

Fortnightly Review

Enabling more dying people to remain at home

Graham Thorpe

When it comes to dying there is no place like home. Since earliest times most cultures have accepted that dying people should remain at home. But this was never possible for all. Some were destined to die in accidents, on battlefields, by execution, and from catastrophic illness, maybe many miles away. Nevertheless, with few exceptions people could expect to die in their own beds and in the bosom of their families.

In Europe from the Middle Ages until a century ago there was a simplicity about dying. Aware that the end was approaching, people would take to their sickbeds and preside over the ritual. The family, including children, friends, and neighbours would congregate. The ceremony was public and doctors often complained about overcrowding. Death was not regarded as a frightening event and was accepted as an inevitable and integral part of life. Dramatic changes in attitudes to death have taken place since the mid-nineteenth century. The natural acceptance of a biological reality has been lost and people are now unable to come to terms with their own mortality. One consequence is that death has become institutionalised.¹

This paper seeks to answer five questions. These refer to where people die, where they would choose to die, where they spend their last year of life, the reasons for admission for terminal care, and whether more dying people could remain at home. Discussion is restricted to adults in the United Kingdom. References are mostly from the past decade.

- Where do people die?
- Where would they choose to die?
- Where do they spend their final year?
- Why are they admitted for terminal care?
- Could more dying people remain at home?

Where do people die?

At the beginning of the twentieth century most people died at home. Progressively the proportion has fallen to 23%, and concurrently deaths in institutions have risen to 71%. Fifty four per cent of deaths occur in hospital, 13% in nursing or residential homes, and 4% in hospices.² The population is mainly urban (80%), but for people living in the country there is a greater prospect of dying at home, which increases the greater the distance from hospital.³

The social context for these changes is an aging population, a declining death rate, and an improvement in survival of very old people. Today people expect to die after retirement, and a high proportion of terminally ill people are over 75.² More elderly people now live in nursing or residential homes. A quarter of the population live alone, elderly people being more

Summary points

To enable dying people to remain at home they need:

- Adequate nursing care
- A night sitting service
- Good symptom control
- Confident and committed general practitioners
- Access to specialist palliative care
- Effective coordination of care
- Financial support
- Terminal care education

likely to do so. Homes and families are smaller, and fewer relatives and friends are available to share the care. Many women are working, and there is more migration of family members. Lack of familiarity with death creates anxiety in carers. In a welfare state with a national health service death and dying are expected to be taken over by professionals and managed in hospital. It is no longer considered appropriate to be born at home and may even be thought to be dangerous, and dying, like pregnancy, has now been medicalised and institutionalised.

Where would people choose to die?

It is generally assumed that most people would prefer to die at home, but there is little hard evidence. Of 59 patients with terminal cancer who stated a preferred place of death, 34 chose home, 12 hospital, and 12 a hospice. Of 18 patients who died at home, 17 stated that home was the preferred place to die. By contrast, only 10 of 32 patients dying in hospital had stated a preference to die there. Had circumstances been more favourable 41 (67%) of 61 patients would have preferred to die at home.⁴

In a prospective study of 160 patients (86 (54%) with cancer) referred to a hospital support team 100 (63%) died in hospital, 41 (26%) died at home, and 19 (12%) died in a hospice. Ninety patients could express a preference for place of death: 48 wished to die at home, 26 in a hospice, 13 in hospital, and three in a nursing home. Sixty four of the 90 patients achieved their choice, but the remainder became too ill to transfer and died in hospital.⁵

In an unselected group of 80 patients terminally ill with cancer 31 died at home, 41 in hospital, and eight in a hospice. The 80 carers were interviewed, and 57 (71%) reported that the place of death had been the right place for the patient to die. Thirty of the 31 carers of patients who had died at home were satisfied with

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the place of death; by comparison, only just over half of the carers of patients who had died in hospital (22 of 41) were satisfied with the place of death.⁶

These studies support the view that most dying people would prefer to remain at home.

First paradox

Most dying people would prefer to remain at home but most of them die in institutions

Where do people spend their final year?

Dying people spend most of their final year at home.⁷ Cartwright, using random sampling in 1969 and 1987, undertook two substantial national studies of the last year of life. In the first study 82% of people spent less than three months in hospital and 63% less than one month, 30% having not been in hospital at all. In 1987 the figures had fallen to 75%, 54%, and 16% respectively.⁸

Second paradox

Most of the final year is spent at home but most people are admitted to hospital to die

Why are people admitted for terminal care?

There are several reasons why dying people are admitted to hospital. Symptoms may be poorly controlled, nursing demands may become excessive, or the strain on carers may become too great. Often a crisis arises—for example, the onset of severe pain or vomiting, or the sudden illness of the main carer. Wilkes found that the difficulties of the relatives were more often a cause for hospital admission than those of the patients.⁹ In a study of domiciliary terminal care in Edinburgh, Doyle found that in 90% of cases in which admission became necessary it was because of stress on relatives, the impossibility of providing more nursing staff, the lack of night sitters, or the absence of equipment. In fewer than 10% was the reason difficulty in controlling the patients' symptoms.¹⁰ Herd, who studied terminal care of cancer patients, divided reasons for admission into social and medical. In the

first category of admissions 45% were of people whose lay carer was unable to continue and 22% were of people who did not have a lay carer. The commonest medical reasons for admission were symptom control (55%), investigations (24%), and nursing needs (20%).³ Admission to hospital does not necessarily imply improved care.⁶

Can more dying people remain at home?

At present many people who would prefer to die at home are admitted to hospital for terminal care because of inadequate support in the community. Can anything be done to change what is clearly an unsatisfactory situation?

Not all dying people can be cared for at home, and some will choose to die in hospital or a palliative care unit. However, a large proportion of those admitted could be cared for at home if better support were provided.^{3,4,6,8,9,11-13} It is quite possible for some people living alone to die in their own homes, though having a carer greatly enhances the prospect. Over 40% of carers are above retirement age, and over half are spouses. Caring involves emotional stress, which may sometimes be excessive, but many people find caring for a dying person rewarding. Carers often show great commitment and endurance, but it is crucial to deploy an adequate network of support. This should be done before any crisis arises and there will then be a better chance of the dying person remaining at home. The possibility of other carers sharing tasks with the main carer should always be explored.

Conditions needed to keep patients at home

ADEQUATE NURSING CARE

Community nurses often work under great pressure with too big a caseload, such that they cannot spend enough time with patients.^{3,4,6,8,10-13} Occasionally, because nurses are working to full capacity, patients are kept in hospital until their needs can be met by the community nursing service. More community nurses should be funded as a matter of urgency.

NIGHT SITTING SERVICE

Caring for someone 24 hours a day for weeks on end is a considerable strain. Often patients are most demanding at night, and night sitters are invaluable, relieving carers of their responsibility and allowing some respite. Only limited provision is available through the NHS, additional help having to come from charitable sources. All purchasing authorities should provide an adequate night sitting service.

GOOD SYMPTOM CONTROL

Cartwright and her colleagues in their 1969 study opened a Pandora's box revealing a plethora of suffering during the last year of life. Pain and other symptoms were poorly controlled, often for long periods.¹² Since then the specialty of palliative medicine has emerged and been given formal recognition, and much knowledge has been documented on symptom management which is readily available to all those caring for people who are dying.¹⁴

CONFIDENT AND COMMITTED GENERAL PRACTITIONERS

Some general practitioners provide an excellent service for patients dying at home, but others have encountered problems in controlling pain and coping with the emotional distress of patients and relatives.¹⁵ Home visiting by general practitioners has decreased, and in one study the most frequent criticism of general practitioners was of their reluctance or failure to visit.⁸ Jones has presented nine guidelines for the terminal care of cancer patients at home.¹⁶ Although nurses



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Until a century ago people would take to their beds and preside over the ritual



VAN DYCK/DULWICH PICTURE GALLERY

Before death became institutionalised

undertake the physical care, general practitioners who have gained experience, knowledge, and confidence in terminal care, and who are prepared to visit regularly, can do much to minimise suffering and support patients and carers.

ACCESS TO SPECIALIST PALLIATIVE CARE

Terminal care is an important part of palliative care. Not everyone dying at home needs specialist palliative care, but access to such a service should be available to anyone who does. Home care sisters and Macmillan nurses work in partnership with community nurses, giving advice on management and symptom control and providing psychological support for patients and families. Consultant physicians in palliative medicine are available to undertake domiciliary visits to provide expert opinions on aspects of terminal care.

There is a great advantage in a strong link between a home care service and a palliative care centre. There is then ready access to beds for symptom control, rehabilitation, respite care, and when a crisis arises necessitating admission. Day care is provided, and additional facilities—either for outpatients or for patients at home—include physiotherapy, occupational therapy, complementary therapy, and advice from social workers and chaplains. Volunteers extend the range of support and services considerably. Items of equipment must be provided quickly and are available on loan. Other sources are often less reliable, with long delays, the equipment sometimes arriving after the death of the patient.⁶

The first home care team was established at St Christopher's Hospice, London, in 1969, and evaluation showed it to be successful. Patients could stay at home until a later stage in their illness, and the length of time they spent in hospital was almost halved. Families were well satisfied with the help given, and there were considerable savings in cost to the NHS.¹⁷

EFFECTIVE COORDINATION OF CARE

Comprehensive terminal care requires scrupulous planning and coordination. Many different professional and voluntary groups may be included. For teamwork good communication is essential, and the

appointment of a keyworker is useful. Often the best person for this role is the community nurse who visits frequently. In other cases the general practitioner or social worker would be more appropriate. Good relationships of trust with patients and carers need to be established early and before a crisis develops.

FINANCIAL SUPPORT

Caring at home for a dying relative is expensive, and the professional team should make sure that information is given about financial support available. The attendance allowance can now be obtained promptly under the special rules. Patients who have a permanent fistula are entitled to free prescriptions, and these should also be arranged once patients can no longer venture out of the house unaided. Additional grants may be obtained from charities.

An interesting initiative was taken during a study of home care for terminally ill cancer patients in Motala, Sweden, where 85% of deaths occur in institutions. Of patients referred to the home care service, 89% were able to die at home. To cover loss of income for relatives choosing to stay at home for months to care for a family member an allowance corresponding to their net salary was paid, and 42% availed themselves of this. Though generous, when considered from a wider perspective, the allowance was a cost saving measure.¹⁸

TERMINAL CARE EDUCATION

Palliative care centres should provide regular education programmes for students and qualified practitioners in all the disciplines concerned in terminal care. Special attention should be given to the needs of community nurses and general practitioners. In several parts of Britain general practitioner palliative care facilitators have been funded jointly by Cancer Relief Macmillan Fund and the Department of Health in order to enhance the continuity and quality of care for patients with advanced disease. They can give advice and arrange educational events.

The Countess Mountbatten House experience

At Countess Mountbatten House, Southampton, a palliative care service for cancer patients is provided within the NHS for a million people in three health districts, and six home care sisters are employed in the care of up to 160 patients in the community. Annual statistics show that in 1982, 35% of home care patients were able to die at home. This figure has risen progressively, such that by 1992 it had reached 52%. Also during the period substantial change occurred in the inpatient unit, where over 600 patients are admitted annually to the 25 beds. In 1982, 62% of these patients died and 38% were discharged. In 1992 the discharge rate was 50%. This figure compares favourably with the national median discharge rate of between 30% and 35%.^{19 20}

There are two important reasons why more of these patients can die at home: these are an efficient and effective home care service and charitable funding of a sitting and nursing service. Of the sitting and nursing service, over 90% has been provided at night and almost 70% is by care assistants and auxiliary nurses, the rest being undertaken by trained nurses. Some funding for home nursing is provided by the NHS and Marie Curie Cancer Care, but the charity Friends of Countess Mountbatten House has always given this aspect of terminal care a high priority, and during the past four years the average annual expenditure on this item has been £62 800.

This example shows that a home care service backed by all the resources of a palliative care centre, in conjunction with a sitting service, can enable more dying people to remain at home.

Government action

Radical reforms inevitably create chaos, and it may be up to 10 years before the turbulence in the NHS settles and any assessment can be made of the effects of the changes. No strategic planning is possible, as purchasing authorities cannot make any commitment with respect to future funding and money does not yet follow the patient. It remains to be seen to what degree general practitioner fundholders will take on responsibility for terminal care and to what extent they will use specialist palliative care services.

Government action

- Expand the patient's charter
- Invest in primary health care
- Implement *The Principles and Provision of Palliative Care*²⁶
- Provide adequate funding for community care

EXPAND THE PATIENT'S CHARTER

In the new world patient choice is given priority, and with respect to childbirth purchasers should now ensure that home birth is a real option for women who want it.²¹ So it should be for dying patients who wish to remain at home. Probably greater importance should be given to making choice available for them than for pregnant women. Giving birth is restricted to less than half the population whereas everyone will die. An eleventh right should therefore be added to the patient's charter—namely, to be able to choose the place of death.²²

INVEST IN PRIMARY HEALTH CARE

The government is committed to improving quality of life²³ and helping people live full and independent lives at home.²⁴ Investing in primary health care is one way to achieve these aims. Action has been taken with respect to London with an investment of £40m to provide better premises and raise the standard of medical and nursing practice. The need to expand the community nursing service was identified. High intensity home care services are to be developed with better respite support.²⁵ The standard of primary health care nationwide varies considerably and investment will also be required outside London. Better primary health care will mean that more people can die at home.

IMPLEMENT "THE PRINCIPLES AND PROVISION OF PALLIATIVE CARE"

An important government report on palliative care services was published in 1992.²⁶ This made it clear that they should be readily available to all patients needing them; that they should be provided not only for cancer patients but for all patients with advanced and progressive disease; that they should be developed as part of normal NHS provision and integrated with general practice; that palliative care should be provided individually for patients wherever they are rather than be centred in units; that purchasing authorities should provide a comprehensive service; that palliative care specialists of all disciplines should be available as a

source of advice and a resource; and that there should be an expansion of education programmes in palliative care. These are important recommendations which when implemented will enable more people to die at home.

PROVIDE ADEQUATE FUNDING FOR COMMUNITY CARE

The National Health Service and Community Care Act 1990 required that from April 1993 local authorities must carry out assessments of individuals in need. If adequate funding is available there is now an opportunity for initiatives to be taken in designing packages of support for dying people in their own homes.

"In the re-organised Health Service the care of the fatally ill patient as yet falls far short of full integration."²⁷ This statement, published in 1976, remains true. The recent history of mental health is that many psychiatric hospitals have been closed or are closing and, despite problems, more people are being supported in the community. If death is to be domesticated again this challenge of enabling more dying people to remain at home must be accepted and action taken. After all, it is a challenge in which everyone has a vested interest.

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