THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

Changing Gear

Guidelines for Managing the Last Days of Life in Adults

Reviewed and updated
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NCPC is an umbrella organisation for all those who are involved in providing, commissioning and using hospice and palliative care services in England, Wales and Northern Ireland. It promotes the extension and improvement of palliative care services regardless of diagnosis in all health and social care settings and across all sectors to government, national and local policy makers.

NCPC is a subscription based organisation that works with external partners in focused policy groups to produce practical policy guidance across the health and social care sectors. The organisation also runs regular national and regional events based on topics of national importance to palliative care, offering learning and networking opportunities for a broad range of delegates.

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Introduction

> “We cannot take away the whole hard thing that is happening, but we can help to bring the burden into manageable proportions” (Saunders, 1963)

These guidelines were originally developed by the Working Party on Clinical Guidelines chaired by Dr Derek Doyle, OBE which was convened by The National Council for Palliative Care in 1997. The original document was drafted by Dr Robert Dunlop, Medical Director, St. Christopher’s Hospice, London. Professor Irene Higginson from the Department of Palliative Care & Policy at King’s College School of Medicine & Dentistry and St Christopher’s Hospice, London, revised them in order to conform to the Clinical Outcomes Group (COG) Guidelines.

In 2006 the National Council for Palliative Care convened a further multidisciplinary working party to update the guidelines in line with recent evidence. Professor John Ellershaw, Director of the Marie Curie Palliative Care Institute at the University of Liverpool led this working party. The guidelines now include a section on the use of drugs in the last days of life. The title ‘Changing Gear’ refers to the care needed during the last days of life, care so distinct from the palliative care provided earlier in the patient’s condition that it resembles ‘a gear change’.

The guidelines have been designed for the use of health care professionals who are caring for dying patients in all settings including primary care, acute and community hospitals, care homes as well as in hospices. The principles apply to the care of people dying of both malignant and non-malignant conditions. Referral to specialist palliative care services is not always necessary but should always be considered based on the needs of the patient and referral is often made before the patient reaches the last days of life. This allows the patient and their family to establish relationships with the specialist palliative care team and enables everyone to prepare for the last days.

Care of the dying: the National Agenda

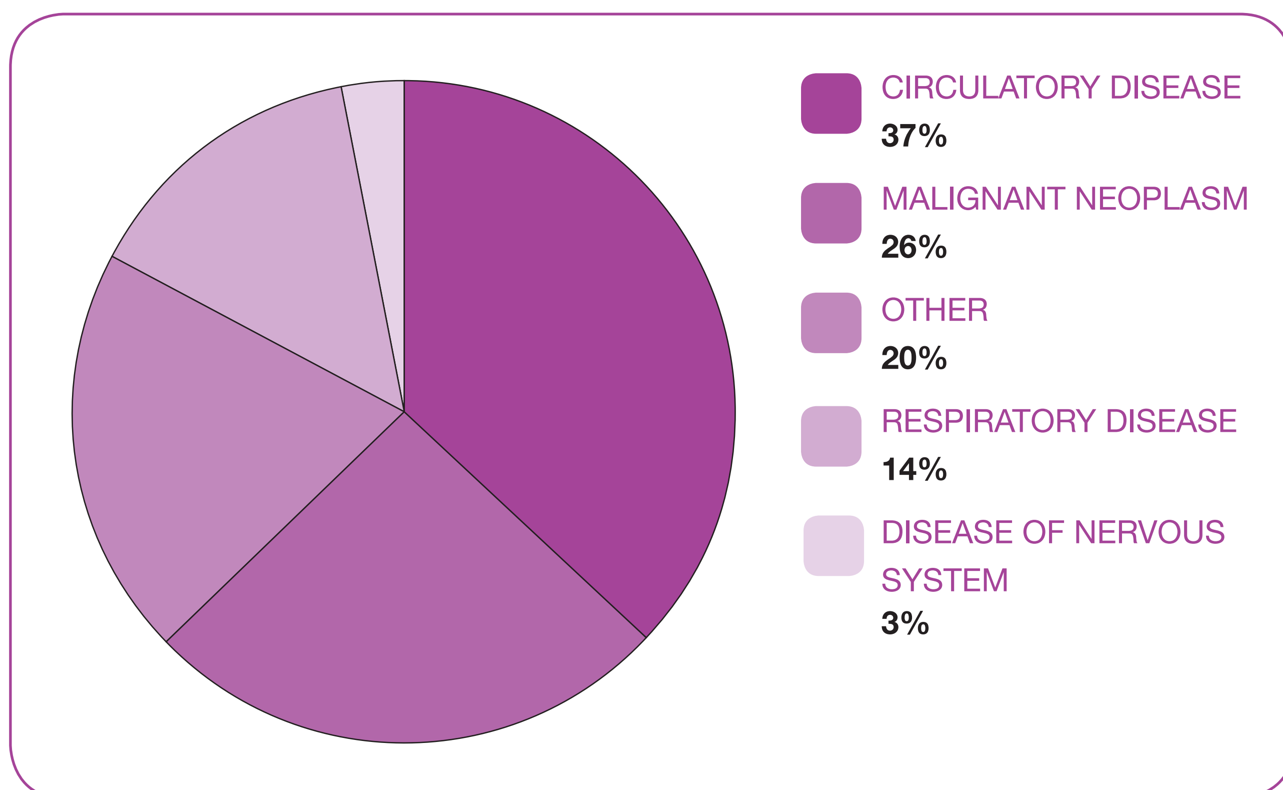
In 2004 in England and Wales there were 512,541 deaths from all causes. 26% of those people died from cancer (Office for National Statistics, 2006). One in three people will develop cancer during their life (The NHS Cancer Plan, 2000). Most healthcare professionals will be involved in the care of patients who are in the last days of life. For some professionals this will happen only occasionally.

Table 1 Causes of death in England 2004

Cause	%
Malignant Neoplasm	26%
Circulatory Disease	37%
Respiratory Disease	14%
Diseases of the Nervous System	3%
Other	20%

Source: Office for National Statistics

Figure 1



The NHS Cancer Plan promised an extra £50 million a year for investment in specialist palliative care services. Further priority was given to improving the availability of specialist palliative care and ensuring that patients are referred at the appropriate time during their cancer journey (The NHS Cancer Plan, 2000).

Building on the Best – (Choice, Responsiveness and Equity in the NHS) was published in 2003 and responded to a public wish to be more involved in making decisions about the care they receive and to have the information needed to enable them to make decisions about issues such as treatment and place of care. End of life care was highlighted in this document and the importance of choice for patients in the last days of life was discussed. Education for staff caring for patients in the last days of life in all care settings is key to facilitating choice and enabling people to be cared for in their preferred place (Department of Health, 2003).

The National Institute for Clinical Excellence (NICE) published their Guidance on Improving Supportive and Palliative Care for Adults with Cancer in March 2004. This document recognised the impact on the patient and their family of the diagnosis of cancer and the treatments that may be given. Guidance is provided on user involvement, co-ordination of care, information-giving, social and psychological support services and access to specialist palliative care services. The use of the end of life tools was highlighted (NICE, 2004). Much of the guidance is applicable to non-cancer patients and patients with life-limiting diseases can also benefit greatly from this approach to care. Examples of such life-

limiting diseases include end-stage heart failure, chronic respiratory disease, motor neurone disease, end-stage renal disease.

The NICE guidance discussed the importance of training and education for healthcare professionals to improve the confidence and competence of those caring for people with cancer, to increase patient and carer satisfaction with the care given and ensure that patients are referred to specialist palliative care services appropriately (NICE, 2004).

Our Health, Our Care, Our Say: a new direction for community services was published in 2006 by the Department of Health. This White Paper recognises the need for additional support and services to enable people to die at home if that is their preferred place of care. The need for further training for all staff to improve the care of the dying patient is again highlighted alongside the importance of using the end of life tools to facilitate good care (Department of Health, 2006).

The End of Life Care Programme, established in December 2004, works in partnership with health and social care organisations including primary care trusts, strategic health authorities and the Department of Health. The Programme aims to improve the care of patients in the last days of life and to enable staff in all care settings to provide good care for patients who are dying. The end of life care tools promote choice over place of care and death. They empower general healthcare professionals to provide good end of life care for their patients. Three tools are promoted to facilitate this care. They are the Preferred Place of Care document (PPC), Gold Standards Framework (GSF), and the Liverpool Care Pathway for the Dying Patient (LCP).

The End of Life Care Programme and NCPC offers specific advice on the care of patients in the last days of life who are in care homes (NCPC,2006). This is important as 1 in 5 of all deaths in England and Wales occur in care homes and this number is likely to increase as the population ages and there are more people living in single households who may require assistance as they become less well.

"Anticipated outcomes of the End of Life Care Programme

- Greater choice for patients in their place of care and place of death;
- Decrease in the number of emergency admissions for patients who have expressed a wish to die at home;
- Decrease in the number of patients transferred from a care home to district general hospital in last week of life;
- Generalists skilled in the use of the models of care tools to improve end of life care."

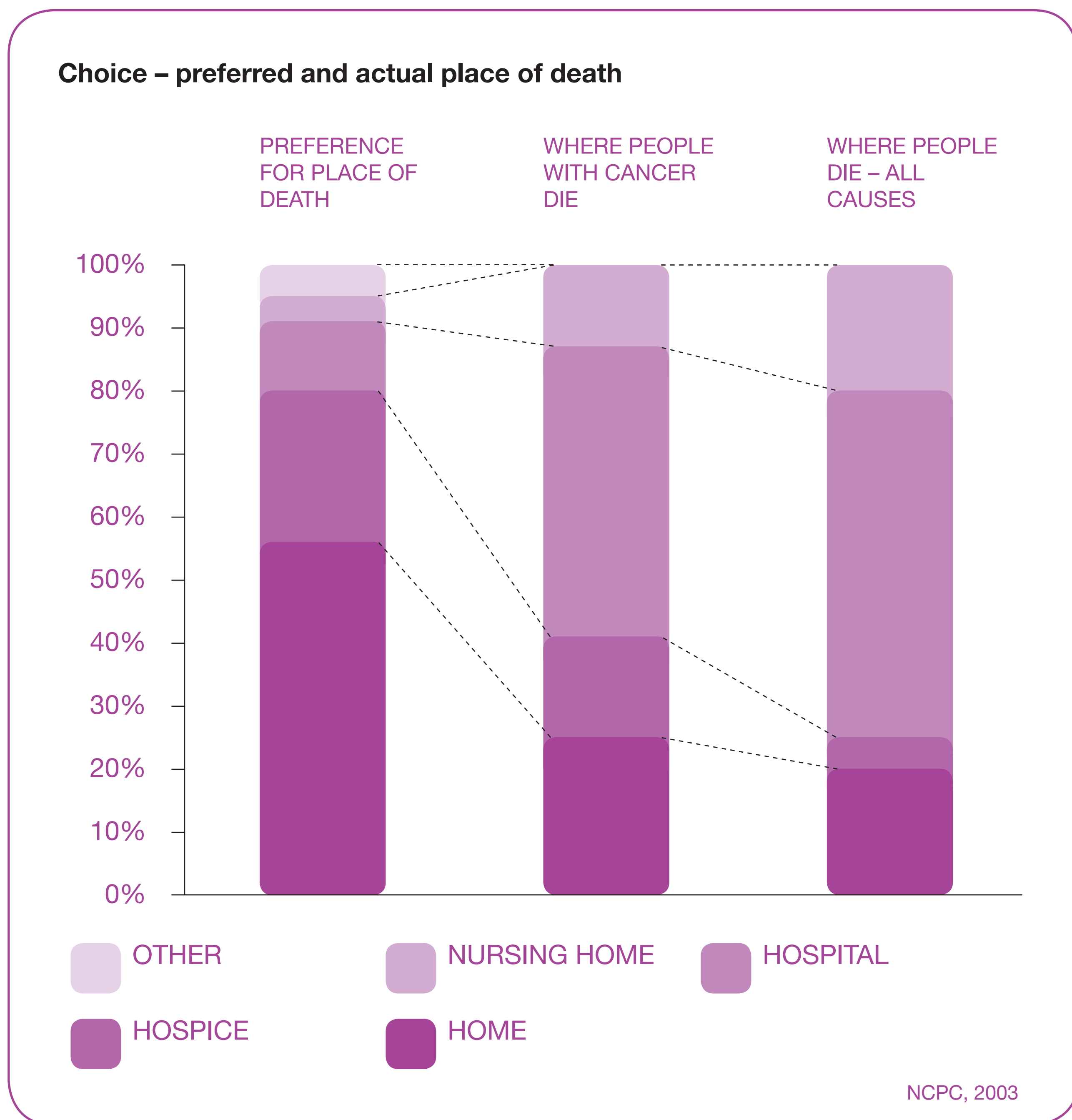
(End of Life Care Programme, 2006)

The Preferred Place of Care Plan is a document that recognises the importance of patient choice and the need for advanced planning to ensure the choice is respected as much as possible. It aims to prevent the emergency admission to hospital of those people who wish to die at home. It empowers patients and their

carers and allows them to express their wishes and be confident that these will be respected. The graph below shows the difference between patients' expressed preferred place of care and the actual place of death.

The Gold Standards Framework provides healthcare professionals working in primary care with a model to improve communication with the patient and their family and with other professionals involved in the patient's care. It facilitates care planning to avoid unwanted patient transfers and hospital admissions at the end of life. The needs and wishes of the patient are identified and this information is shared within the team. The Gold

Figure 2



Standards Framework can be particularly helpful in promoting advanced care planning for people in care homes thereby improving collaboration between the staff of the care homes and the primary healthcare team and helping to alleviate issues out of hours.

The Liverpool Care Pathway can be used in all care settings. It promotes best practice for end of life care and provides a means of documenting and auditing the care given to patients and their families at the end of life. The pathway addresses the patient's physical, social, psychological and spiritual needs.

Caring for patients who are in the last days of life has been given a high priority by several key national documents and initiatives. The guidance set out below outlines the areas of importance in providing this care.

The Last Days of Life

Despite the many advances in diagnosis and treatment, across the disease spectrum, patients still die. Unless death occurs suddenly or unexpectedly, the last days of life have recognisable features and require professionals to reappraise the use of treatments in order to achieve symptom control.

Dying is an important and individual event. Achieving good symptom control is essential. If patients do not have their symptoms controlled, their distress may escalate and can become extreme. Relatives are deeply affected as they cope with the prospect of losing someone they care about. The grieving process is more traumatic when the patient's physical distress is not relieved. The emotional impact of death continues long after the patient dies and causes an increased risk of morbidity and mortality during the bereavement phase.

The role of investigations and treatments changes as the patient becomes less well. The priority is to achieve control of any symptoms that may be causing the patient distress. This document provides guidance on recognising that a patient has reached the last days of life and how to manage the symptoms and other needs that may arise.

Aims of management

1. To ensure the patient remains the focus of all care
2. To enable healthcare professionals to recognise the dying phase
3. To recognise the need to assess the patient's physical, psychosocial and spiritual needs promptly
4. To relieve the patient's symptoms and fears
5. To provide support and encouragement for the family and carers of the dying patient
6. To enable people to die in the place of their choosing whenever possible
7. To provide ongoing support for the family after the death of the patient where needed.

Principles of Palliative Care

1. Patient and family participation
2. Collaborative multi-professional approach by health care professionals
3. Use of appropriate medications, tailored to each patient individually, given regularly to relieve and prevent symptoms
4. Continued regular assessment and support, with emergency back-up available 24 hours per day
5. Access and early referral to specialist palliative care services for patient and family support if needed.

Principles of Management

A. Recognise That Death is Approaching

It can be difficult to predict when death will occur. Low and deteriorating performance status is a predictor of short survival (Maltoni et al, 2005). Experienced nurses, who often see the patient more frequently than other health professionals, usually make realistic predictors.

Studies have found that dying patients will manifest some or all of the following:

- Profound weakness
  - usually bedbound
  - requiring assistance with all care
- Gaunt physical appearance, particularly with cancer unless steroids have been taken (i.e. cushingoid appearance)
- Drowsiness or reduced cognition
  - may be disoriented for time and place
  - extreme difficulty in concentrating
  - scarcely able to cooperate with carers
- Diminished intake of food and fluids
- Difficulty swallowing medications.

With cancer patients these signs usually develop over several weeks. A sudden deterioration over days should prompt a search for a potentially correctable cause such as infection, hypercalcaemia or a recent change in medication.

In some non-malignant diseases, such as heart failure and chronic respiratory disease, patients experience a less predictable illness trajectory. They are likely to experience episodes of acute deterioration on a background of slower decline. It can be more difficult to predict the course of the disease for these patients. The symptoms they are experiencing and any fears or concerns they may have should also be elicited and priority given to addressing them (Murray, 2005; Lynn, 1997).

Advance planning and an understanding of the patient's wishes are essential to their care.

B. Participation by Patient, Family and Friends

Many dying patients will be too ill to participate in decisions about treatment and care. The Mental Capacity Act 2005 will be implemented in England and Wales in 2007. It provides a framework to protect such vulnerable patients who are unable to make their own decisions. It enables patients to plan ahead for a time when they may lose capacity. Patients are now able to appoint someone who will make important decisions about their treatment and care on their behalf at the time when they lose capacity (Mental Capacity Act, 2005). The Independent Mental Capacity Advocate Service will support patients who are very vulnerable, for example, those with severe learning disabilities or dementia, and ensure their interests are protected. However, some patients will remain conscious until very near death. Their views and feelings should be sought. Since these patients are likely to be very weak, where possible, sufficient time should be allowed for clinical interviews and ongoing assessment.

The observations of the family about the patient's condition will become more important as the patient deteriorates. However, they may load their own fears and distress into their reports of the patient's condition. Health professionals should balance the relatives' views with their own observations of the patient.

The relatives should be given time whenever possible, usually on several occasions, to seek and be given information about the illness, to express fears and concerns for the future, and to learn about managing the care of the patient. This includes where the patient would prefer to be cared for. This takes time and needs advanced communication skills. Instructions about medications, contact numbers for emergencies, and the patient's preferred place of care should be written down and kept with the patient. This again highlights the need for advanced planning and the benefits of using end of life tools such as the Preferred Place of Care document and the Gold Standards Framework. Both facilitate information exchange for end of life care, particularly for out of hours services and can assist healthcare professionals who do not know the patient.

Families and carers may wish to participate in the physical care of the patient during the last days of life. This can be important in maintaining their role as carer. It may help them come to terms with the physical changes apparent in the patient. Some relatives wish to be involved in caring for the body after death. This wish should also be respected.

C. Collaborative Multi-professional Approach

Effective care in the last days of life requires a collaborative approach by several professions. The multidisciplinary team approach has been shown to be effective in improving the symptoms of advanced disease in different care settings (Hearn, 1998). A successful team requires open communication and this is a strong theme in each of the three tools recommended by the End of Life Care Programme. Team members also need to be aware of their own feelings about death and dying as these may influence the care they give.

Addressing the training and confidence of healthcare professionals in communication skills is vital. This need was highlighted in the Department of Health publication Our Health, Our Care, Our Say (2006).

"We will ensure all staff who work with people who are dying are properly trained to look after dying patients and their carers. This will mean extending the roll-out of tools such as the Gold Standards Framework and the Liverpool Care Pathway for the Dying to cover the whole country." (Department of Health, 2006)

In the Guidance on Supportive and Palliative Care (2004) NICE both recommends and is developing training to ensure –

'That all health and social care professionals should have the skills to communicate effectively with patients and carers. Those who must communicate particularly complex or distressing information should have enhanced skills or be supported by someone who has those skills'. (NICE, 2004)

Effective multi-professional working depends upon:

- recognising that the need of the patient and family are central
- raising the awareness and knowledge of general palliative care amongst all health & social care staff. An aim the End of Life Care Programme and The National Council for Palliative Care are addressing through their ongoing work
- good communication between professionals
- clear understanding and respect for the value and importance of other professions
- early referral to specialist palliative care services if needed.

The Role of the Specialist Palliative Care Service

Specialist palliative care teams have a role in ensuring the provision of good care for patients in the last days of life. They work alongside the main healthcare providers and offer support and advice. Patients may be referred to the specialist palliative care service at any stage in their disease journey, according to the needs of the individual, but occasionally this is only in the last stages of their life. The service can offer advice on the management of difficult symptoms and psychological and spiritual support for the patient and the carers. Specialist palliative care services are able to advise on the management of patients in all care settings.

Patients should be referred to specialist palliative care if symptoms are causing distress and are difficult to control.

Specialist palliative care services can make an important contribution when:

- one or more distressing symptoms prove difficult to control
- there is severe emotional distress associated with the patient's deterioration
- carers, particularly vulnerable ones such as dependent children and/or elderly relatives, are experiencing severe distress

D. Assessment of Patient's Needs

The condition of patients who are reaching the last stages of life can change very quickly. They require regular and frequent assessment of their needs. It is important to elicit the patient's concerns and priorities and to recognise that some patients will under-report difficulties. Non-verbal cues may indicate that the patient is experiencing pain or other distressing symptoms, for example grimacing may indicate pain.

Obtaining a symptom history

A full and detailed history may not be possible when patients are dying. Family members and professional carers can often provide very useful collateral information. It is important to recognise that their perception of symptoms may not be the same as the patient's experience. The relatives' own fears, concerns and experiences can affect their perception of difficulties faced by the patient.

The most commonly reported symptoms are:

- Pain
- Restlessness/ agitation
- Noisy breathing/ respiratory tract secretions
- Nausea/ vomiting
- Dyspnoea
- Confusion
- Urinary incontinence/ retention
- Dry/ sore mouth
- Extreme fatigue

A full pain history can guide the use of analgesia and help to achieve good symptom control. It is important to elicit information about the site and radiation, the nature of the pain, and its frequency and severity. This information should be documented and communicated with other members of the team caring for the patient.

Depression is an under-diagnosed problem in patients with advanced cancer and the impact of anxiety and depression on other symptoms, such as pain, can be significant (Lloyd-Williams, 2001). Depression is also a common symptom in patients with heart failure and is an adverse predictor of mortality (Barnes, 2006). When taking a symptom history the patients' hopes and fears should be explored. Previous experience of illness or death, concerns over treatments and drugs, and fears about the dying process may be shared. Unresolved anxiety and fear can worsen physical symptoms, including pain, and can cause considerable distress at the end of life.

Some patients may experience spiritual distress and ask questions about the meaning of their illness or ask "why me?" These conversations can be difficult and it may be helpful to involve the specialist palliative care service to help address and resolve this distress. The patient's dignity should be maintained throughout. Dignity is a very personal concern and means different things to different people.

A full family and social history helps ensure that the needs of the family are also being met. It may identify people who need particular assistance or more specialised input, for example young children.

Advice from specialist palliative care services should be sought when there are difficulties in assessing the symptoms and needs of patients and their families.

Examination of the patient

In patients who are very poorly and entering the last stages of life a full examination is rarely appropriate. Earlier in the disease pathway, examination will be guided by the details of the history. For example the examination may be useful in eliciting the cause of pain or nausea. Examination of the patient's mouth, pressure areas and general condition e.g. cachexia, cyanosis are important.

Investigations

These are rarely indicated at the end of life and should only be performed when there is reason to believe the patient has a reversible condition, for example hypercalcaemia, as the reason for their deterioration.

E. Treatment of Patients' Symptoms

The aim of all treatments at the end of life is to relieve any symptoms which are distressing for the patient and all therapies should be tailored to the needs of the individual patient. Pharmacological treatment is one of the most important aspects of therapy but simple non-pharmacological measures such as mouth care are also important. When medications are prescribed and administered appropriately during the last days of life side-effects are unusual. Concern over side-effects arising from the use of medications should prompt a referral to specialist palliative care services.

As they become more poorly, patients have increasing difficulty swallowing medications, even in liquid form. Medications will need to be given parenterally as the patient deteriorates. The subcutaneous route is recommended.

At this time most of the symptoms a patient is likely to experience can be controlled by subcutaneous injections of medication. If the patient requires frequent subcutaneous injections to ensure their symptoms are well controlled, a continuous subcutaneous infusion may be used. This is administered by a portable infusion device, most commonly a syringe driver. (For further details see section on the use of drugs at the end of life). Injections should not be given intramuscularly, particularly in cachectic patients. The rectal, buccal and sublingual routes are not usually appropriate.

The treatment plan should define what should be done in the event of a breakthrough of a symptom. The prescription chart should highlight the appropriate drug to be given if the patient experiences a worsening of any of their symptoms.

Reviewing drugs being taken

Only medications which will control or prevent distressing symptoms should be used at this time. As a general rule the drugs needed in the final days of life are one or more of the following:

- Analgesics – to relieve pain e.g. morphine
- Anxiolytics/sedatives – to relieve distress and breathlessness e.g. midazolam
- Anti-secretories – to relieve respiratory tract secretions e.g. hyoscine hydrobromide
- Anti-emetics – to relieve nausea and vomiting e.g. cyclizine

(For further details please refer to the section on the use of drugs at the end of life.)

Many medications which had been regarded as essential until this stage of the patient's illness can now be discontinued. Stopping treatments requires discussion with the patient (if appropriate) and their family. Some drugs require special consideration before discontinuing them as they can play a significant part in achieving symptom control.

Diuretics may need to be continued in patients with end-stage heart failure. The use of hypoglycaemic agents and anti-epileptics should be reviewed and alternative drugs prescribed in case of difficulties, for example seizures.

Steroids have many roles in palliative care including the treatment of neuropathic pain and the reduction of intracranial pressure. In the final days of life the use of steroids should be reviewed. Continuing steroids by the subcutaneous route may be helpful in maintaining symptom control, for example the headache associated with raised intracranial pressure, although

possible side effects such as restlessness and agitation should be monitored.

Referral should be made to the specialist palliative care service when there is uncertainty over the appropriate use of drugs in the last days of life, for example diuretics or steroids, or difficulty relieving the symptoms a patient is experiencing.

Emergencies

Emergencies in the final days of life are rare with the exception of haemorrhage and respiratory obstruction. These events may be fatal and the distress associated with them can be relieved with sedatives, such as midazolam. If a patient is felt to be at risk of such an acute event it is important to discuss this risk sensitively with the relatives and carers. They must have the information and resources needed to enable them to respond in the most appropriate manner should the emergency occur.

Dehydration

Most patients stop drinking in the final days of life. This is part of the normal dying process. The symptoms of thirst and dry mouth can be relieved with good oral hygiene. Rehydration with fluids is rarely indicated at the end of life and the use of fluids can cause peripheral oedema. An explanation that the reduced oral intake is a normal process can be reassuring for those involved in caring for the patient (Ellershaw, 2005 & Wright, 1997). Further guidance on this aspect is available from the National Council for Palliative Care.

Mouth care

In the final days of life the mouth can become dry and sore as a result of mouth breathing, limited oral intake and as a side effect of medication. The mouth can be kept clean and moist with foam stick applicators. Crushed ice can be sucked. Lips can be moistened. Relatives can be taught oral hygiene and this can help them to feel an ongoing involvement in the patient's care.

Nursing care

Basic nursing care should always continue. Careful positioning will avoid pressure sores and can minimise discomfort from stiff and uncomfortable joints, however at the end of life two-hourly turns are unnecessary. Pressure-relieving aids, for example mattresses, are still important. Relatives may be taught how to care for the patient's skin and how to perform gentle massage.

A urinary catheter may be useful to avoid moist skin or the distress associated with urinary retention. Routine bowel care is not indicated at the end of life. If there are distressing symptoms related to constipation or loose stools advice should be sought from specialist palliative care services.

Advice on the management of a patient in the last days of life can always be sought from specialist palliative care services.

F. Assessment of Relatives' Needs

Health professionals may struggle with the many competing needs of all those involved in the care of the dying patient. It is important to involve everyone in discussions about management changes and to keep carers and family members involved and informed as much as possible. The End of Life tools encourage and facilitate communication with relatives and carers and consideration of their needs. Relatives may be reluctant to make their own needs known for fear of upsetting or disturbing healthcare professionals. Nurses and doctors may avoid relatives because they feel unsure how to approach them or fear causing them more distress at a difficult time.

Communication with carers is vital at all stages of the patient journey, not least at the end of life. Relatives appreciate the chance to ask questions, be brought up to date, be advised what they might need to do and, importantly, to express their own feelings.

Physical symptoms

Fatigue is sometimes a symptom experienced by relatives. They may develop a physical illness which will emphasise the need for them to have assistance with the physical caring they are undertaking.

Psychological issues

Anxiety and depression may result from the impending death of the patient and can be exacerbated by the lack of information about the patient's condition and prognosis because of:

- relatives' reluctance to ask for information
- being anxious not to disturb the routine of doctors and nurses
- frequent changes in junior medical and nursing staff
- perceived lack of support from GP, nurses and the local community
- not being informed of all resources and help available to them

In particular relatives may have fears about:

- the patient's diminishing food and fluid intake
- the patient's distressing symptoms (confusion, cognitive failure, altered breathing)
- the patient falling or dying at home
- how the patient will die and, at home, how they will recognise it
- medications and whether, for example, morphine hastens death

The next-of-kin is not necessarily the only person who should be given information about the patient. Patients should routinely be asked if there is anyone else they would like to be kept informed, for example, partner or neighbour. In the last days of life it is important to consider those who are most important to the patient and who should be the first person contacted when the patient deteriorates further.

Social issues

Caring for dying people has profound effects on the carers and the structure and integrity of the family. Examples include:

- a sense of inadequacy when caring for the patient at home
- a sense of isolation and resentment if unable to leave the patient for a break
- exhaustion if overwhelmed by too many visitors
- loss of earning power with important financial implications
- disruption of family and marital relationships
- redefinition and redistribution of roles
- a need for practical assistance and guidance.

The needs of children and elderly dependants

Children are often considered too young to understand and the dependent elderly too fragile to be told.

Specialist palliative care teams often have the expertise to enable these conversations to happen. They can advise the generic healthcare provider. If further help is needed, it may be necessary to involve a social worker or appropriately qualified counsellor to help adults tell young children, and the frail dependent elderly, that the patient is going to die, to advise about them attending the funeral and how to support them in their grief.

G. Social and Psychological Support

Skilled communications lie at the heart of all palliative care, whether in the final days or much earlier. It is important in all settings, whether home, hospital, hospice or care home. It is essential to listen to what a patient and family are saying and to pick up cues. The following principles apply wherever the patient is being cared for:

- invite the patient and relatives to express their worries and misgivings
- correct fears based on misinformation or misinterpretation. Do not hesitate to ask "What are you most worried about and I will try to help you or explain it?"
- give honest interpretation and explanations of your findings (unless the patient indicates he/she does not want to be told) "Would you like me to explain what is happening so that it is a little less frightening?"
- be sensitive when the family seek to dictate what the patient is told but firmly resist requests to collude with the family
- ask relatives what cultural or religious observances they would like before and after the death. Do not assume you know what is wanted as patients from different religious backgrounds may vary in their practice and commitment

Avoid jargon and always, after any explanation, try to ascertain whether or not what was said was actually understood.

Encourage family and close friends to stay with the patient, even during procedures such as repositioning, washing, and the giving of injections, if they wish to. They

must never be made to feel they are disrupting the care routine of their loved one.

Encourage the family to participate in care if they wish to, teaching them such procedures as mouth care and assisting with washing.

Principles of communication at the end of life

- Patients in the last days of life are easily exhausted and meeting new professionals can be tiring. It is important therefore that all who might be able to contribute to care are introduced as early in the final illness as possible, and not in the final days
- Having said that, provided they are considerate and understanding, a visit is usually appreciated even when the health worker feels they have little to say or offer
- Relatives may need guidance in limiting the number of visitors to the patient if this is tiring
- Fears of the relatives and carers should be explored and taken seriously. Realistic fears should never be brushed aside with reassurance
- Anticipate problems and advise appropriately
- Ensure relatives and carers know who to contact when advice or support is needed

There is some evidence that patients who have witnessed another patient dying experience less anxiety than those who have not done so (Honeybun, 1992).

H. Care in Different Settings

It should be possible to provide good care for patients during the last days of life in all care settings. Ideally patients and their carers should have a choice about the place of care and the place of death.

Several studies have compared care in the last days of life in the variety of settings: acute hospitals, home, hospices, specialist palliative care units, and long-term institutions (Hearn, 1998). Complex pain control and family support are likely to be more effective in hospice and specialist palliative care units, but these units serve only a small proportion of people in the final stages of their lives. Furthermore not all patients want to be cared for in a specialist palliative care unit or hospice. One of the main purposes of the ongoing work of the National Council for Palliative Care and the End of Life Care Programme is to raise the level of knowledge and skills in general palliative care to enable people to be cared for in the place of their choice by staff they know and trust.

There are some principles of care which apply to all care settings and some concerns that are more specific. Some of the principles that should be considered to ensure good symptom control in the last days of life are outlined below. All these principles maintain the patient as the focus of care and place an importance on communication with the patient, their carers and other healthcare professionals involved in their care.

- Control of all distressing symptoms, some of them developing only in the last days of life

- Adequate doses of appropriate medication for each symptom should be prescribed on a regular basis by the appropriate route. This should be reviewed regularly. Medications should also be written up to be given as required
- Keep the relatives up-to-date with everything that's happening, the significance of changes in the patient and his treatment, and everything they should expect
- Recognise the needs of the patient's relatives and their close friends and provide information. Allow the family to share their fears and concerns
- Discuss with the patient and the family any religious/cultural requirements so that they can be respected and facilitated
- Discuss with the family (and, if appropriate, the patient) the features of the terminal phase:
  - increasing tiredness and weakness
  - confusion
  - decreased food and fluid intake
  - incontinence and diminished urine output
  - changing in breathing pattern
- Recognise the impact of a death on other patients and relatives in the same care setting
- Family and carers need support after the death and may need practical advice, for example, how to register the patient's death
- Any requests for post-mortem examination, for example if the patient has been exposed to asbestos, should be handled sensitively

Acute hospitals

The majority of deaths occur in acute hospitals. Recommendations about care in the last days of life in hospitals are contained in the NICE guidance for supportive and palliative care (2004) which states that managed systems to ensure best practice in care of the dying patient should be in place, for example, the Liverpool Care Pathway for the Dying. Further recommendations are also included in the King's Fund Report (Wright et al, 1988).

For some patients who die in a hospital setting it may be appropriate to discuss organ donation. This conversation needs to be handled with sensitivity and the transplant co-ordinator should be involved at an early stage.

Home

Most cancer patients who can express a choice initially want to die at home, but many later change their minds (Higginson, 2000). Care in the last days of life is possible at home but careful planning and support are needed, preferably starting before the patient is clearly in the final days. The Preferred Place of Care document and Gold Standards Framework facilitate this planning.

It can be helpful to identify an alternative place of care in case there are difficulties managing at home. The knowledge that additional support is available can be very reassuring for carers. The family and friends caring for the patient should be shown basic nursing procedures, for

BEST PRACTICE IN THE LAST HOURS AND DAYS OF LIFE

- Current medications are assessed and non-essentials discontinued.
- ‘As required’ subcutaneous medication is prescribed according to an agreed protocol to manage pain, agitation, nausea and vomiting and respiratory tract secretions.
- Decisions are taken to discontinue inappropriate interventions, including blood tests, intravenous fluids and observation of vital signs.
- The ability of the patient, family and carers to communicate in English or Welsh assessed.
- The insights of the patient, family and carers into the patient’s condition are identified.
- Religious and spiritual needs of the patient, family and carers are assessed.
- Means of informing family and carers of the patient’s impending death are identified.
- The family and carers are given appropriate written information.
- The GP practice is made aware of the patient’s condition.
- A plan of care is explained and discussed with the patient, family and carers.

Source: National Institute for Clinical Excellence Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer, 2004

example mouth care and catheter care. They should have the information and resources to enable them to manage symptoms. Most importantly this requires contact details for healthcare professionals who are able to respond as quickly as possible and who have up-to-date information regarding the patient.

Some families may wish to discuss the physical signs seen as death approaches, for example, altered breathing or changes in skin colour. This can be reassuring providing the subject is approached sensitively.

For patients who are being cared for at home it is important to advise the family ofwhat to do when the patient dies:

- do not attempt resuscitation
- do not call an emergency ambulance (crews may be required to attempt resuscitation and take the body to the nearest hospital. This can be very distressing to the family)

- phone for the general practitioner
- contact an undertaker (but there is no urgency for this). The family may wish to spend some time with the body.

Residential and nursing homes

One in five deaths take place in care homes. With an ageing population, it can be expected that in the future more and more elderly people will be cared for in care homes with or without nursing care where, for various reasons, staff may not yet be experienced or skilled in the provision of appropriate palliative care, particularly for those in the final days of life. The End of Life Care Programme tools can help meet these needs.

It is strongly recommended that the staff of such homes avail themselves of the advice, training opportunities and support of their local specialist palliative care service as early in the care of each resident with a life threatening condition as possible. Macmillan Cancer Support have developed a training programme entitled Foundations in Palliative Care (Macmillan Cancer Relief, 2004) which is specifically for care home staff and further guidance on caring for people in the final stages of their lives in care homes is available from the National Council for Palliative Care.

The Commission for Social Care Inspection (CSCI) reviews the social care given by services in England. They aim to promote best practice in all areas. They provide guidance on palliative care and the availability, storage and administration of all medications to care home residents. The guidance also applies to the use of controlled drugs in the care home setting.

I. Bereavement

Bereavement is an unavoidable component of caring for a dying patient and those closest to them. The majority (87 – 90%) of the population do not require any formal bereavement support (Bereavement Care Standards, 2001). The grief shown by patients' carers to the knowledge of the impending death and death itself can be varied in both the types and strength of psychological and emotional reactions.

Bereavement (the death) and grief (the reaction) have often been regarded as a follow-on stage after the care of the patient has ceased. This may mean that staff whose work focuses on the care of the patient feel separated from this, and possibly disempowered to impact on the grief experience of the families of those they have cared for.

Whilst most of the reactions to the bereavement will be experienced in the months and years after the death current thinking suggests that clear communication with, and care shown for relatives during the illness, the dying phase, at the death and immediately after the death can influence this (Neimeyer and Anderson, 2002).

It is difficult to identify which relatives and carers may suffer more following their bereavement. Research shows conflicting evidence of how useful *predictors* or *bereavement risk factors* may be (Relf, 2004; Stroebe et al, 2001). Where research concludes that there may be types of bereavement or personalities (Stroebe et al, 2005) who may suffer more greatly it is apparent that staff will need to know the relatives well and/or have carried out an

assessment to be able to identify such predictors. The task of caring for dying patients in an acute setting is unlikely to be an appropriate setting for such relationships to be formed with carers, and staff are unlikely to have the knowledge and skills to make such assessments.

The circumstances or factors which may influence the reaction to the bereavement and may be identifiable in the relatives whilst you are caring for the patient may be:

- the patient is a young person
- the carer has low levels of trust in self or others
- the carer has a history of psychiatric illness
- the carer has perceived lack of support or understanding
- there is a very dependent relationship between carer and the patient

If such factors are apparent it may be worth considering discussing these with the Specialist Palliative Care Service as they may consider this reason for referral and therefore engage in assessment of or support of the relatives, though this response will be locally determined. If there is sufficient concern about a carer, consider gaining their permission to inform their GP of the expected death and your concerns.

It is important, particularly in the acute setting, to provide all key relatives and carers with:

- Information on grieving – as this may be sufficient to reassure them that their reactions are amongst those which could be expected in someone recently bereaved.
- Information on current local and national bereavement agencies who may be able to offer support and guidance should they require it in the future.
- Information on how they can have questions or concerns answered about the progress of the illness, treatment or care, preferably without following a formal complaint process.

There is a great deal of research which has been completed into many aspects of grief and the conclusions have been equally widely debated. However it is generally accepted that:

- following a bereavement there are increased levels of physical and mental ill health.
- bereavement support is most effective when targeted at those who are experiencing difficulties.

J. Clinical Audit and Outcome Measurement

Palliative care services, like all other areas of healthcare, need to be able to demonstrate the delivery of high quality, user focused care. Bodies such as the Healthcare Commission and the Commission for Social Care Inspection (CSCI) have been instrumental in promoting the need for appropriate outcome based measures that can be used to audit and monitor the quality of care delivery.

The challenges involved in identifying appropriate outcomes and outcome measures for palliative care patients and undertaking robust research in this area are widely documented (eg Grande & Todd, 2000). Obtaining views directly from patients and, to some extent their carers, is fraught with practical, moral and ethical dilemmas that are further exacerbated for the assessment of outcomes in the dying phase. Here, retrospective studies of case notes and/or retrospective questionnaires of carers' and relatives' perspectives offer potential alternative forms of assessment. In addition, Integrated Care Pathways (ICP) can "provide evaluation of the impact of services and projects as a direct product of everyday clinical and administrative recording" (National Electronic Library for Health, 2006).

The Liverpool Care Pathway for the Dying Patient (LCP) is a multiprofessional care pathway that provides generic health care workers with a template of evidence-based care that encompasses the needs of both patients and their carers in the last days and hours of a patient's life (Ellershaw and Wilkinson, 2003). The document is easy to complete and structured in a way that facilitates the extraction of valuable process and clinical data for audit purposes.

Regular audit and feedback of data recorded plays an important role in Continuous Quality Improvement within organisations by providing information about care delivery and identifying areas for future educational input. For example, the LCP has been used to audit symptom control in the last days and hours of life (Ellershaw et al, 2001; Kaas and Ellershaw, 2003; Hugel et al, 2006).

However, the LCP can also facilitate comparative audit across organisations. Two pilot benchmarking exercises have illustrated that data can be successfully brought together to illustrate care in a wider context and to allow individual organisations to understand their own level of comparative performance in relation to similar settings. A national audit of care delivered in the dying phase using the LCP in acute hospital trusts in England is currently underway. The results from this audit are due in the summer of 2007 and should provide a clear picture of care delivered in participating trusts that can be used to develop benchmarks against which future care can be measured in the hospital sector.

The National Council for Palliative Care has been collecting national data about the delivery of specialist palliative care for more than ten years. The Minimum Data Set (MDS) was developed in 1995 to provide annual comprehensive and high quality data about hospice and specialist palliative care services including inpatient care, home care, day care and hospital support (National Council for Palliative Care, 2006). This information is useful for strategic planning and local service management and reports both patient demographic and service uptake details.

Several options for assessing the views of bereaved relatives regarding care at the end of life are now available. In the UK, the questionnaire VOICES (Views Of Informal Carers – Evaluation of Services) was developed in the 1990's. It contains 158 questions about care received in the last three months life and has been used successfully in several research studies (e.g. Karlsen & Addington-Hall, 1998). The

questionnaire focuses mainly on relatives' perceptions of care, service delivery and unmet need in the last three months of the patient's life and has a specific focus on the final three days of life for certain aspects of care.

The "TIME Toolkit" has been developed by Teno and colleagues in the US (Teno et al, 2001). Based on the premise that measurement is essential to quality improvement, two tools were developed and validated. One is a prospective patient interview and the other is an after death interview with relatives. Both questionnaires are designed to be completed via telephone or face to face interview. The prospective patient questionnaire is, of course, likely to be less useful for patients in the dying phase (i.e. last days and hours of life) but the "After-death Bereaved Family Member Interview", versions of which exist for use in Hospital, Hospice and Nursing Home settings (http://www.chcr.brown.edu/pcoc/pdf/) can be used retrospectively to assess relatives' views on the quality of care delivered. Its focus is the patient's "final illness" although there are specific questions on the last week and last day of life. It consists of 125 questions. The overall conceptual model was "patient-focussed family-centred medical care". The themes of the questions were the provision of physical comfort and emotional support to the patient, promoting shared decision-making, focus on the needs and values of the individual and extending to the needs and values of family members and coordination of healthcare and related services (Teno, 2001).

Work currently underway within the Marie Curie Palliative Care Institute at the University of Liverpool, in part building on the work of Teno and Addington-Hall, is developing a questionnaire that focuses more directly on relatives' views of the last days and hours of the patient's life (Mayland et al, 2006) which should provide a valuable tool with which to assess care and service delivery from the perspective of the bereaved relative in this particular phase.

K. Cost Effectiveness

This guidance can be implemented within the current resources available to services.

Changing Gear gives guidance on how to control the distress associated with dying. Failure to control this distress results in considerable human cost, as well as increased morbidity and mortality in the bereavement phase. This can result in increased costs incurred by services in the bereavement phase as well as indirect financial costs arising from increased use of both health and social care services.

Specialist palliative care services such as hospice inpatient units will never be available to or appropriate for all dying patients nor should they be. What is important is that people can be cared for and enabled to die in the place of their choice. Therefore training in palliative care, which is recognised and accepted as an integral part of all good clinical practice, should be included in all health and social care professionals basic training as all professionals across all settings will care for dying people at some point. This point is highlighted in the recent White Paper Our Health, Our Care, Our Say: a new direction in community services (2006):

˝We will ensure all staff who work with people who are dying are properly trained to look after dying patients and their carers.˝

The level of training should be adapted to the experience and needs of the different professional groups and is a cost effective way of helping people at the end of their life. The necessity for collaboration with specialist palliative care services should be emphasised and formal links/contact made. However the availability and scope of such services varies throughout the United Kingdom so other tools such as Macmillan Cancer Support's Foundations in Palliative Care should be tailored to individual localities and services and can be used to train professional carers in the workplace.

The Use of Drugs at the End of Life

This section provides guidance on the management of symptoms that patients may experience in the last days of life. The most commonly used drugs have been described. It is important to refer to local guidelines as practice may vary. Local specialist palliative care services should always be contacted when there is any concern or uncertainty about prescribing for patients in the last days of life. The advice of specialist palliative care services should also be sought if symptoms are difficult to control or the patient remains distressed.

Anticipatory prescribing of drugs is essential to ensuring control of symptoms at the end of life. This enables healthcare professionals to respond as quickly as possible should the patient experience a new symptom.

Patients may experience breakthrough symptoms ie a temporary increase in a symptom, often pain, above a background and otherwise well-controlled level of the symptom. It is important that drugs are prescribed as required, and available, to enable healthcare professionals to respond as soon as possible to this increase in symptom. The doses of drug given for this increase in symptom are termed "rescue doses".

Incident pain should be distinguished from breakthrough pain. Incident pain occurs on movement, is of short-duration and is usually predictable. Medications given for incident pain should not be included when adjusting the 24 hour dose of opioid

administered to the patient. Fast-acting drugs with short duration of effect are needed for the management of incident pain. Referral to specialist palliative care services for guidance on managing incident pain is recommended.

Administration of drugs via the oral route should be maintained for as long as practical. However, as a patient's condition deteriorates, it will be necessary to use an alternative method of administration. Invariably, the subcutaneous route is chosen since it offers a safe and effective option for the administration of many drugs that are considered critical for the continued care of the patient during the last few days of life. The rectal route is rarely used.

Portable infusion devices, commonly known as syringe drivers, allow continuous infusions of medications to be given subcutaneously. This prevents the need for multiple injections and maintains a smooth delivery of medication. There are a number of such devices currently available (Dickman 2005, Twycross 2002). It is always important to follow the manufacturers' instructions for safe administration of drugs. Syringe drivers are not always needed to achieve good symptom control but can be a useful resource. Drugs commonly given by this method include:

- diamorphine/morphine
- midazolam
- hyoscine hydrobromide or butylbromide
- glycopyrronium
- haloperidol
- cyclizine
- metoclopramide
- levomepromazine

Combinations of two, three or four of these drugs are commonly encountered. To ensure compatibility, a suitable reference text (Dickman, 2005) should be checked if more than two drugs are to be mixed together.

Management of specific symptoms

1) Pain

A) Opioids

Opioid therapy can be easily continued by the subcutaneous route. Diamorphine was the opioid of choice, but since supplies have been difficult to obtain since December 2004, morphine is currently the commonly used opioid, although alternative opioids may be encountered in specific circumstances. For example, subcutaneous oxycodone is used in cases where oral oxycodone had been taken. Alfentanil is occasionally encountered, but should only be used under specialist advice.

The safe prescribing of opioids was reviewed in the Department of Health publication "Building a safer NHS for patients – Improving medication safety." (Department of Health, 2004) Confusion may result from generic prescribing of opioids and drug errors have occurred. Prescribing of opioids by brand has been recommended. This advice is thought to be particularly important for the safe prescription of transdermal fentanyl patches (Royal Pharmaceutical Society of Great Britain, 2006).

i) Dose Conversion from Oral Morphine to Subcutaneous Morphine

Calculate the total daily dose of oral morphine

Divide the total daily dose of oral morphine by 2 to give the equivalent daily dose of subcutaneous morphine.

Increase the dose of subcutaneous morphine by 25% if pain is uncontrolled

Infuse the total daily subcutaneous morphine dose by a syringe driver

Ensure that a subcutaneous rescue dose of morphine, equivalent to one sixth of the total daily dose, is prescribed

e.g. MST® or Zomorph® 120mg twice daily

= 240mg oral morphine daily

= 120mg subcutaneous morphine daily

ii) Dose Conversion from Oral Oxycodone to Subcutaneous Oxycodone

Calculate the total daily dose of oral oxycodone

Divide the total daily dose of oral oxycodone by 2* (Dickman, 2005) to give the equivalent daily dose of subcutaneous oxycodone.

Increase the dose of subcutaneous oxycodone by 25% if pain is uncontrolled

Infuse the total daily subcutaneous oxycodone dose by a syringe driver

Ensure that a subcutaneous rescue dose of oxycodone, equivalent to one sixth of the total daily dose, is prescribed

The manufacturer recommends dividing the oral dose of oxycodone by 2 to arrive at the subcutaneous equivalent. This differs from clinical experience and an early increase in dose may be required

e.g. Oxycontin® 80mg twice daily

= 160mg oral oxycodone daily

= 80mg subcutaneous oxycodone daily

iii) Transdermal Fentanyl Patches (Ellershaw, 2002)

Continue to use the patch

Calculate a suitable rescue dose of subcutaneous morphine or oxycodone as shown in the table below

If regular analgesia is required in addition to the patch the additional analgesia can be delivered by a syringe driver. The dose of opiate for the syringe driver is calculated by totalling the total daily dose of subcutaneous opioid given.

B) Other Analgesics

Non-steroidal anti-inflammatory drugs are rarely used at the end of life.

Subcutaneous Clonazepam is occasionally used for the management of neuropathic pain under specialist advice.

Subcutaneous dexamethasone may also be used for pain caused by inflammation under specialist advice.

Determination of subcutaneous “rescue” (breakthrough) doses of morphine and oxycodone for patients using a fentanyl patch.		
Fentanyl Patch Strength	**Morphine subcutaneous rescue dose**	**Oxycodone subcutaneous rescue dose ***
25 microgram/hour	5mg	5mg
50 microgram/hr	10mg	10mg
75 microgram/hr	15mg	15mg
100 microgram/hr	20mg	20mg

* Based on a conversion of 1:1 between subcutaneous morphine and oxycodone

2) Nausea and Vomiting

The choice of anti-emetic will depend upon the cause of nausea and vomiting. Common anti-emetics with usual indications are shown below.

Cyclizine is an antihistamine with some anticholinergic activity. It is useful in the management of bowel obstruction and for central causes and as a generic anti-emetic when the cause is unknown. It must be avoided in patients with severe heart failure. The usual dose is 100–150mg via syringe driver over 24 hours, or 50mg 8 hourly by subcutaneous injection. In the syringe driver, *it must be diluted with Water for Injections* and must not be mixed with hyoscine butylbromide.

Haloperidol is a dopamine antagonist that is useful for drug or metabolic (e.g. hypercalcaemia) causes and it is often used in combination with cyclizine. The usual dose is 1.5–5mg daily via syringe driver, or 1.5–3mg by subcutaneous injection. The maximum dose is 10mg daily.

Metoclopramide is a dopamine antagonist, but also increases gastric emptying. It is useful in the treatment of gastric stasis, but must be avoided in complete bowel obstruction. The usual dose is 30–60mg daily via syringe driver, or 10–20mg 8 hourly by subcutaneous injection. Higher doses may be used under the advice of a specialist. Combination with other anti-emetics listed here is not generally recommended.

Levomepromazine is useful for nausea and vomiting of unknown cause; it is generally a second line agent (Twycross, 2002). The usual dose is 6.25–25mg via syringe driver, or 6.25–12.5mg by subcutaneous injection, to a max of 25mg in 24 hours. It can be a cause of site reactions but can also help agitation so is used for people who have both agitation and nausea.

Hyoscine butylbromide, or *glycopyrronium* may be used to reduce the volume of vomit, under the advice of a specialist.

3) Respiratory Tract Secretions (Hugel, 2006; Lawrey, 2005)

Cough and 'rattly' breathing usually herald tracheo-bronchitis or bronchopneumonia in the last days of life because the patient is too weak to clear secretions. Antibiotics are rarely appropriate in this situation.

The management of respiratory tract secretions in the dying patient is primarily aimed at minimising the distress of relatives or carers, rather then the patient. It is believed that the patient does not suffer distress from this symptom.

When managing respiratory tract secretions it is important to explain the nature of the symptom and its management to relatives in order to reassure them. A change of the patient's position can be very helpful. Difficult cases may require the use of suction. The main treatment of chest secretions involves the use of anticholinergic drugs. These drugs, however, only serve to reduce the production of secretions; they do not remove secretions already present. For this reason, these drugs must be started as soon as symptoms become apparent. There are two drugs to choose from but neither has yet been shown to be superior.

Hyoscine hydrobromide is given in doses of 200 – 400micrograms every 4 hours by subcutaneous injection, or up to 2.4mg via syringe driver. Although it generally causes sedation, it has been known to cause paradoxical agitation. It is the most expensive of the agents.

Glycopyrronium is given in doses of 200micrograms every 4 hours by subcutaneous injection, or up to 1.2mg via syringe driver. Occasionally, doses of up to 2.4mg may be encountered. Unlike hyoscine hydrobromide, glycopyrronium does not cause sedation (or paradoxical agitation).

Patients with heart failure may occasionally be given furosemide by syringe driver under the advice of specialist palliative care services.

4) Agitation/Distress (Cherny, 2006; Lo, 2005)

If left untreated, it can be distressing for both family and carer and may leave unpleasant, negative memories of an otherwise, fairly peaceful dying process.

Exclude correctable causes such as urinary retention (catheterise) or nicotine withdrawal (replacement therapy).

Drug treatment of agitation can involve the following:

- *Midazolam* is generally considered the drug of choice. Initially, doses of 2.5–5mg by subcutaneous injection 2–4 hourly when required, or 5–10mg via syringe driver are given. Higher doses, up to 60mg via syringe driver, may be necessary.

- *Levomepromazine* is a useful treatment option and may be used if midazolam has not been successful. It may be used alone, or in combination with midazolam. Initial doses of 12.5mg by subcutaneous injection 8–12

hourly when required, or 25–50mg via syringe driver are given. Higher doses may be given under specialist advice.

5) Breathlessness (Edmonds, 2001)

May be more distressing than pain. Some patients may have a fast respiratory rate but are not distressed by this and this needs to be explained to carers and family. As the patient approaches the last days of life, the focus of treatment becomes the perception of breathlessness and any associated anxiety. Although drugs are the mainstay of treatment, non-drug measures, such as a fan, or soothing hand may help.

Morphine is presently the subcutaneous opioid of choice. Opioids are believed to be of benefit because they reduce the breathing rate and relieve anxiety. The dose of morphine used depends upon previous oral requirements, but for an opioid naïve patient, a suitable starting dose would be 2.5mg by subcutaneous injection 4 hourly when required, or 10mg via syringe driver.

Midazolam is useful, particularly if the breathlessness is associated with anxiety. It is usually given as 2.5–5mg subcutaneous injections 2–4 hourly when required or 10–20mg via syringe driver.

Bibliography

The original document was based on a systematic review of the literature. The reference details for the original document can be purchased from the National Council for Palliative Care.

Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S. and Small, N. (2006). Prevalence of Symptoms in a Community-Based Sample of Heart Failure Patients. *Journal of pain and Symptom Management,* Vol 32(3): 208–216

Cherny, N.I. (2006). Sedation for the care of patients with advanced cancer. *Nat Clin Pract Oncol,* vol 3(9): 492–500

Commission for Social Care Inspection (2006) *Handled with care? Managing medication for residents of care homes and children's homes – a follow up study.* Commission for Social Care Inspection: England

Cull, A., Sprangers, M., Bjordal, K., Aaronson, N., on behalf of the EORTC Quality of Life Study Group, (1998). *'EORTC Quality of Life Study Group Translation Procedure'.* July 1998, EORTC: Brussels

Deming, W. Edwards. (1994). *The New Economics for Industry, Government, Education.* Second Edition. Massachusetts Institute of Technology Centre for Advanced Engineering Study; Cambridge, Massachusetts

Department of Health. (2000). *The NHS Cancer* Plan. Department of Health: London

Department of Health. (2001). Essence of Care: Patient-focused benchmarking for health care practitioners. www.doh.gov.uk/essenceofcare

Department of Health. (2003). *Building on the Best: Choice, Responsiveness and Equity in the NHS.* Department of Health: London

Department of Health. (2004). *Building a safer NHS for patients: Improving medication safety.* Department of Health: London

Department of Health. (2005). *Mental Capacity Act.* The Stationery Office: London

Department of Health. (2006). *Our Health, Our Care, Our Say: a new direction for community services.* Department of Health: London

Dickman, A., Schneider, J., and Varga, J. (2005). *The Syringe Driver: Continuous subcutaneous infusions in palliative care* (2nd Edition). Oxford University Press: New York

Edmonds, P., Karlsen, S., Khan, S., and Addington-Hall, J. (2001). A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliat Med.* Vol 15(4): 287–95

Ellershaw, J.E., Sutcliffe, J.M., and Saunders, C.M. (1995). Dehydration and the dying patient. *Journal of Pain and Symptom Management* Vol 10: 192–197

Ellershaw, J.E., and Wilkinson, S. (2003). *Care of the dying: A pathway to excellence.* Oxford University Press: Oxford

Ellershaw, J.E. (2002). Clinical pathways for care of the dying – an innovation to disseminate clinical excellence. *Journal of Palliative Medicine.* Vol 5(4): 617–623

Ellershaw, J.E., and Murphy, D. (2005). The Liverpool Care Pathway (LCP): Influencing the UK national agenda on care of the dying. *International Journal of Palliative Nursing.* Vol 11(3): 132–4

Ellershaw, J., and Ward, C. (2003). Care of the dying patient: the last hours or days of life. *British Medical Journal,* Vol. 326: 30–34

Ellershaw, J.E., Smith, C., Overill, S., Walker, S.E., and Aldridge, J. (2001). Care of the Dying: Setting standards for symptom control in the last 48 hours of life. *Journal of Pain and Symptom Management,* Vol. 21 (1): 12–17

End of Life Care Programme. http://eolc.cbcl.co.uk/eolc (last accessed 7th September 2006)

Fowell, A., Russell, I., Johnstone, R., Finlay, I., and Russell, D. (2004). Cluster randomisation or randomised consent as an appropriate methodology for trials in palliative care: a feasibility study. *BMC Palliative Care.* Vol 3 (1) http://biomedcentral.com/1472-684X/3/1 – accessed 17.11.2005

General Medical Council. Withholding and Withdrawing Life-Prolonging Treatments. http://www.gmcuk.org/guidance/library/witholding_and_withdrawing/witholding_lifeprolonging_guidance.asp (Last accessed 26th September 2006)

Gold Standards Framework. http://www.goldstandardsframework.nhs.uk/ (last accessed 7th September 2006)

Grande, G.E., and Todd, C. (2000). Why are trials in palliative care so difficult? *Palliative Medicine.* Vol 14: 69–74

Hearn, J., Higginson, I.J. (1998). Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliative Medicine,* Vol 12: 317–332

Higginson, I.J., Sen-Gupta, G., and Dunlop, D. (1997). *Changing Gear — Guidelines for managing the last days of life in adults: The Research Evidence.* The National Council for Hospice and Palliative Care Services: London

Hinton, J. (1979). Comparisons of places and policies for terminal care. *The Lancet,* Vol. 1: 29–32

Hockley, J., Dewar, B., Watson, J. (2005). Promoting end-of-life care in nursing homes using an ‘integrated care pathway’. *Journal of Research in Nursing.* Vol 10: 135–152

Honeybun, J. (1992). The impact of death on fellow hospice patients. *British Journal of Medical Psychology.* Vol 65: 67–72

Hugel, H., Ellershaw, J., and Gambles, M. (2006). Respiratory tract secretions in the dying patient: a comparison between glycopyrronium and hyoscine hydrobromide. *J Palliat Med.* Vol 9(2): 279–84

Jack, B., Gambles, M., Murphy, D., and Ellershaw, J. (2003). Nurses perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting. *International Journal of Palliative Nursing,* Vol. 9 (9): 375–381

Jones, R.H.V. (1993). Teams and terminal care at home: do patients and carers benefit? *Interprofessional Care.* Vol 7 (3): 239–244

Kaas, R.M., and Ellershaw, J.E. (2003). Respiratory Tract Secretions in the Dying Patient: A Retrospective Study. *Journal of Pain and Symptom Management.* Vol 26(4): 258–264

Karlsen, S., Addington-Hall, JM. (1998). How do cancer patients who die at home differ from those who die elsewhere? *Palliative Medicine.* Vol 12: 279–286

Lawrey, H. (2005). Hyoscine vs glycopyrronium for drying respiratory secretions in dying patients. *Br J Community Nurs.* Vol 10(9): 421–4, 426

Liverpool Care Pathway. http://www.lcp-mariecurie.org.uk/ (last accessed 7th September 2006)

Lo, B., and Rubenfeld, G. (2005). Palliative sedation in dying patients: “we turn to it when everything else hasn’t worked”. *JAMA;* Vol 294(14): 1810-6

Lynn, J., Harrell, F., Cohn, F., Wagner, D., and Connors, A.F. (1997). Prognoses of seriously ill hospitalized patients on the days before death: implications for patient care and public policy. *New Horizons,* Vol. 5 (1): 56–61

Maltoni, M., Caraceni, A., Brunelli, C., Broeckaert, B., Christakis, N., Eychmueller, S., Glare, P., Nabal, M., Vigano, A., Larkin, P., De Conno, F., Hanks, G., and Kaasa, S. Steering Committee of the European Association for Palliative Care (2005). Prognostic factors in advanced cancer patients: evidence-based clinical recommendations. *J Clin Oncol,* Sep 1; vol 23(25): 6240–8

Mannix, K. (2006). Palliation of nausea and vomiting in malignancy. *Clin Med.* Vol 6(2): 144–7.

Mitchell, D, and Gordon, T. (2003). Spiritual and Religious Care Competencies for Specialist Palliative Care: Assessment Tools. Marie Curie Cancer Care: London

Murray, S., Kendall, M., Boyd, K., and Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*. Vol 330: 1007–1011

National Council for Palliative Care (NCPC). (2006). http://www.ncpc.org.uk/policy_unit/mds/index.html (last accessed 7th September 2006)

NCPC. (2003). *Priorities and preferences for end of life care.* NCPC: London

National Electronic Library for Health. (2006). http://www.library.nhs.uk/pathways/page.aspx?pagename=BENEFITS#support (last accessed 7th September 2006)

National Institute for Clinical Excellence (NICE). (2004). *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer: The Manual.* National Institute for Clinical Excellence: London

Neimeyer, R., and Anderson, A. (2002). “Meaning reconstruction theory”. In Thompson N. (Ed), *Loss and Grief: A guide for Human Service Practitioners.* Palgrave Macmillan: Basingstoke

Neuberger, J. (2004). *Caring for dying people of different faiths.* 3rd rev ed. Radcliffe Medical Press: Oxford

Neuberger, J. (2004). *Dying well: a guide to enabling a good death.* 2nd rev ed. Radcliffe Medical Press: Oxford

Office for National Statistics. www.statistics.org.uk (last accessed 26th September 2006)

Preferred Place of Care. http://www.cancerlancashire.org.uk/ppc.html (last accessed 7th September 2006)

Relf, M. (2004). Risk assessment and bereavement services. In Payne, S.A., Seymore, J., and Ingleton, C. (Eds), *Palliative care nursing; principles and evidence for practice.* Open University press: Maidenhead.

Royal Pharmaceutical Society of Great Britain. (2006). *Practice committee considers opioid issues. News Release.* 13 February 2006.

Saunders, C. (1963). The treatment of intractable pain in terminal cancer. *Proc. R. Soc.* Vol 56: 195–7

Standards for Bereavement Care in the UK. Bereavement Care Standards UK Project. 2001

Stroebe, W., and Schut, H. (2001). Risk factors in bereavement outcome; a methodological and empirical review. In Stroebe, M.S., Hansson, R.O., Stroebe, W., and Schut, H. (Eds), *Handbook of bereavement research: consequences, coping and care.* American Psychological Association

Stroebe, W., Schut, H., Stroebe, M. (2005). Grief work, disclosure and counselling: Do they help the bereaved? *Clinical Psychology Review* Vol 25(4): 395–414

Teno, J.M., Casey, V.A., Welch, L.C., and Edgeman-Levitan, S. (2001). Patient-focused, family-centered end-of-life medical care: views of the guidelines and bereaved family members. *Journal of Pain and Symptom Management* vol 22(3): 738–51

Twycross, R., Wilcock, A., Charlesworth, S., and Dickman, A. (2002). *Palliative Care Formulary.* Second Edition. Radcliffe Publishing: Oxford

Whooley, M.A. (2006). Depression and cardiovascular disease: healing the broken-hearted. *JAMA*, Jun 28; vol 295(24): 2874–81

Wright, A., Cousins, J., and Upward, J. (1997). *Ethical decision-making in palliative care: Artificial Hydration for people who are terminally ill.* The National Council for Palliative Care: London

Wright, A., Cousins, J., and Upward, J. (1988). *Matters of death and life: A Study of bereavement support in NHS hospitals in England.* King Edwards Hospital Fund for London: London

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