

## A Lover's Quarrel

*Like Robert Frost's, a prophet's quarrel with the world is deep down a lover's quarrel. If they didn't love the world, they probably wouldn't bother to tell it that it is going to Hell. They'd just let it go. Their quarrel is God's quarrel. (Frederick Buechner, *Wishful Thinking*)*

In 1982 I moved my main profession locus from the cancer wards of Plymouth General Hospital to become the Medical Director of a small hospice for the dying. My work at the hospital already involved a good deal of terminal care so when I was offered the job at the hospice I did not see it as a dramatic change of direction. In the years that followed, however, I have become aware that the hospice has come to stand in prophetic relationship to the mainstream of medical care in our area. I should say at once that this role is neither conscious on the part of the hospice nor specifically articulated by anyone, but I believe that it is none the less true. Nor are we unique, for throughout the country hospices are having an effect upon medical thought and practice which is quite out of proportion to their size.

They are able to carry out this prophetic function because they fulfil three major criteria: they are drawn from the mainstream of society to live and work at one remove from it; they have the contemplative space to reflect upon the problems confronting them; and they do not choose this role but find themselves speaking a truth that they cannot contain. Like the prophet Jeremiah, they complain bitterly:

You have seduced me, Yahweh, and I have let myself be seduced;  
You have overpowered me: you were the stronger . . .  
The word of Yahweh has meant for me

insult, derision, all day long.  
I used to say, I will not think about him,  
I will not speak his name anymore.  
Then there seemed to be a fire burning in my heart,  
imprisoned in my bones.  
The effort to restrain it wearied me,  
I could not bear it.

Jer. 20:7-9

In a consideration of the prophetic role of the hospice movement it is important to be clear on the meaning of the word prophet, for it is often misused and therefore misunderstood. Frederick Buechner, the American author of a pithy little book of theological definitions called *Wishful Thinking*, writes: 'Prophet means *spokesman*, not fortune teller. The one whom in their unfathomable audacity the prophet claimed to speak for was the Lord and creator of the universe. There is no evidence to suggest that anyone ever asked a prophet home for supper more than once.'

Prophets then, are individuals or groups of people who are called both to *listen* and to *speak out*. They must listen to God, to the 'signs of the times' and to the cries of the oppressed and when they have understood the message, speak out, whatever the personal cost. Prophets are no holier than any one else. They are frequently very wounded people - but like Jeremiah or Isaiah, they put their woundedness at the service of God. When they hear the voice which says 'Whom shall I send? Who will be our messenger?' to their horror, they find themselves answering, 'Here I am, send me' (Isa. 6:8).

Christians are familiar with the prophetic books of the Old Testament and the more poetic passages of Isaiah, Jeremiah, Amos or Hosea are declaimed from many a cultured pulpit. It is easy to domesticate the prophets in the same way that we tame the gospel and lose sight of how threatening what they said must have been to those who heard it. It cannot have been easy for Amos to pass this message from God on to his people:

Trouble for those who are waiting so longingly for the day  
of Yahweh! . . .  
I hate and despise your feasts,  
I take no pleasure in your solemn festivals  
When you offer me holocausts,

I reject your oblations,  
 and refuse to look at your sacrifices of fattened cattle.  
 Let me have no more of the din of your chanting,  
 no more your strumming on harps.  
 But let justice flow like water,  
 and integrity like an unfailing stream.

beu'wunog

Amos 5:18,21-24

The fact is that prophetic messages are, almost by definition, unwelcome because they challenge the accepted status quo. As Buechner puts it: 'The prophets were drunk, on God, and in the presence of their terrible tipsiness no one was ever comfortable. With a total lack of tact they roared out against phoniness and corruption wherever they found them. They were the terror of Kings and priests.'

Today's prophets are just as tiresome. Amnesty International shouts its truth about imprisonment and torture from the housetops and persists in writing importunate letters to busy politicians and dictators. Greenpeace gets its silly rainbow boats in the way of important nuclear tests and the anti-smoking lobby keeps drawing attention to the five billion pound revenue the government receives from cigarette advertising. It is the same in the medical world. Just when the government is trying to tidy up the shambolic National Health Service and make it more efficient, health workers will go on about the emotional needs of the sick and ask for more resources for such tedious and unproductive groups as the elderly, the handicapped and the dying.

I myself had a small David-like skirmish with the Whitehall Goliaths a few years ago when the government decided to reduce the nation's health bill by removing about 90 per cent of drugs from the list of those available on prescription. To do them justice it was, by and large, a sensible manoeuvre except that in their enthusiasm they removed a number of drugs which were vital to our use. One of these was a laxative which was the staple diet of expectant mothers and all patients who need strong narcotic drugs to remove their pain. Outraged, we protested. We gave interviews to the press, wrote letters to the government, all to no avail. Eventually we besieged Whitehall itself. It was quite an experience. Ten of us doctors went to London for an interview with the

Pobovici  
smyel  
d'k'as

primidiciu

Minister of Health and put our points as cogently and forcefully as we were able. Alas, we were no match for an experienced politician and he wriggled urbanely out of every attempt to pin him down so we returned home muttering darkly. Eventually, however, protest was so widespread that the drug was restored, so perhaps our efforts were not in vain.

bohucel  
krouh' &  
zdvori' k

Although it was exhausting, I have to admit that I rather enjoyed taking on the faceless giants of Westminster - especially when we won our cause! A much more difficult situation is to find oneself at odds with one's peers - the men and women one meets daily across the lunch table or in the hospital corridors. It happens, from time to time, that we at the hospice are involved in an unpleasant and painful conflict of loyalties between the needs of a particular patient and the unwritten rules of professional etiquette. It normally happens like this: a friend or relative of a patient rings the hospice to ask for help because someone is in pain or very distressed by the attitude of the doctors who are treating them in refusing to answer their questions openly. The medically correct answer to such a question is 'I'm sorry there is nothing I can do. You must go back to your own doctor.' If the distress is severe, however, it is not easy to behave 'correctly' and one is faced with the difficult choice of confronting a colleague or manoeuvring behind his back. It is always better to be open, of course, but this can lead to hard words and feelings because many doctors are very possessive of their patients and bitterly resent any interference from the outside.

by' ka  
koray

v'zavot

(trigent)  
oduv'at

pon' p'ri'sobit  
#

It seems that this problem is one that will not go away, for despite our efforts to conform to the system people continue to beat a path to our door, seeking the help that they seemed unable to find elsewhere. Some of these callers are of course the sort who will always be dissatisfied, taking their troubles from doctor to doctor, unable to accept advice given to them or the fact that nothing can be done to help them. Leaving those sort of folk aside, there have been many that we have been able to help, needs that we have been able to meet, out of what are really quite limited resources. Let us look at some of the most common of these needs which, by their very existence, point to a flaw in the existing health services.

vata, trhline

The first and most obvious thing for which people seek the help of a hospice is the relief of pain. Everyone is afraid of pain, and well they may be for it saps the strength and crowds

mial  
pudkop'evet

the consciousness until the person is overwhelmed and wishes quite simply for death. Pain is very common (though not inevitable) in advanced cancer and yet in a hospice setting it nearly always comes rapidly under control. Why? Why is this not the case in hospital, and in the community? Do we have special instruments, techniques which are not available to ordinary people? The answer absurdly, is no. We use the same drugs, the same techniques and practically no high-tech medicine. It is a question of experience in diagnosis and in the handling of a few very common drugs and of a meticulous attention to detail. More than anything it is an attitude which says pain is soul destroying and unnecessary and we will not rest until it is relieved.

Put like that, it sounds so self-righteous. I do not mean it to be so. I am just as ignorant in other areas of medicine as some of my colleagues are about pain control in the dying. That is why we are specialists. My complaint is not against individual doctors but rather against a system of government which spends money on weapons or tax relief for the rich while people in state hospitals lie curled up in pain which could be relieved.

But distress in the dying is not only about pain and unpleasant symptoms, but about much more fundamental issues such as the inappropriate prolongation of poor quality life and a way of treating people which is, quite unintentionally, terribly hurtful. One of the things which has become very clear to me over the past few years is that, in some situations, doctors get trapped into prolonging the life of people who, frankly, wish they were dead. The reasons for this are very complex, but let me attempt to unravel them. A woman gets, say cancer of the ovary. She has an operation to remove the growth and then chemotherapy to try and eradicate the malignant cells. So far, so good. She goes into remission and is well and happy for the next two years. Then the growth comes back. This time the doctors know from experience with other patients that they cannot cure her. They try to buy more time with other anti-cancer drugs but she feels terrible and the drugs do no good. She loses weight and strength so that she can no longer get about on her own. Then the tumour causes a blockage in her bowels. What should the doctors do then? Do they operate and perhaps give her another month of life, or do they relieve her pain

miss

and discomfort and let her 'die in dignity' without drips and tubes and a colostomy? They must weigh up the needs of an individual patient. An elderly spinster may dread more than anything the indignity of surgery and dependence upon relatives who do not want her, while a married couple may be prepared to pay any price for a few extra weeks together. One cannot lay down the law, only state the basic principle that each patient has a right to be treated as an individual and be given the choice about whether or not they want invasive treatment to prolong their life. It is only by being open with people about their situation that one can learn that, in the vast majority of situations, quality of life is more important than numerical length of days.

All this seems so obvious. What then goes wrong? Why is anti-cancer treatment pushed to seemingly outrageous limits or elderly people submitted to major surgery when they wish that their lives would peacefully end? One of the great dilemmas for doctors is that much of the time they are working at the frontiers of cancer medicine, using drugs which have a 10, 20 or 30 per cent chance of cure. If the drug works they are heroes and bouquets are given - while if they fail everyone mutters that it was criminal that the person was put through so much suffering and died anyway. I thank God that I do not have to make these decisions.

Another factor however is that as doctors we are trained from the cradle to fight disease and to save life. It is instinctive, deep rooted, second nature. Disease is the enemy and death the ultimate disaster. When our patients get better we feel good, affirmed, fulfilled. When they die we feel bad, guilty, a failure. Now in many ways this conditioning is a good thing: it spurs us on to work appalling hours and exhaust ourselves in the struggle to save life. It pulls us out of bed at three in the morning to deliver babies or patch up drunken motorists; it drives us on to work on automatic pilot when head and heart are too exhausted to care if the patient lives or dies. How then can we be expected to change gear and allow nature to take its course, to raise the white flag, to give way to the enemy? Of course, we must and we do: but it is not easy. Pneumonia, haemorrhage, dehydration, the classic modes of death are all amenable to treatment, even if their underlying causes are not. We have to learn a new way of practising medicine,

odorous  
prohibit

lust

spare?

neglect

prohibit

dehloring

a staying of the hand, allowing people to die a gentle death *today* instead of resuscitating them to live another painful week or die a more difficult death tomorrow. And of course if we are to stay our hand rather than fight on we must explain why – to the family, to the nurses, to our colleagues, perhaps even to our patients. We may not be understood, we may be blamed, we may even be sued. It is not easy to stop treatment it is so much easier to do battle, to keep fighting, so that when death comes in spite of our drips and tubes and machines the bystanders will say. 'The doctors were wonderful. They did everything they could.'

Slowly we are learning that the wielding of our high-tech guns is not to be equated with doing everything possible. This involves a different approach, a treating of the whole person a negotiation and consultation and a tailoring of treatment to the individual. It involves making ourselves available to answer people's questions, sitting by the bedside, drawing diagrams, talking to angry relatives and above all admitting that we have no power to cure – that we are not God. And of course, it involves the learning of new skills: how to handle old drugs differently and how to communicate more effectively. It involves making fools of ourselves with role-play and video feedback, learning that we do badly what we thought we did superbly well. And worst of all it involves allowing our citadel to be breached by those we used to perceive as tiresome charlatans: the practitioners of alternative medicine. We have to learn to sift out the useful paramedical treatments from the magic, discarding the coffee enemas but holding on to and evaluating the usefulness of meditation, relaxation and psychotherapy. We have to learn to be whole person doctors because our patients are whole persons. It takes so much more time and energy. It is destroying our protective hierarchies, our sense of omnipotence. Our corridors of power have been invaded and we are having to learn humility!

Another area in which we at the hospice find ourselves in the role of advocate is the way in which patients are liable to be treated as objects, rather than people. Perhaps I should rephrase this, for neither I nor my colleagues would ever consider a patient as an 'object'. What happens is that, for a number of very complex reasons, doctors and nurses sometimes treat people in a way that makes them *feel* as if they are considered as objects. That this is so there can be no

doubt. I have experienced it myself and I have heard the complaint from many patients. The nicest quote on the subject comes from a lady who died in our hospice a couple of years ago; she spoke angrily of the junior hospital doctors as 'underlings who argue about you as they go by'. Poor H., she was spitting with fury. The junior doctors would have been amazed at her perception of them for they were working to help her, struggling to understand the disease processes and how best to relieve her suffering. I believe that there are three major causes of this misunderstanding between doctors and their patients and although it would be difficult to resolve it altogether, much can be done to lessen it and the dissatisfaction that ensues.

The first problem lies in 'the system' – the need for efficiency in dealing with large numbers of patients. This problem has been with us for a long time and it is difficult to imagine that it will go away. If we are to use resources and equipment efficiently, then people must attend clinics together, be registered in a ledger and so on. Unfortunately, they must usually wait to see a doctor because it is impossible to predict how long a given consultation will take and we must see as many people as need to be seen. Most people take this in their stride. What they do find hard, however, is the depersonalising treatment of being stripped and put into hospital dressing gowns before they see the doctor. A patient coming up to see the doctor for the first time will consciously or unconsciously, dress themselves in such a way as to present themselves as they would wish to be seen. Their clothes are body language which declare who they are, individual people with their own tastes and ideas. If we ask people to remove their clothes and put on a uniform *before* they meet the doctor, we are removing from them some of the protective armour they need for this difficult interview. We are in fact depersonalising them, treating them as objects and we make them less able to communicate effectively because they are nervous and embarrassed.

In the same way, if a third party is present at a medical consultation the patient is frequently inhibited. It matters nothing that the third party is a nurse, that she is a professional and that she is friendly: her presence will alter the interaction between doctor and patient and reduce the communication.

Have to wait

not so obvious

opát

polořem

prořizit

radnost  
o to už  
z nich už  
zapřekáží

Why then, do we do it? Mostly, of course we are trying to cram an impossible workload into too small a space of time. The second reason is that most doctors are quite unaware of the emotional discomfort of their patients. They are polite and friendly and the patient smiles back and all seems well. It is only when you ask people how they felt about the consultation that the truth emerges: that many people are angry, humiliated or in other ways dissatisfied with the way they have been treated. There is however, a third issue which is very much more subtle, and therefore both fascinating and threatening; the question of 'distancing'. By 'distancing' I mean the way in which doctors and nurses, quite unconsciously, keep patients at arm's length so that they, the carers, can cope with the constant daily contact with suffering. Distancing happens in two ways: one is the way we organise health care and the other is in the way we handle a given interaction with a patient. The first way, involving the system I will examine here, the second in Chapter 8.

To understand distancing we need to start from a basic premise: life is unfair, and for many people very cruel indeed. We all know that because we have family, friends and neighbours and because we either read the papers, listen to the radio or watch television. Most people, however, have only a limited contact with suffering. Their parents die, perhaps a friend gets killed in a motor bike accident or someone at work gets cancer. They are touched by it for a while but then life goes back to 'normal'. For doctors, nurses, social workers and other health care workers, however, contact with suffering is normal. Every day I see men and women whose lives have been completely devastated. Darby and Joan couples who have loved each other to the exclusion of anyone else are suddenly separated; mothers of tiny children wither and die lingering deaths, trapped day and night with the foetid tumours that replace mouth or breast or genitals. It is indeed cruel and we find it very hard.

How then do we, the carers, cope? We cope in a number of different ways. The most important is that we are skilled in our jobs so we do whatever is necessary to treat the sick. Being able to do something is a marvellous protection from pain. The other thing that happens is that we create a professional distance between the client and ourselves. We

wear a uniform that gives us status and protection. We see them on our territory so that we feel comfortable and in control. We see them with a colleague - another doctor or a nurse, so that the encounter is formalised and contained. And we see them partially stripped of their identity so that we meet them as patients, not as friends and neighbours.

colleagues

Now I am not saying for a moment that any of these things is wrong; just noting that they separate and therefore protect me from the suffering of the other person which threatens to overwhelm me. The converse of all this is to meet someone suffering on their territory, alone and when you are impotent to help. That is when it really hurts: when you share their pain instead of relieving it. That is very costly and we can only take a little of it.

The reality of the caring situation is that we alter the variables to the needs of the patient and what we can handle at any given moment. When I am feeling strong I see patients alone, without my white coat and ask them how they are feeling not only physically but emotionally. I ask them if they are afraid, if they are sad or if they are angry and I ask them how things are at home. This takes time and a lot of emotional energy and I cannot do it for every patient, so I do it for those who seem to need it most. By doing this I am meeting a small fraction of the human needs of the sick for whom I care.

On the days when I am not feeling very strong I see people more formally, with a nurse at my side. I ask them about their physical symptoms and check the progress of the disease. I order investigations, prescribe treatment and then go away and see someone else. That is the way things are. We too are human and, as Eliot says, human kind cannot bear too much reality.

So what is the prophetic hospice movement saying to mainstream medicine? Perhaps, like the prophets of old, we are the spokesmen for the oppressed. We listen to the cries of the people and try to speak out for them. We relate that they want to be treated as normal responsible people. They want to have their illness explained to them in words that they can understand and to be consulted about its treatment. They want to retain their dignity as individuals and keep some control over their lives. They want to participate in their care and share in our decision-making. They want us to be honest

symplicit

ndivice

with them, warm and humble. More than anything, they want us to combine our competence with compassion and when our hands are empty, to stay our ground and share the frightening darkness with them. More than anything, they need our *love*.

### Room for Loving

*There is room in the world for loving;  
there is no room for hate.  
There is room in the world for sharing;  
there is no room for greed.  
There is room for justice;  
no room for privilege.  
There is room for compassion;  
no room for pride.*

John Harriott  
*Our World*

In the previous chapter I wrote of the prophetic role of the hospice movement and one of my favourite and most tantalising intellectual games is trying to identify what it is that makes the hospice where I work so different from the hospital. (I should add that this is a dangerous game which many people play and in which the inexperienced can be badly hurt, because comparisons are both misleading and invidious.) Hospices, like all prophets, are called from the mainstream of society to live their truth on the periphery. Sometimes their lifestyle brings them bouquets; sometimes they are pelted with rotten eggs: perhaps even the balance of these is crucial for too much praise can corrupt while too little can dishearten and destroy.

What is it that makes hospices – all hospices – so different from hospitals? Surely the ingredients are the same: doctors, nurses, patients, beds, machines – all these are to be found wherever the sick are cared for. The difference lies in the way these elements are blended together or, to use another image, in the way that the players in the drama relate to each other. These relations are different because the *philosophy* of hospices is different. It is a philosophy based upon the conviction that