Palliative Care—Past and Future

Questioning Great Expectations

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This paper argues that the future of palliative care cannot be divined reliably without considering how a set of basic questions might be answered by health-care professionals, administrators of health care systems, and citizens in countries throughout the world. Seven of the many questions centering on the mission of palliative care are explored here as pathways into the future of how we care for gravely ill and dying people. That future cannot be predicted from the vantage point of some super observatory. It will rather emerge from the responses we give now to a range of questions such as the seven considered in this paper. These questions identify fundamental dimensions of the mission of palliative care, and our responses will determine when, and where that mission will become reality.

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An attempt to forecast or predict the future of palliative care over the next 5, 10 or 15 years would assume that this future is governed by some central determinism's controlling all the variables out of the interaction of which the future of palliative care will emerge. Such an attempt would assume that the unfolding of this future could be described from the vantage point of some super observatory and that this description as well as the unfolding of the future of palliative care would be independent of the hard questions that we have to face if palliative care is going to have a future.

It is these hard questions, as well as the answers that we manage to work out, which are pathways into the future of palliative care. These questions and our responses will set the conditions for palliative care having one rather than another of several possible futures. So the purpose of this paper is not to develop the argument: 'This is what palliative care will be like in 5 or 10 years'. The paper rather intends to make a set of fundamental statements about what palliative care should be or become and then, in the form of closing questions at the end of each of the eight sections, to direct attention to the conditions that will have to be fulfilled if the fundamental mission of palliative care is to become a reality.

THE MISSION OF PALLIATIVE CARE—STATEMENTS OF BELIEF

The fundamental statements about the mission of palliative care are not simple statements of fact. They are rather statements of belief, for there are beliefs about the way things are and beliefs about the way things should be.

Beliefs about the way things are drive intellectual endeavour in any discipline. There would be no mathematics, no chemistry, no physics, no biomedicine, indeed, no science at all, if people were not constantly involved in acts of believing. In all of the sciences, believing is an intellectual assent to the truth or probability of reliably generated and communicated knowledge, knowledge that one has not generated by oneself. Without acts of believing, one could never get started on the development of new knowledge. Because no one could ever evaluate and verify the evidence for all previously generated knowledge in any given field, believing is at the beginning of each new advance and underpins the whole course of scientific endeavour. That is why scientific fraud is so devastating and evil. It attacks the act of believing, an essential principle, and the beginning of all scientific work.

There are also *beliefs about the way things should be*. Such beliefs are of at least two kinds. Believing may be initiated and reinforced by the power of some authority which, if influential enough, may exclude the critical thinking that 'would weaken its grasp'. Such beliefs can be like 'a womb in which the individual rests without the pain of mental activity or decision' (1). There is, however, another kind of believing regarding the way things should be. This second kind of believing involves intellectual and personal assent not to some authority but to a vision shared with others about how the world can be changed.

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This second kind of believing sets in flow the 'poetry of action' (2), a movement to make real what has been left undone for the suffering and the dying. This kind of believing—what John Henry Newman has called real assent as contrasted with merely notional assent (3)—is no sheltering womb. It rather bonds people together in a fellowship of purpose to mobilize sciences and skills, ministries and institutions, services and resources, to give the suffering and the dying a moment where '… there is no death and time does not unreel like a skein of yarn thrown into an abyss' (4). There are some things that cannot be said, but can only be *shown* in language; and there are other things that can be shown in action only if they are *believed*. The future of palliative care cannot be realistically discussed without reference to such beliefs.

The pathways into the future that this paper will follow are given with seven leading questions:

1. The extension of palliative care/medicine beyond the domain of cancer?
2. Palliative care: maintaining the tension between different kinds of excellence?
3. Palliative care in the home?
4. Are the poor to be excluded from palliative care?
5. Must the debate on euthanasia be unending?
6. Why do we need poets in palliative care?
7. Is humanity too costly a place to keep open?

The extension of palliative care/medicine beyond the domain of cancer?

> Palliative care is at a turning point, a moment rife with opportunities for transformation and growth. This means adopting a proper mode of response for new challenges. One thing will remain constant. The original and governing concept of palliative and hospice care represents one of the modern period's most powerful challenges to unwitting splits of the mind from the body. Modern medicine, marked by increasing specialization and complex technology, was the site of this challenge. The holistic notion of total person care arose in opposition to separations of 'cure' from 'care', of 'patient' from 'family', and of 'clinical objectivity' from 'human compassion'. The governing idea of palliative care has been the enhancement of humanization over any trend to reduce a suffering person to impaired organ systems.
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> The challenge now is to release the full power of this originating insight. Palliative care, though conceived in the crucible of the neglect of dying cancer patients, is not restricted to this particular circle of human suffering and loss. Terminal cancer patients, their families and those caring for them have made their mark on the history of medicine and on the later twentieth-century way of understanding and living with the dying. These countless individual experiences of tragedy might, of course, have remained scattered and without unified impact on our societies. The perception and leadership of Cecily Saunders, Elisabeth Kübler-Ross, Balfour Mount, and others too numerous to mention by name, assured a more humane turn of events.
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> We must now explore how the fundamental insights of hospice and palliative care can be extended, perhaps by quite different methods, into other areas of human illness and suffering. Those dying of cancer are not the only ones who cannot be cured. Many live for months and years under the threat and the fact of impending disintegration, whether it be from progressive neurological disease, chronic dementia or irreversible incapacitation resulting from tragic accident.

I wrote these words in 1985 when, in my first editorial in the new *Journal of Palliative Care*, I discussed palliative care as being at a turning point. The turning has been slow, for these words of 15 years ago need to be said again today. Little has changed since then regarding the extension of palliative care beyond the domain of cancer. Although there have been efforts to develop palliative care for the dying aged and for persons dying from HIV disease, many people suffer through the dying phase of other diseases just as though there were no question of palliative care/medicine being destined for them.

Observers of palliative care were having to say the same things at the end of the 1990s as had to be said in the early 1980s. Irene Higginson, for example, stated in 1995 that there will be an increased need for specialist palliative care for persons with diseases other than cancer (5). Speaking of palliative care, Nick Bosanquet stated in 1997: 'Palliative care has developed through a strong sense of specialist mission. It may well be difficult to share this mission with a wider audience, yet the gains in patients' quality of life would be great … The challenge is how to use this resource so that all patients, including those with non-cancer diagnoses, can benefit from access to better care. In an era of financial constraints, new alliances are needed for shared care if the full promise of palliative care is to be realized' (6).

The full promise of palliative care is not being realized as long as little or no progress is being made in the methods of palliative care needed to bring relief to persons suffering through the terminal phases of diseases other than cancer. Louise Gibbs has observed that many patients in the final stages of heart disease suffer from discomfort, distress and symptoms that are no less severe than the symptoms of dying cancer patients (7). Gibbs' statements on the need for palliative care for persons in the end stages of heart disease are strong and fundamental, but she is reserved regarding the great expectation that palliative care will soon rise to meet this challenge:

> Anecdotal evidence exists that palliative care teams have managed patients with heart failure successfully using the same approach that helps cancer sufferers, but conventional hospice and specialist palliative care services could be overwhelmed by heart disease. Indeed, different models of care may be needed since patients with heart failure are more prone to sudden death than patients with cancer and do not necessarily have a clearly defined terminal phase. Specialist heart failure nurses may founder if they work in isolation. Palliative care is recognizing the need to take stock of other terminal illnesses. Now is the time to collaborate and accelerate this change (7).

Will we find the leadership and the resources required to mobilize the collaboration and to forge the new alliances needed to create new models of palliative care for the many who suffer unto death from diseases that are still outside the ambit of palliative care? For how long into the future will such sufferers continue to be excluded from palliative care?

Palliative care: maintaining the tension between different kinds of excellence?

The interactions between pain and suffering are multiple, many layered, quite unique to each person and irreducibly complex. Complexity's imperatives are set to counteract strategies of simplification for the relief of pain and suffering.

'Do not reduce suffering to pain!' is one of these imperatives. That imperative was ignored when doctors, unaware of a terminally ill woman's intense suffering over the loss of her beauty, over her husband's leaving her for another woman, over his leaving her to die alone, tried futilely to silence her persistent pain complaints by administering various analgesics in increasingly higher dosages.

Two physicians in succession abandoned her, utterly frustrated by her incessant complaining. The third physician entered this scene of desolation. He took the time to speak to her, regularly over a period of a couple of weeks. He brought her a stuffed animal that became a symbol for her of all she wanted to hold onto. Gradually her complaints died down and the physician could adjust and gradually diminish the amounts of analgesics she had been receiving. This physician compared the excellence of top-level medical knowledge and skill with the excellence of deep insight into and steady compassion for a lonely woman's unique suffering.

A second story about palliative care centres on an old woman's terrible anguish over having to leave her garden and her cat to go to hospital to die. This story emphasizes that each person's suffering is utterly unique and cannot be compressed into any general category without that suffering losing all of its reality.

Memories, lost opportunities, guilts, dated moments of hurt or betrayal or abandonment, the fragility of one's most unforgettable loves and joys, and one's unfulfilled dreams are all as unique as the days, times, places and persons to which and to whom they are bound. Suffering is the message between the unwritten lines of a singular biography. For a particular image of this general statement look at her, now an older woman rapidly losing her long battle with leukaemia, as she walks slowly through all the rooms of her home and then out into her garden. She has to leave shortly for the hospital where she knows she soon will die. So she lingers over the goodbye-forever to her garden. Alive it is that garden, peopled with the hundreds of days spent there with loved ones and friends. It is almost as though each rock and flower bed, each tree, bench and carefully selected stone vase are now silent gatherings of all those wonderful days and events and loved ones of so many springs, summers and autumns. How can she not be crushed when she cries over these stones, set down so many years ago by her hands and the hands of others now gone. Taking final leave of that garden is taking leave of all she has lived and loved there. Her biography, punctuated by the meows of her cat, is in her garden, and now she must take leave of all she has been there.

There are some kinds of suffering that are so bound to another person's uniqueness that they cannot be spoken away by other human beings, however compassionate their words may be, however present they may be in sympathy. At times one cannot prevent or protect persons from having to live through certain kinds of suffering. As is the case with the woman having to take final leave of her garden and her cat, one can only suffer with her.

This is what one nurse, who had been visiting this old woman regularly, knew how to do. One special kind of excellence was called for on that sad last afternoon in the garden, the excellence of being able to take another human being's suffering into one's own heart and, crushed as she is, to hold her and cry with her.

Palliative care demands that a constructive tension be maintained between what may seem to be incompatible excellences.

Knowledgeable and sensitive care of those facing death from incurable and advanced terminal conditions is a moving pattern of many interlocking skills and behaviours; of generalizable science and irreproducible insight, of clinical acts, and charismatic words of professional leadership and empathic personal presence. The tight interweaving of these varied kinds of excellence exceeds the competence and strengths of any one individual and may seem dauntingly difficult even for a team or unit. The temptation may be to slide, quietly and almost without notice, into a triage of excellence. We shall excel along the lines of our immediate strengths and sacrifice the attainment of excellence at points where we sense ourselves, as individuals or as a group, to be most fragile.

Sacrifices of this kind are rarely open-eyed and intentional. They may be encapsulated and masked within ideas that we find too natural and evident ever to question, or

within a governing theory presenting itself as the whole or principal truth about *the* kind of excellence that is *really* needed in palliative care. Exclusion in the guise of emphasis is perilous, when one kind of excellence cannot substitute for another in the complex challenge of helping people to suffer and to die with dignity.

A knowledge of the nature of suffering will help us to be compassionate, but we need to suffer with another person to attain that unique kind of individual knowledge of a suffering person that permits us to join hands with another human being at the crossroads of our greatest vulnerability.

John Donne was right. Entering into the suffering of another reveals to me the plight I share with everyone facing the threat of disintegration. The trust and identification required for the individualized knowledge of another person's suffering also open windows onto the communication of hope. The challenge is to touch, awaken and release the saving power of another's latent beliefs. Then, perhaps, each suffering person may find the strength to carry his vulnerability like

> A pine in solitude
> Cradling a dove (8).

Compassion brings it own knowledge. It reveals the solitude to be an illusion. The excellence of systematic, disciplined scientific understanding reveals a commonality in all human suffering. The excellence of individualized knowledge of suffering persons reveals the presence of human community in suffering. The demands and the costs of each excellence are different. Generalizable knowledge and irreproducible compassionate insight may seem to be 'incompatible excellences'. Fusing them in individuals and in a team will release the power of palliative care.

At the turn of this decade, century and millennium a massive and revolutionary process of financial and economic globalization is pitting the power of the market and of profit over against the demands of human compassion. Governments and healthcare systems are constrained to slash budgets and limit resources. Doctors, nurses and other healthcare professionals carry increasingly heavy workloads and suffer from stress. Some propose the triage logic in these economically difficult times, triage meaning: treatment begins with those who are salvageable, then moves on to those who are in lesser danger of dying, and resources, if any are left over, are then spent on those who cannot be saved, or the dying.

One need not be pessimistic to wonder whether palliative care will not be increasingly sacrificed to the logic of triage over the coming years. Will doctors and nurses be able to find the time, to take the time, or to fight for the time to come to know sick and dying people in their full particularity of body and biography? Will the several excellences required for palliative care indeed be found or be judged to be incompatible and altogether too costly?

Palliative care in the home?

Dying at home is by itself no guarantee of dying with dignity. Palliative care in the home can turn into a nightmare if that care is not guided and supported by persons with the highest professional knowledge and skills, i.e. the knowledge and skills of palliative medicine and nursing.

Uncontrolled pain, combined with the multiple losses threatened by impending death and compounded with the weight of fatigue and exhaustion and the rioting of concurrent symptoms and emotional stresses, can drive both a dying person and a surrounding family from coping, courage and integration into chaos and hopelessness. When that occurs, death holds no dignity for anyone.

I saw this happen. I saw it all too late to be able to do anything about it, to reverse the terrible experiences for a young dying woman and her family before she died. I saw this occur up on the hills on a farm where the young woman returned to die after all treatments for her cancer had failed. Her family was alone with her and her little bottle of oral morphine. Hardly any professional ever came to the hill farmers and never when they most needed a skilled doctor or nurse. In her last days at home this woman was reduced to a cringing whimpering creature and her family came to ponder the most extreme of thoughts. The woman died just as I succeeded in obtaining a physician's help for her and her family.

We do people a terrible injustice when we send them home to die without the assured professional accompaniment that is needed both to forestall agony for the dying person and to protect families from horrible and long-to-be-remembered feelings of helplessness and shame.

We must ask, 'How many deaths within it can a home endure?' This question does not seek a numerical answer. In the worst of conditions, one death alone can disrupt a family and spin a home into chaos. Under what conditions, then, can palliative care in the home render death in the home endurable? Little black cottages will seem forsaken, not only because so many of the family have gone out of them into death, but also because the world has never noticed and just passed them by.

Homes can hardly endure death when the world simply passes them by. If, as George Smith said before he died, it is a form of class prejudice to assume that everyone has someone to turn to when they are dying (9), it is also a high degree of social and political naiveté to imagine that families are naturally and spontaneously equipped to care for their dying relatives at home.

Dr Neil MacDonald has rightly implied that palliative care in the home is not achieved or assured by some magical ministerial snap of the fingers:

> Family members are often dispersed, and all may be employed outside the home. For those who do become home caregivers, the technical responsibilities are often awesome and expensive;… setting up a 'hospital in the

> home' places unique demands on family members, who must be trained to carry out unfamiliar and complex tasks, which they may find frightening because of the possibility of making a mistake. Balancing conflicting demands can lead the caregiver into a state of exhaustion or anxiety (10).

Palliative care in the home cannot work without the allocation of social resources needed to train sufficient numbers of professionals able to give families competent, timely and continuing assistance. Without that dedication of resources and without that assistance, home care will come to little more than a deceiving promise. The world will pass by, unnoticing and uncaring, and the homes within which people die will stand, forlorn and forsaken, as enduring symbols of yet another form of man's inhumanity to man.

Are the poor to die excluded from palliative care?

How do the poor die?. This question is about the poorest of the poor, not only about those who chronically have very little money, but even more so about those afflicted with the deeper level of poverty of never really having a place in society. If our question echoes Tolstoy's, it cannot be answered with Ariès' response. Tolstoy once asked: 'And the mujiks (peasants)? How do the mujiks die?' (11). To answer that question, Philippe Ariès borrowed from Solzhenitzen's *Cancer ward* a description of how older folk used to die. They supposedly prepared themselves quietly and departed easily, 'as if they were just moving into a new house' (12, 13).

This, though, is not the way the poorest of the poor die today. How could their dying ever be like 'just moving into a new house' when, after losses of job, money, friends, family and home, many die just where they have lived during their last days—on the street or in a cheap room, largely alone, and above all not in a home?

There are probably not too many of us working in well-organized hospices and palliative care programmes who have any extensive first-hand experience of how the poorest of the poor, of how those who are socially utterly marginalized, live and die. We assume the existence, however modest, of an organized life; of a place of work, of a home, of an address, of a phone and other means of communication; of a network of contacts, including family, friends, neighbours, and acquaintances who can help us when we can no longer help ourselves. But how can persons bereft of all of these normal connections, adrift out there in the shadows of the city, ever find their way, particularly when they are very sick and dying, into that space we call humanity?

How *do* the poorest of the poor die? Do we really want to know? That knowledge could be very disturbing, loaded as it might well be with imperatives for action. It could also be accusatory knowledge if those of us 'in the know' do nothing to mobilize lethargic ministries, governments, healthcare institutions and professional schools to develop and organize the services the poorest of the poor need, to have a chance of dying well. But the imperatives cannot stop there. It would be humanly and socially grotesque if our passion for the poor stopped at helping them to die well.

As we consider how the poor die at the turn of this century we should have little difficulty in understanding and accepting the truth of Ignacio Ramonet's statement: 'Exclusion is the great social crime of our times' (14). When we consider how the poor die, we have to face and answer two basic questions. First, who are the strangers whom we can leave to their own wits and devices as they face catastrophe, suffering and death? Second, who are those, who are so much our very own, that we are deeply perturbed in our own contentment and diminished in our own dignity, when they, whose condition screams out for help, are left alone?

Within the logic of humanity, there are no strangers to us among those who suffer, be it from poverty, social discrimination and marginalization, illness or impending death. Within the logic of humanity, all who suffer are very much our own: when they are diminished, we are diminished, because the logic of humanity is the logic of unconditional solidarity.

The logic of humanity, however, needs the poetry of action, and what is that?

In his novel, *The death of Virgil*, Broch has the poet considering the destruction of his manuscript of the *Aeneid* (14). Why? Because Broch has Virgil coming to realize, as G. Steiner explains, 'that the beauty and truth of language are inadequate to cope with human suffering and the advance of barbarism. Man must find a poetry more immediate and helpful to man than that of words: a poetry of action' (15).

We need both the poetry of words and the poetry of action if human life is to be possible and worth living, but the poetry of action has to come first or the words will never work. The poets of words are hunters of meaning and they keep people on track; they keep people from wandering aimlessly about and becoming totally lost in the forest dark as they hunt for the meanings of their own existence. The poets of action are searchers, they seek out those who, although biologically alive, have never had or have lost a social existence or an existence within the human community. Poets of action seek out those who do not even have enough of an existence to be bothered about its meaning.

When these poorest of the poor are found, what do the poets of action do? They bring the socially excommunicated out of isolation so they can break bread with the living. They mobilize and link ministries, institutions, services, persons and resources to form a tissue of bonds out of which a social existence can grow. What if these poorest

of the poor are found very late and towards the end of a lethal disease when time is running out? Well, that is the time to clean, feed, nurse, carry, hold and comfort, so that those who lived in darkness can at least die in the light.

What do poets of action do for the poor who are dying? They create the conditions that allow them to say of themselves and of the poor what Seamus Heaney, in the last two lines of his poem, *Seeing things*, said of himself and his father:

> And there was nothing between us there
> That might not still be happily ever after (16).

The question at present is whether palliative care will be able over the coming years to mobilize a sufficient number of poets of action to bring palliative care to the poor, to those who are so totally excluded from the goods and benefits of community. The question is, what will the response of palliative care be when the poor ask us, 'Is there nothing between us?'

Must the debate on euthanasia be unending?

If one refers to the Greek origin of the word, euthanasia, etymologically, means a good death, a gentle easy death. That is not what euthanasia, as debated before the courts and as discussed in countless publications, means today. Today, euthanasia means the administration of death to the dying: the hastening or advancing of death.

A gentle, peaceful, easy death: this is the way that Solzhenitsyn describes the dying of older folk in *Cancer ward*. People did not fight against death. They did not pretend that they were not going to die. They prepared themselves quietly and they departed easily 'as if they were just moving into a new house'. A central contemporary problem in Western countries is that people fear that they will not be able to die in this gentle, easy way. They fear that they will have little or no control over their dying. They fear, as an editorial in *Nature* stated, 'a twilight life tethered to feeding tubes or respirators'(17). As they have been doing for over 20 years, people are now still, and with increasing intensity, echoing Montaigne's statement, 'it is dying, not death, that I fear'.

The *euthanasia* that is now being debated in the media, in the courts, in countless symposia and publications is linked to the fact that so many people today do not die 'as if they were just moving into a new home'. People used to die at home, in the midst of their families, surrounded by all the objects, furniture, photos and memories that kept a life history alive and present to the dying during their last days, hours and moments. Most of the time today, people do not die at home at all. They die in institutions, in strange and sterile places, places that bear no mark or memory of where one has lived, of those with whom one has lived.

People often die today in places that are equipped with complex technology capable of supporting and prolonging life, often only biological life, when a cure and return to health, vitality and normal living are no longer possible. Terminally ill and dying patients may be technologically bound to biological existence long beyond the time when they could have died consciously and in mastery of their ultimate moments of life.

However, enslavement to life-prolonging technology is not the primary driving force behind contemporary discussions of euthanasia and current debates over its legalization. The fear of some patients, a fear backed by fact, is not that they will die tethered to life-prolonging technology, but that they will die tethered to unrelieved pain and symptoms. Others fear exactly what they think palliative care has to offer, a release from pain at the cost of their being plunged into a lingering state of semiconsciousness, of being doped into stupor, while all around sit and await one's death. Some find the prospect of this particular kind of loss of control to be quite unbearable.

But there is another quite different experience of loss of control. It comes from heightened consciousness of one's condition, not from an analgesic-induced dimming of awareness. Demands for euthanasia often are most acute when life-prolonging technology has nothing to do with death's delay, and when pain is not the main factor in the agony of the dying. We live in a fragmented world, in a world in which language, to a large extent, no longer conveys the shared vision of humanity, and the shared hopes, within which we could once talk to one another about the terrible uncertainties towards which our own intelligence, if given free rein, would thrust us when we face death. To face those uncertainties, and to confront them openly in fragile conversation with others, would drag us all towards a darkness where no data, no concepts, no hypotheses and no proof can silence or calm the dread, and possibly the rage, with which an awakened human spirit can shake, when contemplating the apparently all-too-real and inevitable fate of personal extinction.

Euthanasia debates. The reasons and arguments advanced today for and against the ethical acceptability, and for and against the legalization, of euthanasia are often substantially the same as those presented in earlier debates over the last 100 years. A defining characteristic of a complex question is that it will and it must be taken up again and again by each successive generation. This does not mean that any given generation cannot learn from the mistakes and from the wisdom of people in earlier times. Yet, it would be naive and intellectually misguided to think that we could simply lift euthanasia proposals and arguments out of their historical contexts to compare and apply them today, as though the social, political and medical particularities of each period had no influence at all on euthanasia reasoning and practice.

People in any generation have to think through for themselves those questions that most deeply affect their own lives and destinies. Ancestors cannot do that, once

and for all for their descendants. Each generation in each society and culture, which regularly differ so profoundly one from another, has to seek, often through intense and even acrimonious discussion, what it stands for, what it stands against and what it can tolerate. Not all questions are so pressing or decisive for individuals and societies seeking to discover who they really are, but euthanasia certainly is one of these questions for us today, as it has been throughout the moral history of the Western world.

However, public debates carried on too long can become highly repetitive, confusing and debilitating. Some may sense that everyone could benefit from a pause for thought, from a period of respite to let the waves of debate damper down. Yet, if public statements continue to stream forth, statements judged by some to be wrongheaded and dangerous, is there not a continuing responsibility to speak out, to clarify matters, even to denounce other views if necessary? Or, is there not then a danger that a long-lasting, acrimonious and often confusing course of public debate, on euthanasia in this instance, can spiral out into a verbal space that is quite virtual, quite out of touch with the space where people suffer and die? Is it responsible to continue participating in a public debate if and when that debate is becoming more important to itself and to its participants than the realities with which it is putatively concerned? But how can one reliably ascertain if and when public discourse on any matter of great importance has strayed away from the public purpose only to become an end unto itself?

Beyond debates about euthanasia?. One of the essential elements of dying with dignity is freedom from pain that dominates consciousness and leaves free no psychic space for the personally critical things that people want to think, say and do before they die. Patients have a right to demand release from pain, and physicians have a responsibility to master the methods of pain control and to administer the analgesic dosages necessary to control pain. There have been recent reports that patients still die in agony. These are the events of suffering that fan the flames of pleas for euthanasia and for help in committing suicide.

Suffering, of course, involves more than the experience of pain. Each person is distinctive, individuated, profoundly different from everyone else. So also is each person's suffering. Memories, lost opportunities, guilts, dated moments of hurt or betrayal, the fragility of one's most unforgettable loves and joys, loneliness and unfulfilled dreams are all as unique as the days, times, places and persons to which they are bound. However, these experiences out of which suffering arises are universally part of the human condition. Suffering of this existential sort cannot really be borne by anyone isolated in loneliness. Compassion for those who are experiencing an untwisting of the last strands of life in themselves demands effective communication of sensitive and unbounded presence. It means mobilizing in another fellow human being the forces of the spirit required to achieve the most difficult of human acts: to hope.

The challenge of civilization to our societies at the turn of this century is to transform our care of the suffering and the dying. The challenge is not to legalize an act that would all too easily substitute for the palliative competence, compassion and community that human beings need during the most difficult moments of their lives.

The question to our societies at the turn of this century is whether we will all be willing and able to mobilize persons and resources to mount the programmes of research, treatment and care that will offer those who suffer an alternative to euthanasia.

Why do we need poets in palliative care?

The great repression and distraction of late twentieth century culture force us increasingly into silence about 'what we feel indeed' on the frontier of death's darkness. We are cut off from the deepest questions that our own intelligence would ask, because these are questions to which neither we ourselves, nor any other human agency, can adequately respond. So, we are not simply silent about these questions, we rather learn not to ask them any more. How could we, when the language we would need, even just to express the questions, let alone to speak meaningfully to them, is now largely dead? We may even reach a point where we so lose touch with these questions, our very own, that we are no longer even aware that our innermost being wants to scream them out. Edvard Munch's painting, Scream, is a haunting depiction of this existential anxiety as a universal and archetypal experience (18). Our being at the surface becomes totally disconnected from our being at the depths, at the depths where we could hear the common cry of humanity within our own cry, as well as the echoes of the human voices of hope and transcendence.

It is to this state of consciousness, marked by the absence of any God, or core of meaning, or sense of common quest that could bind human beings together—marked also by the loss of the ability to notice this absence—that Hölderlein referred when he asked, in his elegy 'Bread and Wine', about what could possibly be the point of poets in an era of emptiness. Heidegger took up Hölderlien's question, 'What are poets for?' and answered that poets are like experienced hunters who can follow the trail of animals fleeing through the woods. These trackers are sensitive to the smallest bent twig, to the slightest imprint of paw in ground. The poets, destined to death though they are, are those who, highly sensitive to human meaning, are hot on the tracks of disappearing and escaping gods. What are poets for? To stay with Heidegger's image, they are there to keep their fellow mortals on the trail, to keep them from wandering aimlessly about and becoming totally lost in the forest dark as they hunt for the meanings of their own existence (19).

How do poets do this? WH Auden gives a clue when he explains what poets mean when they speak of achieving immortality through their poetry. The poets do not mean, Auden says, that they, like Faust, hope to live forever. What they really hope for is to rise from the dead (20). That is the only way in which poets can break bread with the dead. The dead here are those, now long gone, whose communication, whose own breaking of bread with poets who preceded them, continues. It is the breaking of the bread, the ongoing antiphonal song of poet to poet, that survives and continues down all the generations since poets began to open spaces of meaning for the panting hunts of the human spirit. The poets rises from the dead when their poetry enters that undying exchange of song responding to song, expectation responding to expectation, hope responding to hope: Virgil responding to Homer, Dante responding to Virgil, Milton taking up Dante, TS Eliot, WH Auden and other poets closer to us in time extending the breaking of bread with the dead back to the beginnings of the spoken, sung and written word (21).

This breaking of bread with the dead, the continuing antiphony of poet responding to poet, is the undying quest and transcendent desire, voiced in Dante, to say 'that which was never said by anyone' (quello che mai fue detto d'alcuna) (21). That desire answers to another desire, equally deep, to hear what has never before been said by anyone. We are indeed nomads haunted by communion (21), and we share in both desires when we enter into Auden's humanity-spanning and humanity-binding breaking of bread with the dead.

The time of dying is a time for questions that shake the foundation and one's existence and threaten to expose the emptiness of one's deepest dreams. These questions may be only sensed, anxiously, or they may be lucidly faced in all their starkness. Believing and hoping are acts of the human sprit, ways of enduring, of rising above, such questions, acts that no one has ever, once and for all, explained. In ordinary everyday language, people capable of these integrating acts 'have it together' and 'hold together', when threatening disintegration would normally lead them to fall apart. The 'spiritual' need of the dying, it would seem, is precisely for these acts of the spirit that integrate one's person, when every empirical datum indicates one's impending biological disintegration and social disappearance.

Poets reconnect our being at the surface of every fleeting impressions with our being at the depths of the human spirit, at the depths where we can hear the common cry of humanity within our own cry. They channel the 'surface-stream, shallow and light of what we say we feel' into 'the central stream of what we feel indeed' (22).

Poets, as another example of Arundhati Roy's small things cradling big things (23), capture and perpetuate in word and rhythm those seemingly simple and everyday experiences that make real and tie together a lifetime's worth of meanings. These events are the origin of those memories of which Dostoevsky spoke when he said that a person who has even just one memory of having been deeply cherished is a person who can be saved (24).

Why do we need poets in palliative care? We need them to help us all redress our long neglect of attending seriously to the spiritual needs of the dying. Poetry has arisen out of the human spirit's 'immensity of waiting' (21) and of seeking. There are, however, two kinds of poet: the published and the unpublished ones. The published poets sing the songs of the human spirit. However, Matthew Arnold captured the high demand of ministering to the spiritual needs of the dying when he wrote:

> Such a price
> the gods exact for song
> that we become what we sing.

Will we, over the coming years, continue to find and mobilize within palliative care the unpublished poets who become the song that the published poets sing?

The closing question: is humanity too costly a place to keep open?

Towards the end of the 1980s Jaoshua Lederberg, while speaking of HIV infection and AIDS, warned that we will all face catastrophes like HIV disease again if we do not come to grips with the reality of the place of our species humanity, in nature, the place we share on this planet with bacteria and viruses (25).

The place of humanity? Well, humanity is also a place.

Humanity is the place where 'babes and beasts and birds, all small things that have no words' (26) find a voice, a voice to speak on their behalf. But then the question is: who will speak on behalf of the voiceless?

Humanity is the place where those who limp though time, far out in the penumbra and on the margins of respectability, status, power and privilege, are brought into the light of honour and dignity. But then the question is: who will lead them out of darkness when they are in shadows where the elite and established people fear to tread?

Humanity is the place where those who are broken by their losses, their disease, their impending death and, above all, by their abandonment, will not have to live or die alone. But then the question is: who will bring human presence to the unprofitable poor if affluence rather than community dictates the ethics of the societies in which we live?

Humanity is the place where cultures, religions, philosophies and economics clash. But then the question is: do the ideologies and standards of the world have to be unified before we respond humanely to intolerable and death-dealing inequities on this planet?

Humanity is the place where a protective world is prepared for the unborn and for future generations: the place

where there is a will to *act now* so that if others suffer, decades down the line in history, it will not be because of our shortsighted addiction to our own immediate interests. But then the question is: who will represent the future in the present?

We shall face a catastrophe of a kind quite different from that cited by Lederberg if we fail to ensure that the place of humanity is where those threatened with deep loss and with death may find dedicated, scientifically competent and sensitive civilized care. The pressing moral and social question that we face at the turn of this millennium is whether humanity is too costly a place to keep open.

How we answer these questions about the place that humanity is will determine the future of palliative care.

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