Aims and intended learning outcomes

This article aims to provide the reader with an understanding of the issues related to the care in nursing and residential homes of people who are dying. Its aim is to help you understand the complex and inter-related needs of people dying in nursing homes, as well as those of their families and carers. After reading this article you should be able to:

- explain the need for good communication in all aspects of caring for dying people
- understand the concept of a palliative care approach
- define the resources available for coping with adverse symptoms
- explore methods of providing emotional support for the dying person and their family, and for staff and other residents.

Introduction

Caring for dying people is not the primary purpose of most nursing homes and yet it is estimated that 32,000 people in England and Wales will die in nursing homes each year (Sidell et al 2000). Most nurses would like to ensure that every person dies, as far as is possible, in the way that they would choose. Orchestrating a good death amid the bustle of everyday life in a nursing home is a challenge that requires a variety of skills. This article is designed to help nurses consider the range of skills and knowledge they need to help their residents towards a good death.

You may have pictured some of the things you would like for yourself or your loved ones. A person, perhaps, who is resting comfortably without pain or distress and at peace with themselves. They may have friends close by and be listening to their favourite music. What we might want may be similar to what others want, but it might also be very different. To be able to come as close as possible to meeting residents’ needs, it is important for nurses to have not only specialist knowledge and skills but also an understanding of their own emotional needs.

Nurses often see lack of time as the greatest barrier to caring for dying people. In fact, good care need not be time-consuming. It is more about knowing where to seek guidance and being prepared to make an emotional commitment.

The first factor you may have considered is providing a pain-free death, especially for those suffering from cancer. You probably also noted spiritual and psychosocial care as well as support for grieving relatives as important components of the work.

The hospice movement has received world-wide acclaim for palliative care, which is defined as the ‘active, total care of patients whose disease is not responsive to curative treatment’ (WHO 1990). However, this specialist care has been aimed predominantly at people with cancer, and the hospice movement itself can only give direct help to a small proportion of those who have a terminal illness. The most common cause of death is actually disease of a cardiovascular origin. People with such conditions may suffer a variety of unpleasant symptoms (Seale 2000), but are unlikely to have the benefit of hospice care (Box 1 overleaf). One of the reasons for this is that the course of the disease is often slow and hard to predict so it is difficult to determine the point at which people can be said to be dying and therefore in need of palliative care.

The challenge now is for nurses who care for dying people in any environment to learn how to adapt the skills and ideals of palliative care into an approach that embraces a broader spectrum of people dying from a life-limiting disease. The palliative care approach has been described by the National Council for Hospice and Specialist Palliative Care Services as aiming to pro-

in brief

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Summary
Nurses who are confident in their own skills but who know where to draw upon specialist help can provide enormous support for nursing home residents coming to the end of their lives. Promoting a palliative care approach can promote a sense of well-being in older people who are dying.

Keywords
- death
- nursing homes
- terminal care

These key words are based on the subject headings from the British Nursing Index. This article has been subject to double-blind review.
Box 1 Symptoms suffered by patients with different diseases (%)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Cancer</th>
<th>Heart Disease</th>
<th>Stroke</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>88</td>
<td>60</td>
<td>66</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>54</td>
<td>77</td>
<td>37</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>59</td>
<td>32</td>
<td>23</td>
</tr>
<tr>
<td>Difficulty in swallowing</td>
<td>41</td>
<td>16</td>
<td>23</td>
</tr>
<tr>
<td>Constipation</td>
<td>63</td>
<td>38</td>
<td>45</td>
</tr>
<tr>
<td>Mental confusion</td>
<td>41</td>
<td>32</td>
<td>50</td>
</tr>
<tr>
<td>Pressure sores</td>
<td>28</td>
<td>11</td>
<td>20</td>
</tr>
<tr>
<td>Urinary incontinence</td>
<td>40</td>
<td>30</td>
<td>56</td>
</tr>
<tr>
<td>Bowel incontinence</td>
<td>32</td>
<td>17</td>
<td>37</td>
</tr>
<tr>
<td>N =</td>
<td>2063</td>
<td>683</td>
<td>229</td>
</tr>
</tbody>
</table>

Palliative care is about living as much as it is about dying. Where the underlying disease cannot be cured, enhancement of life becomes the most important issue and it is on this that the palliative care approach focuses, promoting an ethos of well-being throughout old age (Lloyd 2000).

Nursing home staff can move towards a palliative care approach by considering the following issues:

- developing an ethos of care
- managing symptom control
- attending to the spiritual needs of the dying person
- offering caring and informative communication to residents and families
- attending to the needs of family and friends
- attending to the needs of other residents
- attending to the needs of other staff.

Symptom control

People who are dying, whatever the cause, can experience a range of unpleasant symptoms. These can include pain, nausea, constipation, agitation, insomnia, oral thrush and breathlessness. Nobody can be an expert in everything and nursing home nurses cannot be expected to know the answer to every question about symptom control. What they do need to know is where they can find the answer.

TIME OUT 3

Think of some of the residents you have been nursing for some time but who are still relatively fit. Do you know how they feel about dying? Do they have any particular hopes or fears? What arrangements have they made in preparation for their death?

TIME OUT 4

Make a list of the people you might approach for specific treatment or advice.
CONTINUING PROFESSIONAL DEVELOPMENT

palliative care

You might have considered approaching your local hospice. Hospices tend to be associated with cancer but the palliative care they provide is aimed at reducing unpleasant symptoms in all dying people. Many hospices have a remit to support dying people in any setting, so it is worth approaching your local one to see whether they would be willing to offer specialist advice if you are having difficulties in controlling symptoms. Avis et al (1999) found that ‘many nursing homes believed they could not access NHS services’. In fact residents have as much right to the full range of services as anyone else. It might be helpful to keep a resource book with useful contact names and addresses such as the Macmillan service, the local hospice and social workers who can advise you on different aspects of care. Some useful practical books on symptom control and management of the dying person might also be helpful and suggested reading is listed at the end of this article. Remember, too, that many symptoms can be treated with drugs prescribed by the general practitioner.

It is not possible to explore here all or any aspects of symptom control in any depth but with good nursing care, grounded in up-to-date practice, most symptoms can be managed well in a nursing home environment. Below is a brief insight into two important areas of care relevant to people who are dying: pain control and breathlessness.

TIME OUT 5

Everybody knows that pain is a central feature for many people suffering from cancer but how much would you think it figures in the last year of life for those dying from stroke or heart disease?

Look again at the figures in Box 1. Pain comes high on the list for adverse symptoms for all three of the major causes of death. Lynn et al (2000) suggest that pain should be seen as a fifth vital sign. They suggest its measurement in nursing homes should be as automatic as taking a temperature, pulse, respiration and blood pressure on an acute ward. It is important therefore to assess and monitor pain regularly and seek appropriate analgesics early. Doctors and nurses who are not trained in a palliative care approach may be anxious about giving opioids, but good pain control may actually extend life (Lynn et al 2000). The World Health Organization (WHO 1990) advocates the use of a three-step approach to analgesic control of pain known as the analgesic ladder (Box 2).

Identify pain early; give analgesics regularly and do not wait until the patient is experiencing pain; do not be afraid to move up the ladder if the painkillers are ineffective. Opioids are safe effective and reliable (Faull et al 1998).

Remember that pain is much more than a physical symptom. The total concept of pain includes psychological factors, such as fear, loneliness or lack of information, social factors, such as worries over money and poor access to family, and spiritual factors – perhaps a lack of attendance to religious needs or more secular issues such as lost hope. Failure to address these will minimise the effectiveness of good pain relief (Faull et al 1998).

Another distressing symptom is terminal breathlessness and the fear of suffocation. Breathlessness in all residents needs to be investigated and treated accordingly. However, at the terminal stage of the illness it can induce great fear and panic and this can be avoided in most cases. Faull et al (1998) argue that:

- no patient should die with distressing breathlessness
- failure to control is a failure to utilise drug therapy correctly
- an opioid should be combined with a drug to reduce anxiety
- if the patient becomes agitated or confused haloperidol or methotrimeprazine should be added.

It is important to anticipate the possibility of breathlessness so seek advice and ensure drugs are prescribed early. In addition, the presence of a calm and supportive nurse can help ease the patient’s distress. It is also important that relatives are supported and fully understand how you are trying to manage the symptoms the resident is experiencing.

With both pain and breathlessness, sleep can bring much comfort to the resident. Insomnia is distressing and can be easily overlooked, especially in those who are already taking opioids. Therefore, residents who find it difficult to sleep need the care of a supportive nurse and require treatment, in addition to that for other symptoms, with hypnotics such as temazepam.

Spiritual needs of the dying person

Spirituality is about finding meaning, purpose, direction and connection in life (Wright 2000). For some this need can be met through their religion. Helping

Box 2 The analgesic ladder

- **Step 1 Mild pain**
  A simple non-opioid analgesic such as paracetamol. If this does not relieve pain move to step 2. Do not persevere with other simple pain-killers.

- **Step 2 Moderate pain**
  Use a weak opioid such as dihydrocodeine, or a combination such as paracetamol and codeine or paracetamol and dextropropoxyphene.

- **Step 3 Moderate to severe pain**
  Morphine is the strong opioid of choice. Fentanyl may be given transdermally, especially to patients who have difficulty swallowing.
people worship according to their faith has long been regarded as an essential nursing role and this is never more important than when caring for somebody who is dying. Even people who belong to the same religion will have very different ways of observing their faith so care plans should contain individual details of people and practices that might enhance spiritual strength.

Spirituality is no less important for those who are of no particular religious persuasion. They may gain strength from being able to give and receive love, or from music or possessions that have particular meaning for them. You may never be able to get it exactly right but, by learning as much as possible about the dying patient, you can always try.

**TIME OUT 6**

Make a list of the sorts of things that might help a resident find meaning, purpose, direction and connection in life. You may wish to think of religious and non-religious factors.

**Communication**

Communication is a basic human need and, perhaps because it comes so naturally to us in everyday life, it is easy to lose sight of its importance. Being prepared to listen to the hopes and fears surrounding death and beyond can help people find meaning in their lives. Sometimes blocking techniques are used to distance any meaningful discussion and comments such as ‘Don’t talk like that’ or ‘You have plenty of life in you yet’ deny the opportunity for people to express their feelings.

**TIME OUT 7**

Try to think of times when you have observed or perhaps used blocking techniques yourself. What words could have been used to help the resident to share their feelings?

Whatever answer you gave is probably right. There is no special formula for talking to dying people, only a willingness to engage with them. It is much more important to listen than to try to find easy answers where there are none. Just being with residents and letting them talk can be enormously helpful. Reflecting on what you have done well and what you could have done differently can help you gain confidence in your own skills.

Appropriate and timely touch can be a form of communication that can help give a sense of belonging and validate the self worth of people. Massage is one way of being with a resident and offering warm and reassuring touch. While deep massage and other therapies such as aromatherapy should only be undertaken by a competent practitioner, a gentle hand or foot massage can easily be performed by either staff or family. A simple oil such as grapeseed, available from any supermarket, can be used. First, check whether the resident would like a massage, then make sure you are both comfortable and gently massage the oil into the hand or foot. Do not apply any pressure, especially to weak skin. Let your own instinct direct your hands.

**The needs of other residents**

Developing a philosophy of care that embraces the needs of all those living in a nursing home is no easy matter. The nurse must aim to co-ordinate the needs of those looking for a home for their remaining years, those needing rehabilitation after illness and those who have reached the end of their lives.

**TIME OUT 8**

Try to think about how it might feel to live in a home in which death is a frequent event. What information might you want about somebody who is dying or who has died?

Most nurses try to stop the presence of death intruding on the lives of other residents. To some extent this is probably a good decision but it may be better not to hide totally the events or emotions surrounding death. Sander (1997) found that residents felt too excluded from the deaths of fellow residents. Where the person who had died had lived for some time in the home they wanted to be as fully involved as any other close friend. They also wanted the death to be marked by putting a rose in the garden of remembrance. Although this proved impractical in the long term, other ways of remembering those who had died in the home were found. What the residents were saying to their carers was that they all knew that their own deaths might not be far away. They wanted not just to mourn their friend but also to know that their death, when the time came, would be seen as an event worth marking. Even when the person who has
died was admitted in their last stages of illness, other residents may take comfort from seeing some mark of respect in the face of death. The only way to know how your residents would like you to handle issues like this is to ask them.

The needs of staff
Hospice managers know well how emotionally draining it can be to invest energy in caring for dying people. Nursing homes rarely have the resources to provide formal psychological support so staff need to care for themselves and their colleagues. There are several points you should consider:

- if you have tried to get it right don’t be hard on yourself if not everything goes as you would have wished it
- don’t be surprised if some deaths affect you more than others. We all bring our past joys and traumas with us and can never predict how events will trigger our emotions
- find a method of making sure that all staff know when somebody has died. Some homes pin a photograph on the notice board or put a ribbon on the door
- provide a safe opportunity for staff to discuss their feelings. Colleagues should not judge or criticise each other but should try to be supportive
- don’t be afraid to share a joke. Humour can be a good way to relieve tension.

Everybody will have a different reaction to a death. Inexperienced staff may need support in seeing the body and coming to terms with a new resident coming to take the place of the deceased. Senior staff, too, may be touched by a death. They may find it particularly difficult to ask for support so it is important that staff develop a culture of caring for each other.

The needs of family and friends
While most attention is focused on the resident it is easy to forget the needs of family and friends. For many of them there is a sense of loss of control and an uncertainty about what the future holds. For many there may also be a sense of guilt that they are unable to manage the last months, weeks and days of their relative’s life. Often these fears and anxieties go unex-pressed so it is important to be clued into the visiting relative’s unspoken voice. Try and pay attention to what they say and what they do not say, listen to their tone of voice and watch their non-verbal mannerisms; note any change to their visiting routines. All these can give clues to the needs of the visiting relative. Above all try to give them time to talk and to be listened to. It is not necessary to have all the answers. Relatives do not expect you to have them but they do want to express their fears and anxieties to someone who has some understanding of the situation. It can be very helpful for some if they can be involved in the care – perhaps helping with a bath, feeding or giving a simple hand massage.

Conclusion
Nursing homes that embrace a palliative care approach can promote a sense of well-being in older people right to the very end of their lives. It may not be possible for all nurses to be experts in palliative care but it is still possible to make sure that your residents get good care. You need the confidence to develop your own skills but at the same time need to know what other expertise is available so that you can call for the help your resident needs. Hand in hand with the technical knowledge and skills goes the emotional work of caring for dying people. Getting involved is about accepting the pleasure and the pain. To be able to give your best you must not only look after your residents, but also care for your colleagues and yourself.

FURTHER READING
REFERENCE
### Box 1. Framework for reflection

1. What have I learnt from this article?
2. To what extent were the intended learning outcomes met?
3. What do I know, or can I do, now, that I did not/could not before reading the article?
4. What can I apply immediately to my practice or client/patient care?
5. Is there anything that I did not understand, need to explore or read about further, to clarify my understanding?
6. What else do I need to do/know to extend my professional development in this area?
7. How might I achieve the above needs? (It might be helpful to convert these to short/medium/long-term goals and draw up an action plan).

### Box 2. Examples of possible practice profile entries

**Example 1**
After reading a CPD article on ‘Communication skills’, Jenny, a practice nurse, reflects on her own communication skills and re-arranges her clinic room so that she will sit next to her patients when talking to them. She makes a conscious decision to pay attention to her own body language, posture and eye contact, and notices that communication with patients improves. This forms the basis of her practice profile.

**Example 2**
After reading a CPD article on ‘Wound care’, Amajit, a senior staff nurse on a surgical ward, approached the nurse manager about her concerns about wound infections on the ward. Following an audit which Amajit undertook, a protocol for dressing wounds was established which led to a reduction in wound infections in her ward and across the directorate. Amajit used this experience for her practice profile and is now taking part in a region-wide research project.

### What do I do now?

- Using the information in Box 1 to guide you, write a Practice Profile of between 750 and 1,000 words – ensuring that you have related it to the article that you have studied. See examples in Box 2.
- Write Practice Profile at the top of your entry, followed by your name, the title of the article which is *Care for dying people in nursing homes* and the article number, which is 854.
- Complete all of the requirements of the cut-out form and attach it securely to your practice profile. Failure to do so will mean that your practice profile cannot be considered for accreditation.
- RCN members are entitled to unlimited free entries. Using an A4 envelope, send for your free RCN assessment or enclose the fee (£15 for non-RCN members) to: RCN CPD articles, Royal College of Nursing, Freepost CF 3790, Cardiff CF23 8ZY by April 2002 (cheques payable to RCN). Please do not staple cheques to your practice profile and cut-out slip – paper-clips are recommended.
- You will be informed in writing of your result. Ten continuing education points are awarded for successful completion of this CPD article. You are entitled to one retake if you are unsuccessful.
- Feedback is not provided: notification of accreditation indicates that you have been successful.
- Keep a copy of your practice profile and add this to your professional profile – copies are not returned to you.
- Study the checklist (Box 3).