

# Foreword

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But I have promises to keep, and miles to go before I sleep.

Robert Frost

The above quotation reminds us of all that people can achieve during the last phase of life. This textbook, now into another edition in response to demand, covers ground much wider than just a systematic approach to symptom control but is concerned with the whole impact of persistent disease upon a person and the whole family. Its historical development was summed up by Wall in 1986:

Up to the 19th century, most medical care related to the amelioration of symptoms while the natural history of the disease took its course toward recovery or death. By 1900, doctors and patients alike had turned to a search for root cause and ultimate cure. In the course of this new direction, symptoms were placed on one side as sign posts along a highway which was being driven toward the intended destination. Therapy directed at the sign posts was denigrated and dismissed as merely symptomatic. By the second half of this century, a reaction set in as seen by such remarkable developments as the hospice movement. The immediate origins of misery and suffering need immediate attention while the long-term search for basic cure proceeds. The old methods of care and caring had to be rediscovered and the best of modern medicine had to be turned to the task of new study and therapy specifically directed at pain.<sup>(1)</sup>

Such pain is not merely physical. By 1964 it was noted that the single word *pain* could refer to 'total pain' with mental distress and social and spiritual problems, with patients making such statements as, 'it seemed that all of me is wrong'.<sup>(2)</sup>

Approaches to death and dying reveal much about the attitude of the society as a whole towards the individuals who go through it. The development of ideas of what constitutes a good death can even be traced to pre-history. Funeral rites can be dated back 50 000 years, and from this time show how early men laid down their dead in grief and in some hope of a continued existence.<sup>(3)</sup> Gentles traces the way funeral rites have become less and less elaborate and comparatively less costly over the millennia in proportion to the wealth of society.<sup>(4)</sup> But there seems to be more to it than that. The fantastic wealth of Egyptian funerals and the expenditure of time and human effort on such memorials as the pyramids were concentrated on the Pharaohs who in some sense personified the longings for immortality of the rest of the populace. Attitudes to death reflect attitudes to religion and community.

Aries reviewed Western attitudes towards death from the Middle Ages to the present.<sup>(5)</sup> At the beginning of the period he describes 'tamed death', when the dying person was sure of his role in preparing for the end according to ritual or custom (ref. 5, pp. 2–9). He was himself the centre of the stage, hopeful, if all was done in order, of a safe passage to the next world. Aries compares this with Solzhenitsyn's description of the death of the simple people of the country who 'departed easily, as if they were just moving into a new house'.<sup>(6)</sup> Similarly, Aries points out, the cemeteries of the early Middle Ages were open and public places and 'the living were as familiar with the dead as they were familiarised with the idea of their own death' (ref. 5, p. 25).

Gradually, during the Middle Ages subtle modifications gave a dramatic and personal meaning to this traditional familiarity. An increasing emphasis

on the Last Judgement and the displacing of this to the end of each life, with all its concentration on feelings of sin and failure, together with a macabre interest in physical decomposition, gave a more personal, threatening focus. One's own death, and an urge somehow to maintain identity despite the loss of all material attachments, took the place of the familiar resignation to the collective destiny of the species (ref. 5, pp. 27–52). The individual has his/her particular place in the Christian Gospel (e.g. the search for the one lost sheep to join the ninety and nine safe in the fold) but the emphasis grew more urgent with the Renaissance.

Aries traces in the exaggeration of mourning that developed in the nineteenth century, a new fear, not so much of the death of the self as the death of another—the origin of the cult of tombs and cemeteries as we know them. This development was sharply brought to an end in many places in the twentieth century by a process far more abrupt than any so far summarized, surely related to the carnage of the War of 1914. From now on we see a process by which death becomes, as Aries puts it, 'shameful and forbidden', something to be hidden from those around.

The increasing tendency not to tell the dying person the truth of his/her condition, the likelihood of dying in hospital, often alone, rather than at home, and the inability of the society to allow any display of emotions in public, all made death an outlaw, a forbidden subject. We have not found our way to come to terms with our mortality, and each person, each family, with little help from ritual, or tradition, or from those around, has somehow to find a way to come to terms with and grow from loss. The old acceptance of destiny has disappeared and a new sense of outrage that modern advances cannot finally halt the inevitable makes caring for the dying and for their families demanding and often difficult, but perhaps all the more rewarding as truth becomes more openly discussed.

The present volume, looking at the whole field of the multidisciplinary speciality of palliative medicine, addresses aspects of this problem and, importantly, shows how appropriate treatment before a patient can rightly be termed 'dying' can make a radical difference to the last span of life and to the way the family lives afterwards.

## The early hospices

A considerable part of this new and positive attitude, with its new range of possibilities, stems from the attitudes and skills of the modern hospice. An ancient word, although not originally concerned with dying, it has some connotations that introduce interesting comparisons with the aims of a modern hospice and palliative care teams. The Latin word *hospes* first meant 'stranger'. By late classical times, the word had changed and denoted a host, while *hospitalis* meant friendly—the welcome to the stranger. From it was derived hospitality and thence many words used today—hospital, hostel, hostelry, hotel—and hospice. Another noun was derived—*hospitium*, originally the warm feeling between host and guest, and later the place where this feeling was experienced. The Greek version was *xenodochium* and by the fourth century came the first of many Christian institutions under both names, arising first in the Byzantine area<sup>(7)</sup> and later spreading to Rome and finally throughout Europe as hospice or hospital.<sup>(8)</sup> They were

based on the Christian command 'As you did it to one of the least of these my brethren, you did it to me' (Matt. 25, v. 40). This was a radically different approach from the Hippocratic tradition in which a doctor did not treat the incurably sick or terminally ill. It was thought unethical to treat a patient with a deadly disease, for in so doing the doctor risked paying the penalty awaiting those mortals who challenged nature and the gods.<sup>(9)</sup>

These hospices welcomed pilgrims, often very battered and perhaps dying, and gradually came the connotation of sickness as Christians set out not only to welcome strangers and give food and drink, but also to care for the sick. As hospices developed along the pilgrim routes, local people in need undoubtedly came for help and were not sent away. Hospices lasted throughout the Middle Ages, but most came to a rather abrupt end with the Reformation. The state of the incurable and dying, no longer the honoured guests but often consigned to Poor Law or equivalent institutions, could be desperate. An example of how the Church's concern for the sick and poor was missed is illustrated by a petition to Henry VIII from the Lord Mayor and citizens of London. They implored the King to re-found the priory of St Bartholomew in Smithfield and that of St Thomas across London Bridge in Southwark 'for the ayde and comfort of the poore sikke, blynde, aged and impotent persones, beyng not able to helpe themselffs, nor haunyng any place certeyn whereyn they may be lodged, cherysshed and refressed tyll they be cured and holpen of theyre dyseases and sycknesse'.<sup>(10)</sup>

## The modern hospice movement

As has been pointed out, the medieval hospice was not primarily associated with dying people, and over the centuries it had come to welcome an impossible mix of patients along with travellers and pilgrims, orphans, and the destitute, with varying degrees of segregation. Such care as could be attained was a primary aim, but with comparatively little to offer many must have died, being cared for to the end with much emphasis on spiritual comfort.

The first use so far discovered of the word 'hospice' solely for care of the dying was by Mme Jeanne Garnier in Lyons, France, in 1842, who founded several such hospices or *Calvaires*. There was no connection with the Irish Sisters of Charity who opened Our Lady's Hospice in Dublin in 1879 and St Joseph's Hospice in East London in 1905, both for incurable and dying patients, but Calvary Hospital in New York (1899) drew its inspiration from this source. Three Protestant Homes had been opened in London by the time St Joseph's welcomed patients. These were the Friedensheim Home of Rest (later St Columba's Hospital) in 1885, the Hostel of God (later Trinity Hospice) in 1891, and St Luke's Home for the Dying Poor in 1893. Several small catholic, protestant, and Jewish homes were founded under different titles in the turn of the nineteenth and twentieth centuries in the USA and Australia. The author's 7 years from 1948 as a volunteer nurse in St Luke's, by then named Hospital, and the reading of its many complete and lively annual reports by Dr Howard Barrett, its founder, were a major influence in the early planning of St Christopher's Hospice.

These reports are full of individual stories of carefully observed people. Here we are not meeting 'the dying' but people, often part of destitute families. In 1909 Dr Barrett wrote:

We do not think or speak of our inmates as 'cases'. We realize that each one is a human microcosm, with its own characteristics, its own aggregate of joys and sorrows, hopes and fears, its own life history, intensely interesting to itself and some small surrounding circle. Very often it is confided to some of us.

None of these homes had much impact upon general care for dying people.<sup>(11)</sup>

There was also much to learn from the Marie Curie Memorial Foundation. In 1952 it published a report detailing a great deal of suffering among patients dying of cancer at home.<sup>(12)</sup> Their response in supplying home nurses and in opening a series of cancer-care homes marked another important milestone in terminal care. But above all, the author's 7 years in clinical care at St Joseph's listening to patients, introducing records, and monitoring the results of the development of pain and symptom control

first seen in St Luke's as the regular administration of oral opioids were crucial. Patients' comments and conditions revealed the need for appropriate treatments, for care in their own homes to supplement the existing community services, and for family support both before and after bereavement. Above all, the need for research and education in what was eventually to become a new speciality was revealed through much reading and many visits during those years.

The opening of St Christopher's in 1967 as the first research and teaching hospice that included home care, family support throughout illness, and bereavement follow up, led to several different systems of offering care. This began to be termed the Hospice Movement in North America, where patterns other than free-standing inpatient units were first developed. Similar systems arose not long afterwards in the United Kingdom. In 1974, The Connecticut Hospice began offering home care with a medical and professional team leading many volunteers, without its own back-up beds. In New York, a consulting team began working throughout St Luke's Hospital during the same year. In early 1975, Mount opened the Palliative Care Service in Royal Victoria Hospital, Montreal. The founders of all these teams had spent sabbatical periods of study and experience at St Christopher's Hospice. These developments demonstrated that hospice care did not have to be limited to a separate building, but that the new attitudes and skills could be practised in a variety of settings. Since those early days, a world-wide spread has shown that the basic principles can be interpreted in widely differing cultures and with few resources other than the family values of the developing world.<sup>(13)</sup>

The Montreal Unit was not the first such use of the word palliative, although apparently there was no connection. In 1890, Dr Herbert Snow, Surgeon to the Cancer Hospital, Brompton, London, published a book on 'The Palliative Treatment of Incurable Cancer, with an Appendix on the Use of the Opium Pipe'.<sup>(14)</sup> He also published an article in the British Medical Journal on 'Opium and cocaine in the Treatment of cancerous disease'.<sup>(15)</sup> The Cancer Hospital (now the Royal Marsden Hospital) was next door to the Brompton Hospital for Diseases of the Chest. Perhaps the pharmacists were in touch when the latter hospital produced the Brompton Cocktail in the early 1930s with its main ingredients of morphine or diamorphine and cocaine. Its regular four-hourly usage in St Luke's Hospital can be traced back to 1935, through the memories of a former matron. The Cancer Hospital was committed to patients with advanced disease. In 1909 Dr Horder was allocated 19 beds for such patients and in 1964 a ward was re-opened with 16 beds in Dr Horder's name. No record of what happened in the interim period can be found.

## New tools for relief

All the new teams set out first to establish the control of the distress that had led to their patients' referral. For this they had many new tools on which to depend due to the work and discoveries of the 1950s, including new psychotropic drugs, phenothiazines, antidepressants and anxiolytics, synthetic steroids, and nonsteroidal anti-inflammatory drugs. New analgesics were also available, although even now none has so far replaced the well-tried opioids. Rather, it has been a continuing challenge to understand their actions, and to compare and test different routines, compositions, and methods of administration. At the same time, reports came from new pain clinics, and work concerning better understanding of family dynamics and bereavement was undertaken at the Tavistock Centre for Human Relations. Developments in both cancer chemotherapy and intensive care units also had their impact in both contrast and continuity with the work of the new teams. A detailed study of 102 matched patients by Hinton<sup>(16)</sup> on 'The physical and mental distress of the dying' documented the need to address problems largely ignored by the main thrust of medical development in general hospitals at that time. A short, but comprehensive, nationwide study by Hughes showed the woeful gap in adequate care of dying people.<sup>(17)</sup> Even earlier, in 1945, four social workers in Boston revealed some of the inadequacies in end of life care in a series of 200 patients.<sup>(18)</sup>

During the 1960s Kubler-Ross began her series of interviews with patients talking about dying in a large general hospital in Chicago. Her book 'On Death and Dying'<sup>(19)</sup> had a major impact on the public and on many professionals, and undoubtedly prepared the ground for the growth of hospice home-care teams in the United States. It also had an impact in other countries, although the original impetus, summarized above, came from more traditional sources, developing 'in the interstices of the NHS'.<sup>(20)</sup>

At about the same time Parkes began publishing his studies of bereavement. His approach to the whole family had a major influence on the planning and early development of St Christopher's and, from there on, the whole movement. He was to carry out much of the early evaluation of hospice work.<sup>(21)</sup>

The influences that came together include barely remembered influences. Most important is the impact of the many hundreds of patients whose notes were summarized, whose conversations were tape-recorded, and whose memories remain. They were the real founders of the hospice movement. Workers in clinical pain research were encountered and studied in researching the hospice foundation. Contacts with pain clinics were also developed.

There are, of course, other sources of the whole spectrum of palliative medicine as it is brought together in this book. The most important element that links the early teams and the present widely developing branch of medicine is an awareness of the many needs of a person and his family as they grapple with all the demands and challenges introduced by the inexorable progress of a disease that has outstripped the possibilities of cure. Although the early foundations took such subtitles as 'for the dying', the new teams had early on established, as their main objective, the quality of life until death. The message was: 'You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die'.<sup>(22)</sup> These words together with the concept of total pain—a combination of physical, psychological, social, and spiritual elements—were built into St Christopher's and from thence into the modern hospice movement.

St Christopher's Hospice brought together these elements to set up this work, to demonstrate and evaluate its practice, and to encourage others to consider similar work in their different ways and settings. This had all been discussed in detail with the Ministry of Health, and in 1966 a research and development grant was awarded to set up a home-care service (established in 1969), to conduct a comparative study of oral morphine and diamorphine (began the same year), and to perform an evaluation of local services and the effect that the presence of the Hospice would have upon them (from 1967). Research and rigour in developing clinical practice and education were built in from the beginning.

It was important to emphasize that what was being developed was not a soft option that would only be termed 'care', but a more appropriate treatment for people with advanced disease and for their families. The main focus on malignant disease enabled the workers to concentrate on a limited range of symptoms and social and emotional problems and to produce a number of studies and publications, first from St Christopher's and soon from other centres such as Montreal and later Oxford, Southampton, and elsewhere. The present volume makes clear how widely these challenges are now recognized and tackled.

If there had not been a great amount of distress documented, among others, by the Marie Curie Memorial Foundation in the home and by Hinton in hospital and felt deeply by all who could remember a sadly unrelieved death in their family or among their acquaintances, there would not have been the spread of interest and action, first in the United Kingdom and then in North America, Europe, Australia, Southern Africa, and many countries throughout the world. If there had not been continued contact with both fundamental scientists and clinicians occupied in research in pain and with many workers in other specialties, there would have been no sound basis of practice to share and to become one of the roots of the whole development of the spectrum of palliative medicine as presented in this textbook with all the updates and additions of this new edition.

## Challenges and principles

A chapter on 'Terminal care' in the 'Oxford Textbook of Medicine'<sup>(23)</sup> was reviewed as 'a characteristic mixture of tough clinical science and compassion'.<sup>(24)</sup> All the work of the professional team—the increasingly skilled symptom control, the supportive nursing, the social and pastoral works, the home care, and the mobilization of community resources—enable people to live until they die, at their own maximum potential, performing to the limit of their physical activity and mental capacity, with control and independence wherever possible. If they are recognized as unique and are helped to live as part of their families and in other relationships, they can still reach out to their hopes and expectations and to what has deepest meaning for them and end their lives with a sense of completion. The family, so often the caring team, will share this.

Awareness of what 'quality of life' means to people now demands full consideration of both the nature of their suffering and the appropriateness of various possible treatments and settings in their particular circumstances. Alertness to any remission of their disease or disability should accompany the optimum control of all the manifestations of an inexorable advance.

Patients should end their lives in the place most appropriate to them and to their families, and where possible, have choices in the matter. Some insight into the serious nature of their disease by the patient will help towards realistic decisions. Continuity of care can be maintained in the midst of change if there is effective care as presented anew by the contributors to this textbook.

When a person is dying the family find themselves in a crisis situation, with the joys and regrets of the past, the demands of the present, and the fears of the future, all brought into stark focus. Help may be needed to deal with guilt, depression, and family discord, and in this time of crisis there is the possibility of resolving old problems and finding reconciliations that greatly strengthen the family. If this time is to be fully used, there needs to be some degree of shared awareness of the true situation. Truth needs to be available (though not pressured) so that the family can travel together. In general, sharing is more creative than deception. The often-surprising potential for personal and family growth at this stage is one of the strongest objections most hospice workers raise for the legalization of a deliberately hastened death or for an automatic policy of 'shielding' a patient from the truth. No one should have information forced upon them, but any continuing communication with a patient is likely to open up the subject sooner or later. The doctor who overcomes his own fears of the subject will learn how, and when, and what to tell.

At times the work will cause pain and bewilderment to all members of the staff. If they do not have the opportunity of sharing their strain and questions, they are likely to leave this field or find a method of hiding behind a professional mask. Those who commit themselves to remaining near the suffering of dependence and parting find that they are impelled to develop a basic philosophy, part individual and part corporate. This grows out of the work undertaken together as members find that they each have to search, often painfully, for some meaning in the most adverse circumstances and gain enough freedom from their own anxieties to listen to another's questions of distress.

Most of the early homes and hospices were Christian in origin, their workers believing that if they continued faithfully with the work to which they felt called, help would reach their patients from God who had Himself died and risen again. Some of the traditional ways of expressing this faith are being interpreted afresh today, but there are also many people entering this field who do not have such a commitment, or who belong to other faiths or none.

Now that palliative care is spreading worldwide it has still, according to the definition of the World Health Organization<sup>(25)</sup> kept a concern for the spiritual needs of its patients and their families. The whole approach has been based on the understanding that a person is an indivisible entity, a physical and a spiritual being. The search for meaning, for something on which to trust, may be expressed in many ways, direct and indirect, in

metaphor or in silence, in gesture or in symbol or, perhaps most of all, in healing relationships and in a new experience of creativity. Those who work in palliative care may have to realize that they too are being challenged to face this dimension for themselves. Many, both helper and patient, live in a secularized society and have no religious language. Some will, of course, still be in touch with their roots in this area and find a familiar practice, liturgy, or sacrament to help their need. Others, however, will not, and insensitive suggestions in this field will be unwelcome. However, if we can come together not only in our professional capacity but also in our common, vulnerable humanity, there may be no need of words on our part, only of respect and concerned listening. For those who do not wish to share their deepest concerns, care is given in a way that can reach the most hidden places. Feelings of fear and guilt may seem inconsolable but many of us have sensed that an inner journey has taken place and that a person nearing the end of their life has found peace. Important relationships may be developed or reconciled at this time and a new sense of self developed.

A human as well as a professional basis has a fundamental bearing on the way that the work is done, and everyone meeting these patients and their families is challenged to have some awareness of this dimension. Their search for meaning can create a climate in which patients and families can reach out trustingly towards what they see as true and find acceptance of what is happening to them.

The values that the hospice movement tried to establish, alongside its commitment to excellence in practice, have shown that there are ways of seeking for 'good death' today. Its 'holistic' approach has been built into the whole spectrum of palliative medicine and is presented anew by the contributors to this textbook.

The hospice movement and the specialty of palliative care that has grown out of it, reaffirms the importance of a person's life and relationships. Focused research, attention to details, and a developing expertise has aimed to avoid the isolation that many have suffered, often increased by inappropriate interventions. If people know they are respected as part of the human family (and here the developing countries have much to teach us all), the ending of life can be a final fulfillment of all that has gone before. As the modern hospice began by listening to patients, let one patient have the last word: 'Loneliness is not so much a matter of being alone as of not belonging'.<sup>(26)</sup>

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