who are nearing the end of life die in hospital. Generally, hospital staff are rightly focused on ensuring that people are appropriately treated and their problems resolved so they can go home. However, most older people who do not get better will remain in the hospital until they die. This requires a different approach to care, which can be difficult to provide in the midst of other priorities. As a consequence, older adults and their families’ experiences of dying in hospital are often reported as being poor.

While many older patients receive good, sensitive care, and their families are well treated, reports of inadequate care with instances of over- and under-treatment, poor communication and experiences of unco-ordinated care are not uncommon. The quality of care given to a dying person in the last days of life matters a great deal, and there is only one opportunity to get it right.

This short guide offers an overview of the key issues that nursing staff and other members of the multi-disciplinary team need to consider when caring for older adults who die in hospital. Within this guide we:

- define the dying period for older people in hospitals
- offer information about the different ways in which older people die in hospital
- identify different aspects of care which need to be addressed to support older people and their families during the dying process
- offer practical suggestions on what to do before someone dies, as they die and in the period after a death
- acknowledge that you and your team are also affected by the death of patients and suggest ways to manage this.
Transitions into dying

Dying is not only a biological process wherein the human body ceases to function, but also a social process of letting go – by the dying person and family, and of the friends and staff around them too. Death in this part of the life cycle may be seen as ‘natural’ and some older people may be ‘ready’ to die. Every older person’s death will be different, reflecting who they are, their medical conditions, their social circumstances and family supports, and their values and preferences in terms of care. For the purposes of this booklet dying is defined as the time when people become aware of death as a possible outcome and the periods immediately before and after the physical death of an older person.

You may recognise some of the following common patterns of dying in older people:

- **sudden death** when a person dies without warning following an event such as a heart attack, a fall or stroke
- death following a terminal illness, where the death is usually anticipated: this may happen where people have been living with
conditions such as cancer or a neurological condition such as multiple sclerosis or motor-neurone disease;

- death following an **acute episode** such as a chest infection, stroke or exacerbation of a chronic condition such as heart failure, where it becomes apparent that the person will not recover and will die shortly

- **general deterioration** describes the condition of many older people who live with multiple illness conditions and gradually become frailer and less able to manage, with a need for greater support and care: this kind of dying can occur over a long period of time.

The exact way in which an individual dies is not always predictable, even in the light of the patterns described above. There are instances of unexpected deaths, of prolonged dying and of ‘bouncing back’. Older adults do die suddenly, sometimes naturally in their sleep. Prolonged dying lasts for a number of weeks, when the person seems to be in limbo between life and death. They continue to live even when all the signs indicate that they will die soon. In instances of ‘bouncing back’, an older adult is deemed to be dying, but then recovers. The sheer unpredictability of death can be difficult for the family members, and the staff, to whom you offer support.

**Recognising dying**

It is not always easy to know when a person is dying, particularly if they are frail and their condition is deteriorating slowly. Much research is being carried out on how to identify when someone is dying. Depending upon the medical condition(s) an older person has, there may be recognisable stages of severity that will tell you that they are moving into a dying phase.

- Changes in someone’s physical condition, such as:
  - increasing frailty and tiredness
- decreasing mobility and ability to carry out daily activities
- reduced appetite and thirst
- repeated infections.

(Care needs to be taken, as some of these indicators can also apply to treatable conditions.)

- Changes in their responses to the world around them as they withdraw socially and emotionally from family, friends and other people around them.
- You may also identify differing patterns of health service use among older people whom you encounter in different units and wards in the hospital, such as:
  - repeated hospital admissions
  - repeated treatments for infections, such as antibiotics for recurrent chest infections.

These may indicate altered health needs associated with underlying changes in the person’s physical condition, though they are not necessarily an indicator that the person is near death.

If you and your team know that an older person is dying and you can anticipate a person’s death, you should make sure that their current medications and care is reviewed more frequently than usual. You may also have time to prepare the person and their family members for what may lie ahead. Some older people may value the opportunity to be involved in discussions about death and dying, such as whether they want further antibiotics for chest infections or not. They may have spoken about their preferences for end-of-life care and/or written an advance statement of wishes and preferences (such a statement also known as a ‘living will’). Hospital staff need to be aware, in whichever country they work, of the laws governing how people can be helped to make their own decisions about their care, especially when issues of capacity are raised. (See resources section.)
Family members may value knowing about the anticipated death so that things can be prepared in advance. For staff, too, this provides an opportunity to give appropriate end-of-life care that meets the person’s needs.

Remember, if the older person recovers, it is better to have begun preparations for death rather than to have assumed that they will get better.

Key points

- Older people who die in hospital do so in various ways.
- Preparation for dying allows older people and their families to express their wishes and preferences.
- Often there are times of uncertainty about exactly when someone is dying.
- Recognising that an older person is nearing the end of life is not easy but will be helpful in planning their care.
- Family members are likely to look to staff as an authority on the dying process, care options and healthcare needs. It is important that staff are prepared for this role.

Nurses and other staff can provide information about the likely course of dying and indicate the types of care options available to the older person and family members. These options will depend upon what is locally available.
Care of the dying

This section describes key principles for giving maximum comfort and care to an older person dying on your ward, as well as care for their family. A useful document, the Liverpool Care Pathway for the Dying, can help guide and record the care given in the last days of life; it can also encourage a greater openness and involvement with families, as well as encouraging greater cohesion and continuity within your ward team.

What to expect when someone is about to die

When an older person’s death is imminent, three distinct stages can be observed:

- **Peripheral shutdown** This happens when the feet and legs, hands and nose feel cold to the touch and skin appears mottled. The person is semi-conscious, but will still be able to hear you and communicate.

- **Central system shutdown** This occurs when the breathing becomes laboured (known as Cheyne-Stokes respiration). It is followed by a thin and ‘thready’ pulse, at which point it is likely that the person has only hours to live.

- **Point of death** At this point the person remains unconscious and takes their final breaths, which are like gasps. At the same time the face muscles may twitch and the back may arch. Most families find it comforting to have a member of staff with them at this time.

On your ward, however busy it is, you and other nurses need to try to create an atmosphere which is calm, respectful of the dying person and offers dignity. This can be achieved in many ways and does not require special facilities – just an effort to create personal space and give attention to the comfort of the dying person and their family.
Comfort care

The comfort of the older person who is dying should be paramount. They are likely to be very weak and require you to help them turn regularly in order to relieve any stiffness that can occur from lying in one position. Pressure points, especially on the outer edge of the ear and ankles, may occur even if an airflow mattress is used; gentle massage of these areas as well as other pressure points will help to restore the flow of blood to tissues and prevent tissue breakdown. Some people can be very hot and require regular changing of the sheets and pillowcases along with tepid bathing to relieve discomfort.

You will find that the mouth of a dying person will inevitably be dry, but it should not be dirty or sore. Thirst receptors are thought to be inactivated in very old people dying naturally, so in most situations giving additional fluids, other than what the dying older person desires, is not appropriate. While he or she may be unable to drink, you may find that the dying person can still manage to suck from a piece of sponge or gauze containing crushed ice.

Besides good comfort care, regular attention needs to be given to three common symptoms that occur in the last days of life. In frail older people these are:

- **restlessness/anxiety** Restlessness may be due to a full bladder or problems with bowels – check for urine retention and constipation. More significant anxiety needs diagnosis and management: for example, distress may be caused by a sudden discontinuation of an anti-psychotic or anti-depressant drug.

- **pain** Dying itself is not physically painful, but if a person has previously required regular painkillers these analgesics must be continued via an appropriate route. Caution needs to be taken when giving an opioid for the first time; dying older people are often dehydrated and hallucinations or skin irritation can be precipitated by opioids, especially in advanced dementia. Small ‘prn’ doses of
subcutaneous morphine/diamorphine may be sufficient. Fentanyl patches should be avoided if no previous analgesics have been required.

- **chest secretions** A ‘rattly’ chest is common in the last days of life. In older people this is often due to pneumonia. Changing the position and lying the dying person flatter by removing some of the pillows may help, especially if medication to dry secretions has been ineffective.

Appropriate medication to control these symptoms should be prescribed, on an ‘if required’ basis, in advance of symptoms occurring, so that there is minimal delay in treatment of symptoms. You may want to talk to the doctor on your ward about such prescriptions.

**Psychological and emotional care**

Most frail older people are very aware when they are near death. For the majority this is welcomed and they may want to talk about it. In such circumstances it is often the staff who need the courage not to cut short these conversations. A few people will be frightened; the challenge then is for you to try to help the person express their fears. Some people fear that they may ‘wake up’ in the mortuary, so it is very important to reassure them that nurses and doctors know how to verify that someone has died.

When dying, some older people appear to see people who have already died standing at the bottom of their bed or up in the corner of the ceiling; they often name them quite spontaneously. This is not confusion. The dying person is rarely distressed by it and families can feel comforted.

**Social care**

During the dying phase the person may pay less attention to things around them. However, family, grandchildren and very close friends remain important. Relatives must be made aware that a loved one is
dying, so that the opportunity is given to say ‘goodbye’. Some families feel awkward, and do not know what to say or do during the visit. Sitting and chatting with them at the bedside, giving them permission to just sit and read a newspaper, or listen to the radio or television while holding their loved one’s hand may enable them to visit for longer. It has even been observed that a dying person will sometimes wait for the arrival of a specific person before ‘letting go’. A time of waiting can be difficult for everyone, including the family, especially if goodbyes have been said and death is expected imminently. However, such a time can be used to involve and get to know the family and to remember together times and significant events of the past.

If an older person does not have any family or friends available, nurses can provide reassurance and support by remaining near them, using touch, such as stroking or holding their hand, even when they appear to be unconscious.
Spiritual care

Journeying with the dying person by making yourself available to sit with them is part of the spirituality of caring. Taking time to read from a favourite book or religious text, playing music that you know they would like to listen to, or just sitting quietly holding their hand are especially important when family are not present.

Spiritual care may require attention to religious needs and rituals. People will not be offended if you ask them what they would like to do and it is better to check than to make assumptions. For people who have had a strong religious faith, albeit sometimes earlier in their lifetime, it is important always to ask them or their family if they would like a priest/minister, imam, rabbi, Brahmin or other faith workers to visit. Occasionally there may be ‘unfinished business’ that can prolong the dying period if it is not addressed (see above box).

Sometimes a dying person needs ‘permission to go’. They may need to hear that the family or a loved one is OK and will be able to cope. A visit by a faith worker or chaplain can provide this permission but it can also be given by a member of staff or a family member.

Miss P. was a 71-year-old who had been resident in a care home for three years. She had been estranged from her sister who was married and lived in Australia. Her sister’s husband visited Miss P. in May when he was over on business after learning she had only a few months’ to live. Miss P. was told that her sister would visit in October. By August Miss P. was dying. Miss P. hung on until mid-November but the sister never came. Finally, after receiving spiritual care in the form of prayers for forgiveness, Miss P. died two days later.
Death as a process

‘Death must simply become the discreet but dignified exit of a peaceful person from a helpful society ... without pain or suffering and ultimately without fear.’

(Aries 1981: 614)

This section describes how nurses are involved in the final care of the dead person’s body and considers the impact that death has on nurses and the older person’s family. We all have feelings of sadness, and sometimes of shock, when a person has died, however expected that death may be. The death may trigger strong emotions and memories. It may also be the first time that a care assistant or junior nurse has seen a person die, and it is as well to recognise that they may need support too.

Key points

- Be prepared to use the word ‘dying’ with family/relatives instead of euphemisms such as ‘more poorly’ or ‘deteriorating’.
- Be prepared to allow the dying person to speak to you about death and dying.
- Recognise imminent dying and inform family and friends.
- If possible, talk to the older person about any faith/religious requirements they have. If this is not possible, speak to the family or friends.
Following a death, it is often the nurses’ job to lay out the body. Most hospitals have procedure manuals that specify what needs to be done. The aim is to continue to care for the dead person with respect – cleaning them, removing any medical equipment, arranging their hair, dressing them in clean clothes and providing fresh bed linen, to create a dignified appearance for the deceased person and a sense of care and serenity. You should ask if families want to help you with the laying-out. It should not be rushed. After a period the body will be removed from the ward to the mortuary. It is helpful to explain to other patients what is happening, rather than assume that they will not notice.

Some practical guidance on what to do to help family members immediately after a death follows.

**Suggestions for supporting people immediately after a death**

- Help the family to realise that the person has died. It may not be obvious to them. Tell them in a gentle and quiet way, in a private place.

- There are no ‘right’ words to say immediately after a death, but having the time and ability to listen to whatever the newly bereaved person may wish to talk about is generally valued.

- Recognise that those who are bereaved may express powerful emotions such as anger, anguish and distress – or no apparent emotions at all. Do not assume that people are unmoved just because they do not display emotions.

- Obtain medical confirmation and certification of death as soon as possible.
If a close family member was not present at the death, ask them if they wish to see the deceased person. Offer to accompany them to the room, if the dead person is still on the ward, or to view the body elsewhere.

Warn them what their dead relative may look like, especially if they have visible injuries, bandages, etc. Explain why they may look pale, or their skin looks mottled. Many people have never seen a dead person and may be fearful.

Offer to remain with them until they feel comfortable in the presence of the deceased person, and then offer to withdraw.

Make it clear that they can touch the deceased person, kiss and caress them, and talk to them if they wish. Warn them that the deceased may feel cold if it is some time since they died.

Allow the relative as much time as they wish to remain with the body. Do not appear to be rushing them to leave.

Enable family members to take mementos of the deceased, such as a lock of hair.

Ask if family members wish to have a faith worker to pray with them or perform religious rituals.

Enable family members to perform any cultural or religious practices that are meaningful for them.

Help family members to leave the hospital when they are ready. Ensure that they are able to get home, assist with arranging transport, and, if they wish, offer to contact friends or other family members who are able to offer support.
- Provide written information about procedures such as the collection of the deceased’s property, and how to register the death and arrange a funeral.

- If there is to be a post-mortem examination and if body parts need to be removed for examination, request permission and obtain written consent. Make clear the reasons for any legal procedures (such as an inquest).

- In certain circumstances, enable family members to consider organ and tissue donation.

- Provide family members with a contact telephone number in case they have questions they may wish to ask at a later date about the care of their loved one prior to or at the time of death.

- Offer information and contact details relating to bereavement support such as Cruse or local organisations.

(adapted from Payne, in press)

**Working with dying people and their families**

Nurses and other team members may find working with older people who are dying and their families both deeply satisfying but also very challenging and difficult. This is especially so if nurses have formed close long-term relationships with them during repeated or lengthy hospital admissions. Loss of a loved one triggers painful memories and experiences for many of us, especially if a particular death resonates with our own lives. Your ward manager should acknowledge the impact of older people’s deaths on nurses and other team members.
There may be very difficult deaths that are traumatic, unexpected or ‘messy’ which leave nurses feeling powerless and dissatisfied. In such circumstances, it may be helpful to discuss them in a ward meeting to understand more about what happened and why, but it is important not to blame individuals or scapegoat others. This meeting may provide an opportunity to learn more about end-of-life care, perhaps by inviting a specialist nurse, social worker or doctor to help develop your knowledge and skills.

There are other things that you and the team can do to take care of yourselves and each other, including:

- enabling one or two members of the nursing team to attend the funeral, if the family agrees
- attending a memorial event in the hospital, once or twice a year, to commemorate those who have died
- inviting families to the memorial event, which may help to show that most people find themselves able to cope with bereavement, even though it may be difficult at first.

**Key points**

- Engaging with dying older people is emotionally challenging and requires both the warmth of human understanding and an ability to stand back and observe clear boundaries.

- Nurses and other staff need to be aware of their own needs to grieve for older people with whom they have formed relationships.

- There are opportunities for improving clinical practice by learning from each death.
References


Resources


Mental capacity legislation and guidance

*England and Wales*

Mental Capacity Act (2005) and Code of Practice

*Scotland*

Adults with Incapacity (Scotland) Act 2000
http://www.publicguardian-scotland.gov.uk/awi/index.asp

*Northern Ireland*

No equivalent law exists

Liverpool Care Pathway
http://www.mcpcil.org.uk/liverpool care pathway
As part of its Dignity on the Ward campaign, Help the Aged commissioned a series of pocket guides that began with *Working with Hospital Patients with Dementia or Confusion*. Other titles in the series include *Promoting Dignity in Hospital, Bereavement and Loss, Pain and Older People* and *Working with Older People from Ethnic Minorities*, as well as this title, *Dying*.

We hope that this guide will help hospital staff to understand better the needs of vulnerable older patients and their families and perhaps to appreciate more fully the importance of taking a person-centred approach.