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SOURCES AND SELECTION CRITERIA

We searched the *Cochrane Database of Systematic Reviews*, Medline, Embase, and Clinical Evidence online. Search terms included “death or dying” and “home or community”. Studies were limited to those conducted in adults that were written in English. They included recent systematic reviews, meta-analyses, randomised controlled trials, and high quality prospective or retrospective audits. We also consulted relevant reports and national guidelines, including those published by the National Institute for Health and Care Excellence.

Care of the dying patient in the community

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The consensus from international studies of patient preferences is that, given adequate support, most people would prefer to die at home.¹⁻³ However, more than half of all deaths in the United Kingdom occur in hospital, with only 18% of people dying in their own home.⁴ Suggested reasons for this include a lack of anticipatory care planning, poor coordination between healthcare agencies, and insufficient community resources. National and local policies now focus on facilitating home deaths, and recently there has been a small increase in the proportion and absolute number of people dying at home.⁵

The demographics of deaths across Europe are changing with the ageing population, with deaths from dementia, cancer, and chronic diseases becoming more common.⁶⁻⁷ Caring for such patients in hospital will probably become unsustainable in terms of capacity, cost, and patient satisfaction. The focus of end of life care is therefore shifting to the community—to homes and care homes—where the role of the general practitioner, with support from the community palliative care team, is key. The onus is on all health and social care professionals to work collaboratively across settings to enable patients to receive high quality end of life care in the place of their choice.

Where do people want to die?

The English national end of life care strategy states that, whenever possible, people should be able to spend their last days in the place of their choosing.¹ In Europe and the United States, more than half of patients express a wish to be cared for and to die at home.^{1-2, 8} Wherever their final place of death, most people spend most of their last year of life at home. Younger patients have a higher preference for home death, whereas older patients tend to prefer home or hospice.⁹ Patients' preferences should be interpreted with the caveat that they usually come from surveys of well people. A recent systematic review reported that around a fifth of patients changed preference as their illness progressed.¹⁰ This highlights the importance of ongoing discussions with patients and carers over time and of providing rapidly accessible high quality end of life care across settings.

Where do people die?

Demographic data from 2010 show that over half of all deaths in England occurred in hospital, with 18% in care homes and

5% in hospices.⁹ The proportion of deaths at home increased slowly but steadily—from 18.3% in 2004 to 20.8% in 2010.⁵ This is a welcome reversal of the previous trend towards a decrease in home deaths, which in 2008 had been predicted to fall to 10% by 2030.¹¹ This latest trend mirrors that reported in the US, where hospital deaths have decreased to 36%.¹²

What factors are associated with achieving preferred place of death?

Comparison between preferred and actual place of death shows a gap of at least 39% (see table on bmj.com).⁹ Systematic review has identified several factors associated with achieving home death, including younger age and a diagnosis of cancer.⁹ A recent UK population based study found that home deaths for patients with cancer have increased to 24.5%,¹³ compared with 12% for respiratory or neurological diseases and 6% for dementia.¹⁴ Other factors associated with home deaths are living with relatives, patients' low functional status, and support from extended family or home care services.¹⁵ Patients receiving specialist end of life care community services (such as “hospice at home”) are significantly more likely to die at home than those receiving usual care.¹⁶⁻¹⁷ For many patients, care homes are home. More than half of deaths from dementia across five European countries occur in care homes.^{7, 14}

Although many patients express a wish to die at home they also recognise “the practical and emotional difficulties of exercising this choice.”¹⁶ Social trends have seen changes in family structure, with many more people living alone with a low level of informal support. Patients express concern about being a “burden.” They also worry about their families seeing them in distress or having to help with intimate aspects of care.¹⁸ The preference to be cared for at home ranks higher among patients than among family and carers.¹⁰ Carers can become overwhelmed by the enormity of the task they have committed themselves to and if inadequately supported may seek hospice or hospital care as an alternative.

How can we facilitate home deaths for patients who want this?

Step 1: Identification of patients in the last year of life

Patients need to be identified in advance to discuss and plan care, anticipate the physical and psychosocial problems that are likely to arise, and enable patients to make informed decisions about all aspects of care, including ceilings of management and preferred place of care.

It can be difficult to identify these patients, especially those with non-malignant disease who may experience a slower and more fluctuating deterioration than those with cancer. Systematic review found that the lack of a clearly predictable disease course in chronic heart failure and chronic obstructive pulmonary disease had a marked impact on the patient's level of awareness of deterioration and on engagement with advance care planning.¹⁴ By contrast, those with long term neurological conditions had a heightened awareness of their deteriorating condition and often planned ahead.¹⁴

SUMMARY POINTS

Most people report a preference for dying at home

To support this preference, doctors in all settings need to identify relevant patients early

Anticipatory care planning should include discussion and documentation of patient preferences, anticipatory prescribing, and completion of a do not attempt cardiopulmonary resuscitation order

General practitioners have a key role, in both homes and care homes, before and after death

Good communication and effective coordination of care 24 hours a day are essential to prevent unwanted and unnecessary hospital admissions towards the end of life

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- ▶ Multiply myeloma (*BMJ* 2013;346:f3863)
- ▶ Glaucoma (*BMJ* 2013;346:f3518)
- ▶ Managing unscheduled bleeding in non-pregnant premenopausal women (*BMJ* 2013;346:f3251)
- ▶ Diagnosis and management of recurrent urinary tract infections in non-pregnant women (*BMJ* 2013;346:f3140)
- ▶ Investigation and treatment of imported malaria in non-endemic countries (*BMJ* 2013;346:f2900)

Several initiatives can help identify patients in their last year of life. The “find your 1%” campaign in the UK refers to the identification of the 1% of the population who die each year. GPs in the UK see on around 20 deaths a year, most of which are predictable.¹⁹ Only about five of these deaths are from cancer. Although no direct evidence exists to support the campaign, there is evidence that early engagement in end of life care can increase home deaths and patient satisfaction.²⁰

The question “would you be surprised if this patient were to die in the next year?” is a useful starting point to aid identification.¹ The supportive and palliative care indicators tool (SPICT) provides a more detailed algorithmic approach, using a combination of specified general clinical and disease specific indicators of deterioration.^{21–22} Clinical indicators include poor performance status, increasing care requirements, progressive weight loss, and multiple unplanned hospital admissions. Disease specific clinical indicators are more detailed for each category of disease—for example, urinary and faecal incontinence in dementia and cardiac cachexia in cardiac disease. Similar tools are being developed in Holland, the US, and Spain.^{23–25} Despite the implementation of directives advocating early intervention, most patients with advanced chronic illness are not identified before they die, so further work is needed.²⁶

Step 2: Assessment

After identification, the next step is to gently explore the patient’s insight into his or her condition and complete a holistic assessment of the full range of physical, psychological, social, spiritual, and cultural needs. An assessment of carers’ needs should also be completed.¹ Patients with symptom control needs, complex psychosocial needs, or terminal care needs benefit from referral to the local community palliative care service. Consider referral to other health and social care professionals with expertise in all aspects of the patient and carer’s holistic care to help meet identified areas of unmet need (box 1). These include help with applications for appropriate benefits and early support from social workers if young children are involved or complicated bereavement is anticipated. The evidence basis for spiritual support may be lacking,²⁷ but many patients value an opportunity to raise existential issues, and guidance for this is available.²⁸

Step 3: Anticipatory care planning

Retrospective studies have shown a positive association between having an advanced care plan and meeting patient preferences,²⁹ whereas failure to implement a timely end of life care plan has been identified as a key obstacle to high quality end of life care.³⁰ Give patients the opportunity to have early anticipatory care planning discussions. This should be done in a sensitive way so that damaging communication is not imposed at the wrong time or on patients who will never cope with this kind of thinking. Barriers to advance care planning in primary care have been identified and include prognostic uncertainty, desire to maintain hope, and resistance to a “tick box” approach.³¹

The principle is to give patients control of the information flow, within a wider context of open communication with family and carers. For example, if a parenteral feeding tube is an option—as in motor neurone disease or head and neck cancers—elicit and document patient preferences in advance,

while the patient is well enough for the procedure. The subject may be best broached with open questions, such as: “Do you like to plan ahead with regard to your health?” progressing to more specific questions as guided by patient cues. “Some specific interventions are useful to plan in advance. Have you thought about whether you would consider a feeding tube if you aren’t able to swallow safely? If so, it’s often better to have the tube placed sooner, so it’s ready for when you need it. The procedure itself can be risky if you’re not well enough.”

Information giving is a continuous process. At each stage, check what patients or carers already understand and whether they have any particular concerns, perhaps around practicalities or what to expect during the dying process. Inform patients and carers about what to expect so that, as far as possible, there are no surprises. Adjust how much information you give, and how and when you give it, to the individual circumstances. A recent European survey of patient preferences found that 73.9% wanted to be fully informed of poor prognosis.³² A large minority of patients therefore prefer not to be fully informed. It is a doctor’s duty to distinguish between these patients and communicate accordingly.

Regular review allows professionals to provide information and manage any deterioration in the patient’s condition. Medication review is recommended to rationalise oral drugs. This should be tailored to the individual but may include stopping drugs with mostly long term benefit (such as statins) or those with intolerable side effects, such as constipation from ferrous sulphate. As patients become less well and lose weight, blood pressure and blood glucose monitoring should guide appropriate reduction in antihypertensive and hypoglycaemic drugs.

Agree and document a plan for managing predictable complications such as a bleed, seizure, or infection. Share a copy of the current care plan and contact numbers (including out of hours) with the patient and the family or carers. The overall aim is to avoid crises and to ensure the right care is given at the right time and in the right place.

Coordination of care

A coordinated team approach results in better outcomes for patient experience, quality of care, and family or carer satisfaction than when professionals work in silo. Patients in their last year of life have a high frequency of hospital admissions (average 3.5; varies from 2.3 for patients with stroke to 5.1 for cancer).³³ Discharge planning for end of life care is a multidisciplinary process. An integrated model of care across settings, with effective communication between hospital and primary healthcare teams, is essential to avoid recurrent unnecessary and unwanted hospital admissions.

The gold standards framework provides a systematic approach to formalising best practice in end of life care in the community, starting with a register of patients in their last year of life and regular multidisciplinary meetings (level one). Level two helps to structure symptom assessment and level three focuses on carer support.³⁴ Introduction of the framework into primary care has improved end of life care (as reported by the practices involved).^{35–36} The framework has since been introduced into care homes and more recently to some hospitals, where identification using a systematic approach may be useful.³⁷ An evaluation of national uptake and further research into clinical outcomes is needed.³⁸

Box 1 | Key agencies in end of life care in the UK

- General practitioners
- Specialist palliative care services: community teams, hospital support teams, outpatient clinics, hospices
- District nursing teams
- Social services
- GP out of hours service
- Hospice at home service
- Marie Curie nursing service
- Hospital specialists
- Ambulance service
- Allied health professionals: physiotherapists, occupational therapists, speech and language therapists
- Clinical nurse specialists: heart failure, respiratory, diabetes, oncology
- Tissue viability nurses
- Social workers
- Chaplains

Box 2 | Clinical indicators for terminal care²²**Q1 Could this patient be in the last days of life?**

Clinical indicators of dying may include:

- Confined to bed or chair and unable to self care
- Having difficulty taking oral fluids or not tolerating artificial feeding or hydration
- No longer able to take oral drugs
- Increasingly drowsy

Q2 Was this patient's condition expected to deteriorate in this way?**Q3 Is further life prolonging treatment inappropriate?**

- Further treatment is likely to be ineffective or too burdensome
- Patient has refused further treatment
- Patient has made a valid advance decision to refuse treatment
- A healthcare proxy has refused further treatment on the patient's behalf

Q4 Have potentially reversible causes of deterioration been excluded?

These may include:

- Infection (for example, urinary, chest)
- Acute renal impairment or dehydration
- Biochemical disorder (calcium, blood sugar)
- Drug toxicity (for example, opioids, sedatives, alcohol)
- Intracranial event or head injury
- Bleeding or severe anaemia
- Hypoxia or respiratory failure
- Delirium
- Depression

If the diagnosis of dying is in doubt, give treatment and review within 24 hours

If the answer to all four questions is "Yes," plan care for a dying patient

Recent international initiatives include the implementation of electronic palliative care coordination systems (or EPaCCS), such as electronic medical orders for life sustaining treatment (eMOLST) in New York and coordinate my care (CMC) in London.^{38 39} EPaCCS share the care plan electronically. The aim is to ensure effective handover of information between professionals (without duplication), improve continuity of care, and prevent hospital admissions. Provisional reports suggest that use of an EPaCC increases the number of patients dying in their preferred place of care.³⁹ However, only a small proportion of the target population is covered by EPaCC projects and any improvements probably have a multitude of causes.

How can the dying phase be managed in the community?

Most, but not all, patients have an identifiable dying phase that lasts hours or days, and occasionally up to a week or so. Box 2 provides help in identifying transition to the dying phase.²² Diagnosis of dying should prompt a further holistic needs assessment to guide anticipatory care and access to appropriate 24 hour support. If possible, discuss spiritual care needs with the patient or carers to enable practices in keeping with the patient's religious beliefs to be observed before and after death.

Use of an integrated pathway

Integrated pathways for end of life care, such as the Liverpool care pathway, have been introduced into the community setting with the aim of translating the gold standard of hospice end of life care to home and care homes. Such pathways may act as a prompt for improved communication and regular reviews of symptom control. Owing to the adverse media

attention regarding the use of the Liverpool care pathway in the acute setting in the UK, it is the subject of an independent review by the Department of Health, with results due to be published later this year.⁴⁰

Physical symptoms

Whatever the cause of death, patients may experience pain, shortness of breath, agitation, secretions, or nausea. Drugs should be prescribed pre-emptively for these common symptoms and be available at the patient's home or care home.⁽⁴¹⁾ A community drug prescription chart should be completed. If a patient requires two or more injections for symptom control within 24 hours, or is taking essential drugs that can no longer be given orally (such as long acting analgesia or antiepileptics), a syringe driver should be used to deliver a continuous infusion over 24 hours. It may be useful to have a provisional prescription for a syringe driver in case the need arises out of hours. If a syringe driver is not immediately available, four hourly subcutaneous injections can have the equivalent effect. Box 3 outlines symptom control drugs commonly prescribed in the terminal phase. For prescribing advice, contact your local palliative care team or consult Palliative Care Adult Network guidelines.

Setting may affect the symptom burden. A trial of hospital at home services for patients with dementia found that significantly fewer patients in the hospital at home group had problems with sleep, agitation, aggression, and feeding compared with those receiving inpatient hospital care.⁽⁴²⁾ The hypothesis is that a familiar environment helps reduce symptom burden, but evidence for this effect is insufficient in diagnoses other than dementia.

Hydration and nutrition

It is good practice to speak with the patient and family about hydration and nutrition towards the end of life, before specific concerns are raised.⁴³ It is useful to explain that oral intake gradually decreases in the terminal phase as the body becomes frailer, the coordination of an effective swallow becomes impaired, and the risk of aspiration increases. Simple modifications to diet, such as thickener, can be useful. Good mouth care helps maintain physical comfort.

Administration of parenteral fluids in the terminal phase can increase respiratory secretions and oedema, and in most cases it is unlikely to prolong life or improve quality of life. In certain situations, however, such as identifiable distress associated with thirst, parenteral fluids should be considered. Other such situations include a prolonged period of reduced level of consciousness or of dysphagia, or gastrointestinal obstruction, which make oral intake impossible. In such cases, administration of subcutaneous fluids (such as 1 L normal saline subcutaneously over 12-16 hours) may be useful. In the community setting, these can be prescribed by the GP and administered by district nurses or nursing home staff.

DNACPR

Patients should have a DNACPR (do not attempt cardiopulmonary resuscitation) order in their home or care home, with a copy shared electronically by EPaCC. The DNACPR decision is the responsibility of the doctor in charge of the patient's care (usually the GP). It should be discussed in advance with family and carers and also with the patient, if appropriate, unless it is likely to cause "undue distress."⁴⁴ It may be useful

Box 3 | Symptom control drugs commonly prescribed in the terminal phase (based on routine practice from authors extensive experience in the UK and Australia)**Opioid analgesics (for pain and shortness of breath)**

For example, morphine sulfate 10 mg/24 h subcutaneously through a syringe driver plus 2.5 mg subcutaneously as needed, or oxycodone 5 mg/24 h subcutaneously through a syringe driver plus 1 mg subcutaneously as needed

Anxiolytics (for anxiety or agitation and seizure prophylaxis)

For example, midazolam 10 mg/24 h subcutaneously through a syringe driver plus 2.5 mg subcutaneously as needed

Antiemetics (for nausea and agitation)

For example, levomepromazine 6.25 mg/24 h subcutaneously through a syringe driver plus 3.125 mg subcutaneously as needed, or haloperidol 1 mg/24 h subcutaneously through a syringe driver plus 0.5 mg subcutaneously as needed

Antimuscarinic drugs (for secretions)

For example, glycopyrronium 1.2 mg/24 h subcutaneously through a syringe driver plus 0.4 mg subcutaneously as needed, or hyoscine butylbromide 120 mg/24 h subcutaneously through a syringe driver plus 20 mg subcutaneously as needed

Tailor the prescription to the individual, taking account of the medical history. Doses given are examples of starting doses in a patient who is not taking opioid analgesia or on a complex symptom management regimen

to explain that when a patient is deteriorating from incurable disease with no reversible cause and is expected to die within days or weeks, cardiopulmonary resuscitation is futile.⁴¹ Framing the DNACPR order within the context of the patient's and family's goals for end of life care can be helpful. Explanation that a DNACPR order helps support a dignified death in the patient's place of choice and does not affect care up until the point that the heart and lungs have stopped (natural death has occurred) can also help. Families may seek reassurance that medical and nursing care will continue to be provided, including close attention to symptom control needs plus assessment for other medical interventions (such as antibiotics, bisphosphonate treatment of hypercalcaemia) as appropriate.

What should be done after death?

Care of the body after death should be guided by cultural and religious beliefs. Family and carers may need practical advice regarding verification of death, death certification, and registration of death. These procedures vary by country. In England, death can be verified by medical staff (for example, the patient's GP or out of hours GP) or appropriately trained nursing staff (for example, the district nurse). The death certificate should then be completed by a doctor who has seen the patient within the preceding two weeks (usually the patient's GP), otherwise discussion with the coroner is needed. If the coroner (or in Scotland, the procurator fiscal) will definitely need to be consulted (such as in cases of mesothelioma or death from an unknown diagnosis), it may be best to speak to the family about this process in advance because it may delay funeral arrangements. If the coroner does not need to be involved, after verification of death, the family can contact the undertaker of their choice directly to collect the body from the house.

What is the doctor's role in bereavement support?

Bereavement is one of the most stressful of all life events and is associated with subsequent worse mental and physical health.⁴⁵ Most people choose informal bereavement support from friends and family. The need for formal bereavement support is associated with poor social support and the nature of the death.

The effectiveness of risk assessment tools in predicting who will benefit most from formal bereavement support is

unclear. Risk factors for complicated grief include multiple recent losses, low acceptance of impending death, and death in hospital.⁴⁵ Those who are bereaved may be best placed to judge their need for formal support.⁴⁵ GPs play a key role in ensuring links between hospital and voluntary sector bereavement support (box 4 please see bmj.com).⁴⁶

Studies of effectiveness of bereavement support are scarce, particularly in care homes. The strongest evidence is from small non-randomised studies of complex grief reactions. In one systematic review,⁴⁷ relatives considered bereavement support to be an important aspect of the GP's role and expected contact from the GP immediately after bereavement.

What changes are needed?

Retrospective studies of relatives' experience of end of life care show that poor communication is the main reason for an unsatisfactory experience.^{30 47 49} The most valued aspects of home care are individualised care and quality of communication.⁵⁰ Strategies to improve communication include anticipatory care planning and coordination of care supported by increasingly sophisticated information technology systems (EPaCCS).

Undergraduate and postgraduate medical curriculums have failed to incorporate the complex communication skills and palliative care training that are central to providing good end of life care. There are signs that this is improving. Palliative medicine has this year been awarded specialty status in the US. Improved multidisciplinary education in end of life care is a recognised requirement, particularly in care homes.⁵¹

The need for 24 hour community services, including access to GP home visits and urgent care, is highlighted across studies.^{16 50-52} Recommendations include coordination of care by a multidisciplinary team with access to a doctor,⁵² support for carers, and provision of night services.⁵³ In the UK, existing end of life care services have been mapped so that gaps can be identified.⁵⁴ A more extensive end of life home care service has been recommended in Norway to reduce hospital admissions.⁵⁵

The challenge is to provide end of life care for increasing numbers of patients with dementia, long term conditions, and multimorbidities across all community settings, from home to care homes.^{6 7 51} The number of patients needing palliative care is increasing, so increased provision of such services is recommended.⁵⁶ It has been suggested that resources should be reallocated to the community to make the proposed savings from the acute sector.⁵¹ A recent Cochrane review found evidence to support the effectiveness of home palliative care services but insufficient evidence to support its cost effectiveness.¹⁷ The palliative care funding review should help answer this question.⁵⁷

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