

“ENABLING THE GOOD ENOUGH DEATH – AFFIRMING THE NON CLINICAL ASPECTS OF PALLIATIVE DAY CARE”

I want to begin by quoting some comments from a patient who was attending palliative day care in April 2007. In talking about what her attendance – and in this case particularly diversional therapy – had meant to her, she said “I felt myself healing inside”. Later in the conversation, following a description of the years she had spent as a carer, followed by a diagnosis of cancer, she said that in the day hospice “I found some identity again”.

It is by no means uncommon for patients to report the benefits of palliative day care in these kinds of terms. The frequency with which experiences of this depth and intensity are described should raise questions for us about the function of palliative day care. Is it our job to help people to be “healed inside”, even when facing the end of their lives? Should we be helping people to “find their identity again”?

On many occasions I have heard staff in palliative day units complain that very few people – particularly their fellow professionals in the NHS – know what palliative day care is really about. The NICE guidelines, published in 2004, certainly did not know either. The short section on specialist palliative day care (from para 9.40) is headed “Specialist Palliative Care Day Therapy Facilities”, and goes on to admit that “there is insufficient evidence to support the adoption of any particular model (or models)”. Day care is not seen as an integrated whole; commissioners are urged to agree the “types of interventions” to be offered as part of specialist day care, which “might be delivered alongside other supportive care services such as complementary therapy and rehabilitation”.

Although it might be convenient for commissioners to isolate and pay for specific medical interventions and other readily measured episodes of specialist care, such activity is as we know only a part of the whole palliative day care story. Therapeutic interventions alone will not help people to heal inside or to rediscover their identity.

It is my belief and experience that at least some palliative day units lead a kind of split existence, and their staff do too. Because hospices relate primarily to the NHS, and receive most of their statutory funding from that source, they are forced to justify their work both to commissioners and to fellow professionals in terms that the NHS understands. This inevitably skews the description of day care activity in the direction of clinical intervention, numbers of patients, measurable outcomes, and “specialist” activity. At the same time, what is much less often acknowledged is the existence of a huge amount of value and benefit which is about transforming lives. Is this transformation simply an accidental by-

product of palliative day care? If it has the value that patients and their families ascribe to it, and which most palliative day care staff know and acknowledge, then do we not have a responsibility to measure and to affirm this aspect – the non clinical aspect of palliative day care?

In what follows I would like to step back from the conventional way of trying to describe palliative day care, and look at things through a different lens. The old social model/medical model type of analysis has yielded little by way of insights into models of day care. We are still in a situation where staff in palliative day care “know” its value, but have largely failed to convince the rest of the NHS or indeed the wider community. The difficulty in attracting referrals or self referrals from the point of diagnosis of a life threatening illness is for many of us an indication that we have so far not convinced people of what it is that we *really* do.

Let me start with a quotation: “loneliness is not so much a matter of being alone as of not belonging”. Some of you may recognise the author: if not, you may wonder what these words have to do with palliative care. They were written, of course, by Cicely Saunders- almost the last words of hers to be published. They come at the end of the foreword to the 2004 Oxford Textbook of Palliative Medicine, and the whole quotation is as follows: “if people know that they are respected as part of the human family ... the ending of life can be a final fulfilment 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””.

It is very significant that there is no reference here to the clinical aspect of care for the dying. Instead Saunders’ concluding thoughts are about loneliness and belonging. She is saying that the good death, when in her words the ending of life is a fulfilment, is dependent not primarily upon good clinical care, but upon the dying person’s sense that they are respected, that they have value in themselves: and that, crucially, this value derives from the sense that they are a member of the human family, that they know they belong. Of course, Cicely Saunders would be the last person to deny the vital importance of first class clinical care: but her message here is that such care is not an end in itself but serves a higher objective. Saunders is pointing firstly to the need for community, which is the only context in which people can know that they “belong” and therefore that they are valued: and secondly to the possibility that within community “the ending of life can be a final fulfilment”. This should give all of us pause for thought. If we are to follow Cicely Saunders in placing such emphasis on the importance of overcoming loneliness at the end of life, then the implications for those of us providing palliative day care are profound.

If you ask the average person in the street what words they associated with a

good- or at least a good-enough- death, I suspect that very few of them would mention fulfilment and community. Death is not part of our community- it is very far from a naturally accepted part of our social and cultural life. Nor is fulfilment generally recognised as a component of a “good death” despite the writings by such diverse witnesses as Ira Byock, Anthony Bloom, and of course Cicely Saunders herself. The “good death” is much more likely to be associated with a pain free and, if possible, peaceful slipping away.

It is, though, gradually becoming accepted that a new openness about death is needed: that the realities of death and dying should become integrated into our normal social life. The fourth report of the Parliamentary Select Committee on Health published in July 2004 states that “finally we believe that the right to a good death should be fundamental and that social attitudes contribute to problems in helping people achieve this. We hope that the Department for Education and Skills will address this area by examining the place of death education within the curriculum and within teacher training”. This theme is taken up by Age Concern in a policy position paper on dying and death published in November 2005. The paper states “several commentators and the Health Committee enquiry have suggested that it is only by removing the taboo of the discussion of death, throughout all stages of life, that a better understanding of the realities of dying and death, better communications and ultimately better service provision will be delivered”.

Alan Kellehear is of course one of the champions of this proposed openness, which is part of what he sees as the necessary public health approach to palliative care. In his 2005 work “Compassionate Cities”, Kellehear argues for the care of those at the end of life to be returned to the community as a whole, rather than being seen as the preserve of specialists. Kellehear is critical of some of the ways that hospice care has developed. He says “research and policy work within hospice and palliative care services rarely include public education, community development, and workplace, school and municipal partnerships. Dying, death and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour. This reinforces the view that clinical rather than community skills should take priority in palliative care education and training”. (Compassionate Cities p 9)

Kellehear’s arguments are cogent and important, but they perhaps underestimate the difficulties in reintegrating death into contemporary culture. We cannot do this simply by a programme of education or public information, important though these are. Resistance to the acceptance of death and dying as indeed a “normal part of life” is not simply rooted in ignorance. In order to understand this it is helpful to revisit the work of Emille Durkheim and Peter Berger, and their sociological perspectives on death, meaning, and culture.

Durkheim, working in France in the 19th century, developed the idea of “anomie” – meaninglessness. In Durkheim’s view, all culture is a defence against anomie, a way of generating and legitimising a social structure which provides a sense of purpose and therefore of meaning. It should be noted that although Durkheim famously studied suicide amongst young men who apparently had no material reason to take their lives, his term “anomie” is primarily a sociological rather than a psychological one. What is important to note is Durkheim’s conclusion that the collapse of a shared sense of meaning leads to anarchy. Societies are therefore very strongly motivated by instincts of self-preservation to maintain their structures of meaning.

Peter Berger, writing in the last part of the 20th century, studied the sociological functions of religions. Berger noted the way that all the major world religions provided a “metanarrative”, or overarching framework of explanation, which could provide some meaning and significance to suffering, death and dying. Berger’s interest was not in whether the claims of religion were in any sense objectively “true”: he was looking at how religious belief operated within society, at what its social or psychological functions were. It might be thought that the abandonment of religious belief, with its concomitant ethical demands and in some instances the need to appease an angry God, might lead to a reduction in personal and social anxiety: but in fact the change from a predominantly religious to a secular way of explaining “the way things are” has removed one of the defences against anomie. As Durkheim saw, the threat of meaninglessness is ever present, and secular ideologies have been less successful in offering explanations for traumatic personal events – including, of course, death- than the old religions, whatever the “truth” of the latter. The deep need for security and “ontological significance” is now being met in a variety of ways, perhaps most obviously through the consumer culture.

Religious discourse is familiar with the idea of “theodicy”. From a psychological point of view – and again, without making any religious truth-claims- theodicies perform the function of enabling us to live with some kind of equanimity in a world where bad things often seem to happen at random, and in which we know we will all eventually die. The religious form of a theodicy puts things in religious language- using such terms as “the attempt to explain how a loving and all-powerful God can permit the existence of suffering, evil and death”. But theodicies don’t need to be specifically religious. For the purpose of our analysis, a theodicy can be seen as arising from the inherent and seemingly universal human need for justice- for the need to believe that there is ultimately some fairness in the way that apparently random events happen, even if this does not, on the face of it, seem to be the case. Theodicies are therefore a way of staving off meaninglessness at both an individual and a social level. Inherent in a

theodicy is the search for *significance* for the individual person and the social group - after all, if people had no objective significance whatsoever, then trying to justify or explain the “bad things” that happen would be completely pointless.

It has been claimed that for modern western society meaning is no longer provided by religion but through consumerism. It is often remarked that shopping is the modern religion, and that shopping malls are contemporary cathedrals. This light-hearted observation contains a significant truth, which has been the subject of a good deal of recent study. People do not find their worth by reference to a god, but through what they own and consume. It is claimed that modern identities are structured around the experience of consumption. Tim Jackson at the University of Surrey has developed this theme, and has shown that consumption and ownership act to ward off terror and provide security- they perform some of the functions of a theodicy. He cites President George Bush’s injunction to Americans to “go out shopping” after the atrocities of 9/11 in support of his thesis. But as Jackson points out, and of course Berger reaches the same conclusion by a different route, the theodicy of consumerism is inadequate to deal with deep suffering and of course with death.

These analyses of contemporary society all demonstrate why death is not part of our social discourse; not simply because it is just an unpleasant subject, but more fundamentally because our current frameworks of social and individual explanation do not incorporate death, in contrast to the earlier religious frameworks. The purpose of Jackson’s work is to examine how current patterns of unsustainable consumption in the west can be changed. He reaches the conclusion that this will only take place if people’s sense of meaning and identity can be derived from some other source than the primary one of consumption and the possession of material objects. Looked at the other way round, it will be seen that, within the present cultural context, a diagnosis of a life threatening illness is a threat to an individual’s very identity. Death is therefore the elephant in the room. Because its existence undermines the very basis on which our consumer society is built, its reality (as opposed to its images on screen) remains unacknowledged and taboo. The meaninglessness that it threatens is a profound challenge, and an affront, both to the individual and to society. The nature of this challenge has been described by Coyle (2004) who wrote that a diagnosis of a life threatening illness jars open a door of awareness, the same door which, for most of our lives, comfortably allows us to keep thoughts about death in the background. For many individuals the opening of this door precipitates a crisis, and an acute encounter with great total pain.

From the patient’s subjective perspective, Mount (2003) writes eloquently about these existential moments when he says:

“To our dismay, a crack appears in our carefully crafted concept of reality. These existential moments wrench us into a new way of perceiving....The existential

moment...entails a paradigm shift, a jarring, visceral reframing of reality. The very nature of reality is experienced in a new way. We are sucked into the startling realisation that the rules of the game are not what we had imagined. Not only does life depend on unfamiliar rules, it never was defined by the terms we had always held to be reliable”.

Given all this, the potential position and role of day hospices in relation to the rest of society becomes clearer. Hospices are expected by society to perform the function of “holding death” on its behalf, because society can no longer hold death within its midst. The analogy with the old lunatic asylums is obvious: they are places in which the unspeakable is sequestered, institutions which are essential but shunned. This means that hospices perform a vital function for society, but one with which most people want to have nothing to do: hospices are a standing critique of social attitudes, but places which at the same time are needed. Every palliative day care leader is familiar with the extreme reluctance of people to come to the hospice early on in their disease journey, precisely because of the word “Hospice” and what it denotes. At the same time every fundraiser is familiar with the enormous emotive power of the word “Hospice” in generating donations, for precisely the same reason.

It is time to return to Cicely Sanders and her recognition for the need for hospices to be and to provide a community to which people could belong. It should now be clear that the day care community is not- potentially- just a pleasant environment in which the therapeutic work can take place, but can be the very *means* through which the work of preparing for death can be done. The consequences for our work of this understanding of community are considerable.

The “asylum”- the refuge- offered by the Day Hospice is an essential context for the labour of reconstructing shattered identities and finding significance. Our patients frequently refer to the “haven” offered by day care. This haven, this safe space, is constituted by the offers of unconditional acceptance, backed up by the gifts of time and the development of relationship, which our staff make to those we care for. Without this place of safety many people would not have the courage to face for themselves and work through the deep questions and fears that follow the existential slap and the total pain that often succeeds it.

I want to suggest at this point that perhaps the elephant in the room for palliative day care- the fact that we are all aware of but don’t openly acknowledge- is the dynamic of love. Love is a difficult word, in that it encompasses a huge range of experience and emotion: and it does not sit easily in the context of the provision of “professional care”. But if what I have said about palliative day care communities is true- if we offer unconditional acceptance, time, and the development of relationship, what is that other than the offer of love? Love in this context does not of course mean romantic love, in the sense of falling in love with our patients- though that happens, as Cicely Saunders herself experienced. The fact that Cicely Saunders did, twice, fall in love with a patient would probably

be seen nowadays as an inappropriate crossing of professional boundaries : but it also shows that she was prepared to be open and vulnerable in the relationships that she developed with patients. She often said that patients gave her more than she gave them, which again indicates a relationship of equality and mutual respect. Love in this context, therefore, means a model of relationship which requires the professional carer to, as it were, take off the uniform and to engage with patients and families as a fellow human being.

This kind of relating is complex, very demanding, and difficult. It requires a great deal of self-awareness if it is to be done safely and without hurt either to the staff or to the patient. One of its complexities is precisely the different roles that the staff have to assume. The essential clinical role is one where the nurse does have the knowledge and skills that the patient does not- the relationship is therefore unequal in the sense that the patient is the passive recipient of the treatment that is being offered. But outside the treatment room, or away from the discussions about symptoms and diet, the roles are different. If the ideal of community, of mutual acceptance, that I have described is to be realised, then the encounter must be one of mutual sharing, involving the valuing by the community of the gifts that the patients bring to it by virtue of who they are. They are significant because they are themselves and their presence is important just because of that- not because of what we can do to help them.

The sort of relationship I am describing is not without boundaries- it is crucial that the relationships and their emotional demands are contained within the day unit and, as far as possible, within the time spent at work- but it does involve vulnerability and therefore considerable personal cost. It must be recognised- and most people in day care do so, though those outside often do not- that this work of providing refuge and accepting the pain and suffering of others is hugely demanding on staff. It would not be surprising if defences were put up against it, both at the institutional and at the personal level. M. de Hennezel (1998) writes:

“How can we retain our humanity and be sensitive to someone else’s suffering without losing ourselves in that suffering?” She also writes that dying people arouse in professionals, fear, the confrontation with ultimate anomie - “particularly the fear of our own undoing in the agony of the other, of being submerged in or even disintegrated by suffering and chaos.”

I have, I believe, sketched out here not just an ideal, but also a description of what actually takes place day by day in many palliative care units. And having described it, I am once again deeply impressed with the sheer quality of the work- in human, not just professional terms- that our staff undertake. But I also believe that because the nature this work is often not openly acknowledged, let alone recognised by commissioners or other health professionals, the demands on staff can be extreme, and that a retreat into a detached professionalism, or burnout, is a real and understandable risk. We owe it to them to work hard to affirm what I have describes as the non-clinical aspects of palliative day care.

Palliative day care is therefore faced with choices- do we follow the “safe route” of the medical model, offering what health commissioners can easily specify and measure? Or do we try genuinely to attend to death, with all the demands- seemingly limitless and therefore frightening- that such an intention will generate? Of course, the two objectives are not incompatible- provided, I would suggest, that the building of community comes first, and that medical interventions are seen within that context. Or do we continue to hover uneasily between the two, acknowledging to ourselves the merits of our “non-clinical” work, but unable to find the words- let alone the evidential proof- to articulate and promote what we know to be so valuable?

It was one of the tenets of Cicely Saunders’ beliefs that “it is looking at the patient that will teach us how to care for the dying”. (Letters p 76). She says in a letter to a physician “Many times I have quoted you as preferring the phrase “dying with a sense of worth” to “dying with dignity”. (Letters p344). If we are to incorporate these aspirations in our own practice, then we need- we badly need- to have the courage of our convictions and to insist that what we are doing is providing a community which enables people, to the extent that they are able, to find fulfilment, and therefore some healing, at the end of their lives.

Duncan Forbes