

THE BEATTY MEMORIAL LECTURE

“LESSONS IN LIVING FROM THE DYING”

GIVEN BY

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In responding to this title I have many people - indeed innumerable people - to salute, beginning with my own patients and friends.

“I do not want to die, I do not want to die” said a man with much to live for. Yet three weeks later he was able to say “I only want what is right.” He had lived a lifetime in that three weeks, and made a journey into peace and acceptance against all the odds, completing his life as he died quietly at age 60. Freedom and growth may come as we say Yes to much of what life throws at us.

People move fast in a crisis and over the years I have seen growth through loss, healed relationships and recovered faith. But I have also seen anger and resentment at the unfairness of leaving an unfulfilled life or unfinished responsibilities. I have seen fear and confusion, weakness and dependence, stark realities of the end of life. Nevertheless without idealising any of those I met on my own journey since I entered this field in 1948, it is the often unexpected triumphs that stand out and leave me with the conviction that there is much to learn about priorities from people who are facing life's end. Whoever said, “I wish I had spent more time at the office” as he was dying?

The incentive, or rather, the commission to enter this field, came in early 1948 when, having been invalided from nursing with the back that remains tiresome today and forces me to lecture sitting down, I had become a medical social worker. In my first ward I met a man of 40, a polish jew from Warsaw, called David Tasma, who had an inoperable cancer of the rectum. I took care to meet him when he returned to the Out Patients Clinic and when he collapsed five months later and was admitted to another hospital, I visited him many times during the two months before he died. We discussed somewhere I could plan which would help people in his predicament; somewhere more suited to the need for symptom control and above all give a chance to come to terms with the situation more easily than in a busy surgical ward.

Two phrases he used in our long talks formed for me the challenge I came to believe I had to respond to. Referring to a small legacy of £500 he said "I will be a window in your Home." And again, "I want what is in your mind and in your heart." The first phrase gave me a commitment to openness - openness to and from the world, to all who would come and to all future challenges. From the second, although at the time it was a very personal exchange, came the commitment to everything of the mind; research, learning, full scientific rigour, always matched with the friendship of the heart, the vulnerability of one person before another. After he died, having made a private peace with the God of his fathers I had the assurance that he had made his journey with his own quiet dignity in the freedom of the spirit. So openness, mind together with heart and the freedom of the spirit are the three founding principles, not only of St Christopher's Hospice, but of a now worldwide movement. David Tasma, the polish jew who thought he had made no impact on the world by his life, started a movement founded on the Judea-Christian ethic, which has shown it can flourish in different cultures, each initiative with its own characteristics, but with

the common aim that people should be helped not only to die peacefully, but to live until they die, with their needs and their potential met as fully as possible.

After David died I spent the next three years as an evening volunteer in an early Home for the Dying, St Lukes Hospital. As a registered nurse I found myself in charge of a ward carrying out the evening drug round. I saw oral opiates being given on a four hourly regime, balanced to the patients' need and remarkably effective. For the first time I saw the constant pain of terminal cancer receiving constant control, patients free of pain and alert, not having to earn their morphine by having pain first; that constant switchback I had been accustomed to seeing as drugs were given prn, as necessary.

After three years the surgeon I was working for finally said, "Go and read medicine, it's the doctors who desert the dying. There's so much more to be learned about pain and you'll only be frustrated if you don't do it properly and they won't listen to you." With his help and my father's support I enrolled as a first year medical student at the age of 33. I continued as a Volunteer for a further 4 years and then, after qualifying and some hospital experience, a clinical research fellowship enabled me to introduce and monitor pain and symptom control in another early hospice, St Joseph's, in a deprived area of London and at that time virtually untouched by medical advance. The 7 years work there enabled me to lay the foundations of palliative care and raise the money to build St Christopher's, the first modern research and teaching Hospice.

Seven years of listening to patients, 1100 analysed cases and endless networking, finally enabled the Home to be built round the window; 19 years in all of learning what dying people are asking

of us and can teach us in their turn. A whole body of research has grown from that early work both in our Hospice and in many other centres.

There were other foundations. Dr Alfred Worcester put three lectures to the medical students of Harvard on The Care of the Aged, the Dying and the Dead into a book published in 1935 (1). I was introduced to it by a Nurse Tutor in 1953 and it was an inspiration. In 1927 Peabody wrote in the journal of the American Medical Association on The Care of the Patient and concluded “the secret of the care of the patient is in caring for the patient” (2). There were researchers in the USA such as Beeching, Eddy and Lasagna to meet, other early homes to visit, an admittedly sparse literature to discover, and many concerned nurses and doctors to contact. In 1959 Herman Feifel published a book of essays “The Meaning of Death” including a chapter by Carl Jung on The Soul and Death. Jung wrote, “We are never more convinced of this “running down” than when a human life comes to an end before our eyes, and the question of the meaning and worth of life never becomes more urgent or more agonising than when we see the final breath leave a body which a moment before was living.” He also said “It would seem to be more in accord with the collective psyche of humanity to regard death as the fulfilment of life’s meaning and its goal in its truest sense, instead of a mere meaningless cessation” (3).

In the same year Renee Fox published Experiment Perilous, a description of a ward where the first research and treatment of some previously incurable and life threatening illnesses with steroids was carried out by a group of young doctors. The stresses and strains on both patients and doctors and their interaction, including the importance of humour, were observed over several months in a fascinating study of the sociology of medicine and science (4). That same year Cruse,

a foundation caring for the bereaved, began work in London and I published a series of six articles on the Care of the Dying at the request of the Editor of the Nursing Times, London. Published the following year as a booklet it sold many thousand copies. (5)

As Professor Patrick Wall wrote in an editorial in the journal Pain as it celebrated its first 25 volumes “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.” (6).

But above all, those 19 years were spent in listening to patients. So, also, the years since St Christopher’s opened in 1967, though now I listen to staff and mainly meet patients at second hand but I continue to learn and, perhaps especially, observe the families as they face loss and share when appropriate. Above all, the lesson is - listen!

Science and evaluation has progressed alongside these many meeting. The psychiatrist Dr Colin Murray Parkes began his detailed study of the memories of the carers of dying patients in our

locality as we opened and as our patients began to enter his cohort of more than 270 carers. He found much unrelieved pain, whether the patient died in a hospital or at home. As our patients came into the study he was able to show that people with serious pain problems were referred from the start to the hospice and were largely relieved (7).

Twycross compared morphine and diamorphine (Heroin) in a double blind within patient cross over study in St Christopher's in the 1970s and found no clinically observable difference between the two drugs. He also reported the absence of tolerance and drug dependence (8). Clinical and evaluative studies have continued, always balanced with the development of patient care. As Peabody wrote, "The treatment of a disease may be entirely impersonal; the care of a patient must be completely personal." (2). So back to patients. Some accepting, many questioning. The total pain observed at St Josephs Hospice in the 1960s, with its physical, psychological, social and spiritual components, has been met in the whole experience suffered by countless people and their families. The concept of "total pain" developed during my early years at St. Joseph's Hospice and was spelled out in an answer given to me by a Mrs. Hinson in 1963 when I asked her to tell me about her pain. She said, without further prompting, "Well doctor, it began in my back but now it seems that all of me is wrong." She spoke of several other symptoms and went on "I could have cried for the pills and the injections but I knew that I mustn't. Nobody seemed to understand how I felt and it was if the world was against me. My husband and son were marvellous, but they were having to stay off work and lose their money. But it's wonderful to begin to feel safe again." Physical, emotional and family pain and the spiritual need for security and self worth, all in one answer. That sometimes elusive search for meaning by people of many faiths and none was strongly expressed by a dying Primary School Head Teacher, Brenda

Dawson.

“God, you need to ask my forgiveness.
Your world is full of mistakes.
Some cells, like weeds in the garden,
Are growing in the wrong place.
And we your children
Have polluted our environment.
Why did you let it happen God,
We prayed with faith, hope, love,
We perceived no change in our bodies or environment,
We are made sick by your world.
God you need to ask my forgiveness.
Was this why you sent your Son?”

There is a place and function for protest for our patients and their families. Lives can be desperately unfair as health fades, relationships sour and are broken and parting becomes inevitable. Yet there can be a way through and if there is honesty about these negative feelings even they can have a positive outcome. And for those who are involved as professional carers the anger that is part of compassion can be a force for change. The movement for Hospice and Palliative Care has arisen around the world as a protest against the pain, isolation and neglect suffered by dying people. The World Health Organisation Centre for Cancer and Palliative Care has estimated that at a conservative estimate their number on any one day has to be counted in several millions. There are other painful diseases, poverty and starvation afflict countless millions more. What is relevant in the gutters of Calcutta is totally inappropriate in Canada or the United Kingdom, but there is a common theme; human dignity should be recognised and enhanced by the assurance of worth. The Hospice philosophy is summed up in the words “You matter because you are you and you matter to the last moment of your life and we will do all we can not only to help you die peacefully but to live until you die.” The message of Mother Theresa and the best

resourced Palliative Care Units are one and the same. Professors Melzack and Mount, with all their initiatives in better patient care, have illustrated this in this City.

As well as research, another difference is found in our concern with the families and friends of our patients, for most of Mother Theresa's are destitute and alone. In our home care patients and in both the Day Centre and inpatient group all workers in this field find themselves alongside many opportunities for reconciliations and forgiveness. At times it seems to be somewhat paradoxically. I recall one outstanding example from my husband's last stay in St Christopher's. We had been very aware of a small boy on his tricycle up and down the corridor of our ward of single rooms and came to know something of his grandfather, our patient. A thoroughly unpleasant man, he had abused his children and lived an aggressive life in many ways. He was not an easy patient and did not mellow with illness.

However, during the few weeks he was in the Hospice, his daughter came daily and supported by an experienced Social Worker, used the time to work through her feelings for her father, to forgive him and to lay down her memories of hurt and abandonment. Determined to do better herself, she calmed her father's tempers and entertained her little boy, resolved to give him a very different life from her own.

Our patient died on Christmas Day, and afterwards the nurse in charge called in the son, who had until then refused to visit, to join his sister, a single parent. Not only that, she enabled the son, too, to make a gesture of forgiveness for his father and carried out his last shave as his body was prepared. I do not think religious language was used during all this time but who can doubt that

a spiritual battle had been fought and won. A year later the daughter brought her little boy to join in carols round the wards on Christmas Eve. The Social Workers who told me the full story in which I shared only as another family in a ward having a tense Christmas Day, is keeping in touch in case her support is needed again, but so far all goes well. From her own Christian background an experienced Social Worker has helped this daughter to mature impressively on her own terms and in her own way. Need I emphasise how much we have to learn from her?

The spiritual needs of the dying are not merely appropriate rituals of their religion (if practised or recalled) but far wider, as relevant to atheists as to believers. They are: to find a meaning in life, to search and question, to be listened to with respect and answered with honesty even where the answer can only be "I don't know." People, both patients and families and all of us, need to be accepted and to give as well as to receive love. We may only be silent companions but as we accompany their journeys we see growth through loss even in despair and that the travelling continues towards hope. Ever since my first days as a volunteer in St Luke's, throughout my 7 years in St Joseph's and since 1967 at St Christopher's, I have witnessed the resilience of the human spirit, how so called "ordinary people" overcome adversity and make it the very means of what can only be called victory and growth. There is no hierarchy among such achievements. Who is to say who has done best, the young woman who fills a Day Centre with a party feeling for weeks on end and never shows how much it costs her or the old reprobate who manages to stop grumbling for his last ten days? There is endless respect and not a little humour (often rather black) to be found in this field.

Most of my personal work now is in seeing all our over 300 staff and many of our 800 volunteers

for annual appraisals and I have no doubt that they too are developing their potential for growth and character through their individual contributions. Again, I step back from idealising what is going on. To everyone who is embarking on projects of this nature I want to say "If you don't have problems you don't have a Hospice". I might add "a University or anything dynamic and creative."

Maybe I sound as if all dying people come through their journeys with open eyes, or that I believe people should be told both diagnosis and prognosis. Treatments presume informed consent and I have seen much greater openness develop during my years of practice. I believe sharing among families is calmer and more creative than deception and that although some may hide truth even from themselves yet most will find it ultimately releasing.

It is a risky business to destroy an entrenched denial and we often have to wait our time, or never attempt it. Truth lies in a relationship rather than in words. I remember a man who, after weeks of caring, suddenly asked me bluntly "Am I dying?" I found I could only say "Yes" without any softening words. "Was it hard for you to tell me that" he said, "Well, yes, it was." "Thank you, it is hard to be told but it is hard to tell too. Thank you." It should be hard; we must care what we do with our words for they can hurt or heal, open or close exchange and development. We should care what people do with what we give them; whether the moment or the manner was right. That man, the same speaker as the one with whom I began this lecture, who said "I do not want to die" and finally "I only want what is right", came close to me in a journey we shared during the next three weeks. He taught me much of what I know of what it feels like to be so ill, to be parting, of finding in losing. Such teaching is a gift to be used as we come alongside any kind of loss. Much has been built into palliative care. And not into palliative care only, into

ordinary living and learning.

The review of my chapter in the first edition of the Oxford Textbook of Medicine” referred to “the characteristic mixture of tough clinical science and compassion” (9). “Feelings are facts in this House” said one of the nuns at St Joseph’s. We need both the facts of feelings and the facts of science if we are to learn and go on learning how to practice medicine in its widest sense. We need “evidence based medicine” as much here as in the Intensive Care Unit and any other ward in a hospital. We need it too in the home, where our patients spend most if not all of their time. Evaluative studies began as we opened; as I have already said, we have continued them. One comparative study between hospice and hospital matched patients has been carried out three times during our 30 years at St Christopher’s and reveals that while pain control in hospitals in the vicinity of St Christopher’s has improved greatly, family anxiety and the impersonality and urgency of a busy general ward are not so well addressed. (10).

In 1966 I was invited for a visiting lectureship by the graduate school of Nursing at Yale University and took part in a seminar with Dr Colin Murray Parkes and Dr Elizabeth Kubler Ross and others. Colin, Elizabeth and I had supper together one evening and he made a very interesting remark to us, pointing out that we were working in different time scales. At that time Elizabeth was carrying out her series of one off interviews in teaching behind a one-way screen, I was working with patients at St Joseph’s in days or weeks, and Colin was interviewing a series of widows from one to two years after their bereavement. We were all seeing acceptance and growth but responses to different time pressures led to different speeds of resolution. The husband of a very close friend of mine died of a dissecting aortic aneurysm just as she was

returning home after the initial admission. On her return she was left for half an hour alone with his body in the Intensive Care Unit. That pause, enabling her to begin to absorb the enormity of her loss, did not soften an anguished journey of grief but she remains grateful to the Nurse who made those moments of farewell possible.

Sudden death gives no time for important communications, cancer usually gives us time to say "I'm sorry", "thank you" and "goodbye". Seale in his paper *Heroic Death* summarises accounts provided in a survey of 250 individuals who had died of this and other diseases in the United Kingdom. His abstract reports on the interviews with their carers, "The analysis counters the view that the denial of death is widespread in conditions where religion no longer offers individuals a meaningful narrative for the dying self. Scripts for proclaiming heroic self-identity in the face of death are promoted by cultural experts and appropriated by many lay individuals. This involves a struggle against external and internal enemies to gain knowledge, the opportunity to demonstrate courage and a beatific state of emotional accompaniment in which 'carers' and dying people participate. Unlike more traditional forms of heroism, this script deviates from celebrating solely masculine qualities and includes a female heroics of care, concern and emotional expression". One quote states "I feel he had a lovely death, very peaceful. I'll never forget how he seemed to accept everything" (11).

The regional survey in the United Kingdom from which this paper comes is a unique study of many facets of the last year of life of 3,696 people. Among the reports from this work one paper is concerned with the patients' view on euthanasia. Their carers were asked "Looking back now and taking the deceased's illness into account do you think she or he died at the best time - or

would it have been better if she or he had died earlier? What about the deceased? Did she or he ever say they wanted to die sooner? And (if yes) did she or he ever say they wanted euthanasia?"

28% of the respondents, with a bias towards the younger carers, and 24% of the deceased expressed the view that earlier death would be, or would have been preferable. However only 3.6% were said to have asked for euthanasia at some point during their last year (12). This figure is very unlike those quoted in National Opinion Polls where figures of 70-80% are given, they illustrate what people who are facing the end of life are actually saying from the memories of their carers.

It is interesting that the House of Lords of England Select Committee on Medical Ethics, the New York Task Force on this subject and your own special Senate Committee on Euthanasia and Assisted Suicide all recommended the spread of palliative care rather than any change in the law. Interestingly too, it was a visit to the Netherlands after a year of taking evidence that finally decided the very prestigious team of their Lordships. Kathleen Foley of Memorial Sloan - Kettering Cancer Centre, New York who recently published an important article "Competent Care for the Dying instead of Physician Assisted Suicide" in The New England Journal of Medicine (13) discussing the Supreme Courts decision in this area, summed it up to me last month in saying "They said there was no constitutional right to assisted suicide, rather a right to the refusal of intrusive treatment and a right to palliative care".

My husband, a Professor of Art, at age 93 and at the end of a ten year battle with several life threatening illnesses summed up his life thus. "I am completely happy, I have done what I had to

do in my life and now I am ready to die.” He became somewhat impatient but said firmly “God will know what to do with me.” 3 days before he died he completed a delicate line drawing of one of his nurses. 3 hours before he died the son of another patient came into his room to shake him by the hand and to thank him for the inspiration of his pictures all round the hospice. So many people I have known have reached a reconciliation or received important thanks which they would have missed had they been able to choose an earlier death, perhaps in distress or bitterness. The last word on this subject comes best from an elderly lady who wrote to the London Times some years back “Human nature being what it is, euthanasia would not be voluntary for long.” Many vulnerable people would so easily be undermined and the line between voluntary and involuntary euthanasia is, I believe, impossible to draw.

But to end with a hospice story which one of our patients told a local journalist last month. “I found out I had cancer of the bones in 1988. The doctors told me if I responded to treatment I would be cured, but if I didn’t, then my chances of survival would be 50-50. They gave me radiotherapy, chemotherapy and other medication in tablet form. I also had to have a blood transfusion together with the chemo. The treatments had a great effect on me and I felt much better. Eventually, though, they had given me as much radiotherapy and chemo as they could; any more would have just made me sicker than the cancer did. It was in 1994 that the doctors recommended St Christopher’s Hospice. They said that it was a place that specialised in pain and symptom control. At first I was looked after by their home-care team of nurses, doctor and chaplain, but then I had a bad patch and became an inpatient for seven weeks and three days. On the days that I wasn’t feeling too bad, they would take me down to different classes. The very first day, I made a pot out of clay. My hands ached a little bit but the second time I tried it I liked

it - and I've been doing it from that day to this. My hands are much stronger now. Not only do the things I make give me something to look back on and give me a thrill, but they also show that I haven't given up on life. It takes courage when you are ill not to give up, and I haven't; I have continued to do things even if it's just making animals out of clay. I have achieved something new. I have given lots of pots to my friends. The classes also give me a chance to be useful to others and to encourage people. The cancer is stable at the moment. After my bad patch in 1994, when I also had a heart attack, no one thought I would be here today. But now I'm being looked after at home again. I am still here, still not giving up."

Those I have met have shown me that they were not merely dying from a terminal illness, they were living with a life-threatening illness. They show us all there is no end to challenge and discovery in life, and I, like my husband, and some of those I have quoted, would add, "and death itself is a gateway to a new way of being".

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