

ABC of palliative care

Care in the community

Bill O'Neill, Ann Rodway

The physical complexities of progressive and life threatening disease, coupled with attendant emotional and psychological consequences, demand careful coordination between primary, secondary, and tertiary care. Across the whole range of health services, an increasing amount of care is being provided on an outpatient basis or independently of hospitals altogether: most terminally ill patients spend most of their time at home.

In the planning of care and agreeing a management plan, patients must be given an opportunity to express their wishes and these must be taken into account. Patients can make valid choices between treatment options only if they know what is happening, what help is available, what is likely to happen, and what help will be available in the future.

It is important to document accurately at each point what a patient's wishes are. Information must be tailored to patients to meet their need for knowledge and given at a pace with which they can cope. Rarely, patients may choose not to be informed. Some patients may wish to complete an advance statement, giving instructions about their wishes in the event of their losing the capacity to decide or to communicate.

Demands of home care

It can be much easier to care for patients in a hospital, hospice, or nursing home because of the infrastructure and immediate support available. Caring for a patient at home presents a challenge, and sometimes a burden, that is not as easily shared as in an institutional setting.

Although most patients wish to die at home, barely a quarter manage to do so. Over 90% of all patients with cancer spend some time in hospital during the last year of life, while 55% die in hospital and 17% die in a hospice. The desired place of death may change with altered circumstances, the most obvious being difficult symptoms and lack of practical help at home. Patients who are frightened, insecure, or lack confidence in their support network are more likely to seek urgent admission to hospital or hospice. Equally, if informal carers are physically or mentally tired they are more likely to seek admission, even when death is imminent.

Managing a patient at home requires not only an accurate assessment of the patient and his or her illness, concomitant physical and psychological symptoms, and support network but also an assessment of the patient's home. This may require an occupational therapist or physiotherapist to advise on the need for aids and, if necessary, modifications to the home. Forward planning is crucial, and much effort has to go into the general structure of care, which must be individualised for each patient. While primary care teams can systematically work through the aspects noted above, there is no automatic formula for all cases.

Stressed families caring for a dying patient are unlikely to have their thoughts well organised at the time of a first meeting. Primary care teams should help families and patients to evolve their thoughts, feelings, anxieties, and fears so that they can verbalise them, discuss what needs to be discussed, find answers to those problems that have solutions, get reassurance when it is appropriate, and develop a plan of action for problems that have no easy solution and are likely to worsen.

Issues of concern for terminally ill patients

- Specific symptoms
- Practical issues
- Family concerns
- Social factors
- Psychological factors
- Longevity *v* quality of life

Patients who make advance statements must be made aware that they cannot authorise or refuse in advance what they could not normally authorise or refuse—unlawful procedures such as euthanasia or futile or inappropriate treatment

Equipment and modifications that may be needed for home care of patients

Practical equipment

- Commode
- Wheelchair
- Hoist
- Incontinence supplies
- Raised toilet seat
- Bath aids
- Bed elevator
- Pressure mattress

Medical equipment

- Syringe driver
- Nebuliser

Home modification

- Hand rails
- Widening doors
- Stair lift
- Ramps



A range of equipment is available for fitting to a standard domestic bath

Life threatening disease often exposes ambiguities in family relationships. General practitioners are in an excellent position to understand past and present relationships, but they can be surprised by old unresolved problems uncovered in the stress of a terminal illness. An understanding of past relationships and behaviours, coupled with discussion and explanation of what is happening, may ease the situation. More complex problems may require referral to a clinical psychologist or a professional trained in family therapy. However, do not expect to resolve 30 years of conflict in the three weeks before death.

Primary care teams must maintain a role as gatekeepers to care, not just for referrals to specialist centres but also for referrals to specialist teams in the community. General practitioners should be consulted before hospital patients are referred to specialist community teams prior to discharge. Timing of referral is important, and, while referrals should be made early rather than late, there should be explicit agreement on the extent of involvement, including responsibility for counselling and emotional support for patient and family.



Many specialist nurses provide detailed advice and recommendations on drug therapy, a task that was previously the exclusive remit of doctors

Coordination of professionals

Communication

If a patient is to be cared for at home, good communication from hospital or hospice to primary care team is essential. Practical difficulties make it harder to achieve high standards of communication in the community and between institutional and community staff than within institutions.

Some primary care teams allow specialist community teams access to records held at the practice. Others invite members of community teams to practice meetings when patient care is being discussed. There is an argument for patient held records, in which details of proposed treatment and any subsequent changes could be recorded. Community nursing notes are commonly kept in patients' homes, and it is important that others caring for patients should consult these notes and make entries in them in order to facilitate communication.

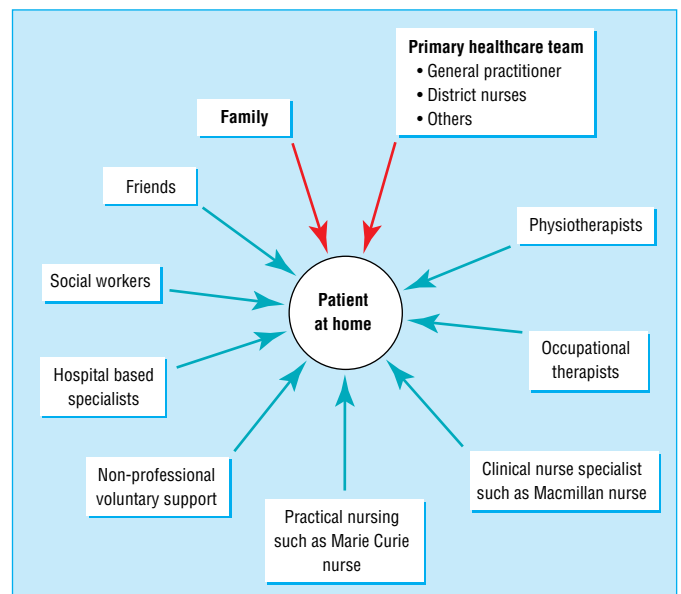
Advances in information technology and the resolution of concerns about confidentiality and security of data offer opportunities for sharing computerised records so that all those treating a patient have immediate access to details of treatment and any investigations performed.

Teamwork

Effective teamwork requires mutual understanding of the roles and responsibilities of each member of the team. General practitioners must maintain overall responsibility for the medical care of patients at home. Depending on patients' particular needs, the delivery of care is shared with the various members of the primary care team and members of the community team. District nurses play a key role when nursing care is required.

Regrettably, many patients have to be admitted to hospital or hospice because of inadequate practical help at home. Many families are disillusioned by the "package of care" provided. Needs are often not met—a common example is that even frequent visits by district nurses cannot always coincide with the needs of a patient to use the commode or toilet or to be turned in bed. Informal carers, particularly those looking after a patient single handed, find this very difficult and frustrating, especially when it results in admission to hospital or hospice. The ability to mobilise support often depends on local resources but also on organisation and structure.

Accurate and clear information must be rapidly available to primary care teams about the disease, treatment, expected events, likely prognosis, what the patient has asked and has been told, and who should be contacted if a problem arises



Groups involved in delivery of care to terminally ill patients at home

Complex rotas of visiting arrangements may be required, particularly for patients who are living alone, and these may involve social workers, home helps, district nurses, specialist palliative care nurses, and night sitters. The rota of care may include support from neighbours and other voluntary help

Nursing services

The availability of nursing services varies widely. In some areas district nursing services are limited to daytime, but available seven days a week; in others there is a twilight service; while in others a 24 hour on call service is provided. High dependency care may require a night sitting service, which can be provided by care assistants or by trained registered nurses. The choice may depend on the complexity of care and the need for drugs to be administered. Some health authorities have contracts for a service provided by Marie Curie nurses specially trained in the care of dying patients.

Palliative care teams

Most districts in Britain now have palliative care teams based in the community to advise and support primary care teams and patients and their families. The composition of these teams varies. All have specialist palliative care nurses (also known as Macmillan nurses), with varying levels of medical and other support. Some are attached to hospices and other specialist inpatient units. Many specialist nurses provide detailed advice and recommendations on drug therapy, a task that was previously the exclusive remit of doctors.

Financial and legal help

The greatest difficulties often arise in the boundaries between health and social care. The responsibilities of social workers in the community will include assessment for a "package of care" and, when appropriate, assessment for residential or nursing home care.

Although this is not always accepted by social services staff, many healthcare workers assume that financial and legal advice should be provided via a social worker. Patients and families may benefit from advice on access to benefits such as disability living allowance (DLA) and mobility allowance. Some patients and families find it necessary to supplement the care provided by statutory services with paid help, and this may warrant a claim for disability living allowance. Many patients need help in completing the forms required.

Macmillan Cancer Relief and other charities provide grants to patients with terminal diseases for specific purposes—help with paying electricity or gas bills, paying for the installation of a telephone so that patients have access to emergency support, home equipment such as a food liquidiser for those with difficulty swallowing, and the provision of bed linen.

Attendance at specialist clinics

For some patients, such as those presenting with advanced lung cancer, the diagnosis may be made after a single outpatient visit and procedure. Depending on the symptoms, no further hospital attendance may be indicated. Effective medical care at home depends on the role of the patient's general practitioner and the avoidance of unnecessary outpatient visits, which serve to perpetuate the sharp divide between hospital and community care.

At all stages of disease, there is a need to demystify the care provided in hospital, and for each visit the reviewing doctor should carefully consider whether it is justified. In some situations continuing hospital attendance may be appropriate as long as the patient is able and wishes this—for example, a patient who benefits from recurrent abdominal paracentesis for ascites or who needs three weekly infusions of bisphosphonates to prevent recurrence of hypercalcaemia of malignancy.

An efficient model of care should include arrangements for general practitioners to plan specialist outpatient visits at short notice. Visits made solely for a blood test or to allow hospital staff to check on the progression of disease should be avoided.



Some patients require complex drug regimens, in which case pills can be laid out in a dosette box by a family member or community nurse

Disability living allowance for patients with a prognosis of less than six months

- There is a fast track system for access to disability living allowance which obviates the need for assessment by a doctor appointed by the Department of Social Security
- In addition to the standard form, a further form (DS1500) must be completed and signed by a doctor

Macmillan Cancer Relief and patient welfare

In addition to providing medical nursing and social support for patients with cancer, Macmillan Cancer Relief has five caseworkers in its patient welfare department offering help and advice to healthcare workers on grant applications by patients

Caseworkers for different regions in the United Kingdom can be contacted on the telephone numbers below

- | | |
|-----------------------------------------|---------------|
| • Scotland, Wales, and Northern Ireland | 0171 867 9492 |
| • North of England | 0171 867 9493 |
| • Midlands | 0171 867 9490 |
| • South and south west | 0171 867 9491 |
| • London and south east | 0171 867 9496 |

Questions to ask about patients' visits to hospital

- What were the benefits of the visit?
- What were the negative features of the visit?
- Was this a justified visit?
- Who else is seeing this patient?
- What does the patient want?
- Has the situation been communicated properly with the general practitioner?

Emergencies

Emergencies (the subject of an earlier article in this series) are among the most challenging aspects of palliative care in the community. Primary health care teams should give clear, unambiguous advice about who should be contacted in an emergency. The advice should be agreed by all agencies caring for a patient, and there should be clear understanding of who should be called and how they can be contacted and a general discussion of the situations that may herald an emergency.

It may be appropriate to leave supplies of drugs in a patient's home for emergency use by community nursing staff and possibly family carers. Many patients are terrified of having uncontrolled symptoms overnight or at weekends, and a supply of suitable drugs may help to allay this fear.

Arrangements should be made for general practitioners, district nurses, and other community health workers to have access at all times to specialist advice from consultants in palliative medicine, pain, oncology, and surgery. Advice alone is often sufficient, but in some cases emergency outpatient assessment or home visits will be needed.

Foreseeable emergencies

Some emergencies can be anticipated, and appropriate arrangements made. Decisions should be taken on whether patients and their family carers should be advised of the risk of sudden bleeding, convulsions, or other potentially catastrophic events. The amount of information given will depend on the illness and its likely progress, the probability of an emergency occurring, the patient's wish for information, the family's need for information, and the support available immediately on site.

District nurses and specialist nurses, as well as general practitioners, should be aware of the importance of changes in symptoms that herald emergencies. Patients should be advised to report the development of muscular weakness or difficulties with bowel or bladder control, which could indicate spinal cord compression.

Respite care

Respite care can take the form of increased support in the home or attendance at a day centre, perhaps even once a week. The latter has the additional benefit of providing a change of environment, which is stimulating for the patient.

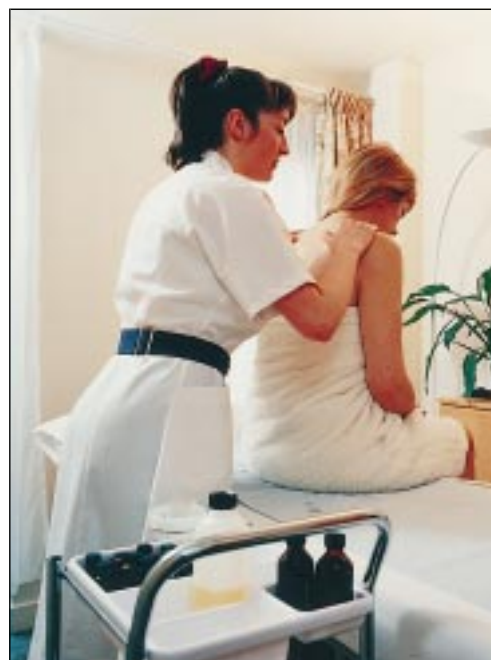
The range of services available at day centres varies greatly. Some are modelled on outpatient hospital departments, and arrangements can be made for treatments such as intravenous infusion of bisphosphonates or blood transfusion. Others, based on nursing care, can provide changes of dressings, treatment of lymphoedema, and more basic nursing needs such as access to an assisted bath. Others are based on recreational and diversional therapy, occasionally with additional services such as those of a hairdresser.

Inpatient respite care may be provided in inpatient units managed by general practitioners, hospices, or hospitals. During these admissions there is time to reassess symptoms, both physical and non-physical, and to attempt rehabilitation if appropriate. A common assumption is that patients with advancing cancer naturally "take to their bed," despite the fact that many patients benefit enormously from physiotherapy, occupational therapy, and other rehabilitative support.

Respite facilities are offered by certain nursing homes that admit patients on a temporary basis. Macmillan Cancer Relief and other charities may finance a week of respite care in nursing homes and residential holiday homes.

Drugs for emergencies in palliative care

- Diamorphine (or morphine) ampoules 10 mg or 30 mg
- Midazolam ampoules 10 mg
- Methotrimeprazine ampoules 50 mg
- Haloperidol ampoules 5 mg
- Hyoscine hydrobromide ampoules 0.6 mg



In addition to conventional treatment, some outpatient and day centres offer a range of complementary therapies



Occupational therapy at a Marie Curie centre

Death in the community

If death is anticipated and likely to occur at home it is important that the patient and family carers have an opportunity to discuss any anxieties that they may have about this. Many carers will never have been present at a death or seen a dead body, having been shielded from the death of parents, grandparents, or other relatives. Any impressions or experience they have may be based on violent or distressing deaths in films or on television.

While emergencies resulting in sudden death are not uncommon, the mode of death of many terminally ill patients can be anticipated. An explanation of progressive loss of consciousness and awareness, and of how any pain or breathlessness can be treated, will lessen many anxieties. Care must be taken not to make promises that cannot be fulfilled—promising total relief of pain or breathlessness that cannot then be achieved is likely to lessen confidence and cause difficulties in the future care of the patient and of surviving relatives.

After death

When given the opportunity many relatives ask about what will happen after death—what care is required for the body, who should be informed, and what procedures must be undertaken. In advising patients of the requirements after death, it is usually sufficient to explain the need for certification and registration of the death and to assure them that when they contact a funeral undertaker they will get all the necessary support and advice. Many undertakers provide written information for bereaved relatives, and information is also available from the Department of Social Security.

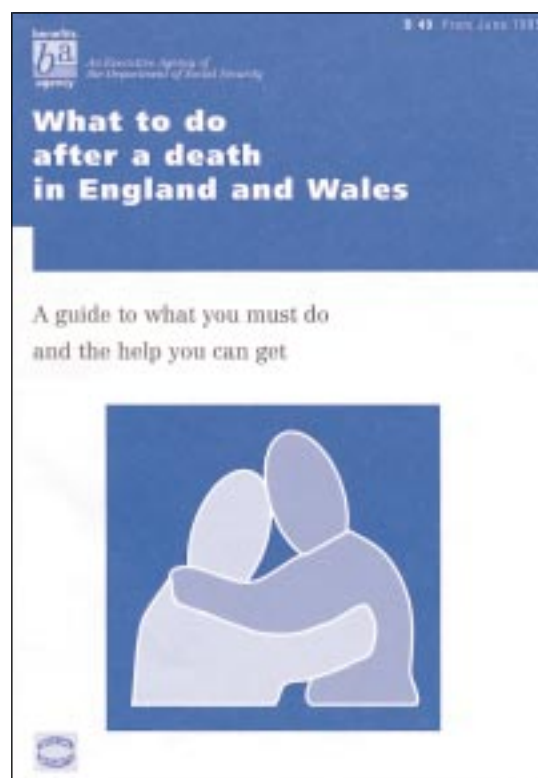
The responsibility for notifying a death to the registrar rests with a relative or, in the absence of a relative, a person present at the death or the owner of the premises in which the death has taken place. A doctor who attended the patient during his or her last illness will normally issue a medical certificate of the cause of death or report the death to the coroner. If the body is to be buried there is no legal requirement for it to be seen by a doctor after death, although it is advisable for the doctor who issues the certificate to do so. Some funeral directors refuse to move a body until it has been seen by a doctor and the death confirmed. In many institutions—including nursing homes, hospices, and hospitals—appropriately trained nurses can verify a death and agree to the removal of a body. The Royal College of Nursing has issued guidance on this.

If the body is to be cremated it must first be seen by the certifying doctor and by a second, independent medical practitioner whose registration is of at least five years' standing and who is not a partner or a relative of the first doctor or of the deceased. Membership of the same hospital clinical firm is interpreted as similar to partnership in general practice.

Although there is no legal obligation for care after the death of a patient, many doctors recognise their role in the care of bereaved relatives. Most palliative care teams offer a bereavement visit some time after the death, while many general practitioners also have relatives of the deceased as patients. Bereavement is the subject of the next and final article in this series.

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The ABC of palliative care is edited by Marie Fallon, Marie Curie senior lecturer in palliative medicine, Beatson Oncology Centre, Western Infirmary, Glasgow, and Bill O'Neill. It will be published as a book in June 1998.



The Department of Social Security provides information on the requirements after a death and on available services and benefits

Circumstances in which a death must be reported to the coroner

- Deceased was not attended in last illness by a doctor
- Deceased was not seen by a doctor either after death or within 14 days before death
- Cause of death is unknown
- There is any doubt about natural cause—suggestions of violence, neglect, or other suspicious circumstances
- Death was due to industrial disease or poisoning (including alcoholism)
- Death occurred during surgery or before recovery from anaesthesia (often interpreted as within 24 hours)
- Death was due to an abortion
- Death occurred in prison or in police custody

Some coroners advise that deaths that occur within 24 hours of admission to hospital and those where there is any allegation of negligence should also be reported.

Adapted from: Knight B. *Legal aspects of medical practice*. Edinburgh: Churchill Livingstone, 1992

The photographs of the bath aid and the dosette box are reproduced with permission of the Disability Living Foundation. The photographs of the specialist nurse advising on drug therapy, of the nurse providing complementary therapy, and of occupational therapy at a day centre are reproduced with permission of Marie Curie Cancer Care.