

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

people, all people, however far gone, are infinitely precious and their treatment must be tailored to their individual needs. We are treating not just a case of breast cancer, but a woman called Mary, her husband John and their children Sally and David. Here we get to the heart of the matter: the dying individuals, complex human beings whose needs are legion: physical, intellectual, emotional, spiritual, social. In hospitals we provide high quality treatment to the tip of the human iceberg: we diagnose disease and try to cure it. We attend to the basic physical needs as well as our resources permit. We are as patient and kind as we are able to be given the shortage of personnel and the pressures of work. We try to help the families when they are in difficulty, but mostly, we dare not open the Pandora's box of human fear and anguish. We are not encouraged to ask people what it *really* feels like to have cancer, to be dying. We are not taught to hold their hands when they are lonely or afraid, or to cradle them sobbing in our arms, smoothing the hair, holding them until the paroxysms pass. We are not trained to *love*. Or rather we are trained to *suppress* our love, to don a protective uniform especially for work: a uniform that keeps us at a safe distance from our patients so that our meetings are those of professional and client, not of the frail human beings that we all are.

Could it be that we are unconsciously denying our patients the one thing that they long for, the one gift that it is in our power to give: our human warmth?

*To love tenderly*: how sweetly the phrase rolls off the tongue conjuring up images of nurses smoothing fevered brows and fatherly doctors comforting weeping relatives. In the world of the terminally ill, 'TLC' - tender loving care - does indeed involve this and good deal more besides. In exploring the spirituality of the carer we need to look no further than the gospels, for the pattern of Jesus' loving provides a model for our own. It confirms our twentieth-century intuition that loving is a costly business demanding a radical renunciation of human distaste and prejudice, a gift of self which is often more than we had bargained for. If the sugar-sweet comforting image of the gentle Jesus is a tawdry piece of kitsch masking the harsh and terrible love of our God made man so too is a sentimental concept of those who care for the dying.

pril k p...  
 zachvaty  
 potlacit  
 vykousit  
 TLC  
 obeknuti se  
 vyhodit  
 byc kmit

Love, especially in the hospice context, can be a very practical and earthly business. I think especially of David, a bachelor in his late forties who is a patient in the hospice as I write.

David is a wonderful man, one of the poor of our successful affluent society who has lost even the one possession that remained to him: his physical integrity. By the time he was referred to our service, the cancer in his mouth had recurred despite treatment and he had a painful malignant ulcer where his teeth should have been. I saw him regularly in my outpatient clinic, always accompanied by a young psychiatric community nurse who cared for him, but he refused admission, jealously guarding his independence despite a growing terror of choking to death. On Christmas day he gave in and came to spend the day with us. Never will I forget the moment when he handed me a bottle of champagne and a torn scrap of paper on which he scribbled 'I appreciate all that you're doing for me'. I asked him if he could manage a little liquidised turkey and was hard pressed not to cry when he said, 'Thank you, but a little watery porridge will be fine.'

'A little watery porridge, thank you.' His words went round and round in my mind all day, as I cooked and ate the Christmas feast with the various members of my family. How indeed could I banish from my thoughts the man whose mouth was full not of Christmas food, but of a foul necrotic tumour?

We all thought David must die soon, and indeed so did he, but in the perverse way of tumours of the face, although he was horribly mutilated there was nothing to actually kill him. Today, as I write, two months have elapsed and he is still alive, a gaunt figure crouched before the television, clutching his tissues and vomit bowl, mercifully oblivious of the appalling stench from his tumour which fills the room. It is difficult to explain the love-hate relationships we have with these spectres at the feast of life. We are not immune to the smell of decaying flesh, and like anyone, we long to escape to where the air is pure. We too are unable to understand his mumbled words and must kneel patiently by his chair as he struggles to write a few phrases on his notepad. We have long since admitted to each other that we wish his suffering could end. And yet alongside this wish, cohabiting peacefully with our distaste, is a real love for this broken man. We have come to

must be  
 povolit  
 sukale  
 vyhodit  
 zaponoviti  
 stravit

value his humour and respect his courage, and like Professor Higgins, we've grown accustomed to his face. We are proud that he feels sufficiently at home with us to leave the privacy of his room and expose his disfigured face in the dining room where all the world passes by. People mutter of him, as of others, 'how awful. If it was a dog, you'd have it put down.' True. But then David is not a dog, but a man with cancer in his mouth, who is living out his last precarious days among friends, loved and cherished in a way that he has never known before. His is the experience described in this poem by Sidney Carter: the one surprise of being loved:

No revolution will come in time  
 to alter this man's life  
 except the one surprise  
 of being loved.  
 He has no interest in Civil Rights  
 neo marxism  
 psychiatry  
 or any kind of sex.  
 He has only twelve more hours to live so never mind about  
 a cure for cancer, smoking, leprosy  
 or osteoarthritis.  
 Over this dead loss to society  
 you pour your precious ointment,  
 call the bluff  
 and laugh at the  
 fat and clock faced gravity  
 of our economy.  
 You wash the feet that  
 will not walk tomorrow.  
 Come levity of love,  
 Show him, show me  
 in this last step of time  
 Eternity, leaping and capering.

It is in this lavishing of love on patients like David that the hospice movement stands in a prophetic relationship to society at large, for it affirms the value of the brain-damaged, the mutilated and the old to a world which values the clever, the physically beautiful and the athlete. Only recently I spent the afternoon with a young French doctor who, when I took him to see our new hospice, still under construction,

*marvelous  
prophetic*

*feelingly helpful*

exclaimed, 'I never before imagined that someone would build a place which is specially designed to provide comfort for the dying.'

What I am arguing for here when I talk about love is not for more hospices or more time spent at work but about a set of attitudes. It is about developing a degree of insight into the patients' world - what the psychologists call empathy. With that insight goes a heightened sensitivity to the patient's distress and a searching for ways to relieve it - or at least not to make it worse. At heart, professional loving is about competence, empathy and communication. It is about becoming sensitive to the pain of others and therefore terribly vulnerable. For me, as for many, it is a way of caring which I aspire to, but achieve only some of the time. It is a costly loving for which I am repaid a hundredfold.

*to give for  
nothing*  
*structure*

One of the most sensitive issues in professional caring is 'becoming involved' with the person we are caring for, the patient, or in psychological jargon, 'the client'. There is no standard teaching on 'how far one can go' in professional loving, and indeed any one carer will probably work differently with different people and at different times, depending on the time and personal resources available.

My own involvement with caring for the terminally ill in the hospice 'style' has led me in a particular medical direction, which ten years ago I would not have dreamed of. After qualifying as a doctor I embarked upon a career as a surgeon. I am good with my hands and planned to use my skill in treating hand injuries and burns, cancer and congenital deformities. To put it another way, I was a 'body' doctor who enjoyed reducing fractures, suturing wounds and generally patching up broken people. It simply did not occur to me to explore how my patients felt about their illness: my job lay in the diagnosis and healing of bodily ills and my psychiatric colleagues would take care of the depressed and psychotic. Psychology I wrote off in my youthful arrogance as being nothing more than common sense, which I thought I had in plenty. I blush now to think of my ignorance - though I know my life was less complicated and my work less costly before it dawned upon me that good medicine demands care of the whole person, body, mind and spirit.

*reluctant  
to  
work  
in  
the  
space  
of  
depression*

The doctor specialising in terminal care is usually referred

potentially  
misleading

4. Nurses' Power common illness  
D

the cases where 'there is nothing more to be done' - where surgery, radiotherapy and anti-cancer drugs are either inappropriate from the outset or have ceased to do any good. In practice (mercifully for our self-esteem and professional survival) there nearly always is something more physical to be done: a fine tuning of pain control or drug manipulation to alleviate unpleasant symptoms. When this is done, however, we are in the same position as our colleagues - empty handed. What we have to do then is learn to work with these empty hands: to use them for comforting and healing of a different kind. A certain proportion of this kind of work is what is known as 'counselling': a skilled listening and interpretation of psychological problems and distress. This is what psychologists and psychotherapists and professional counsellors do. Even among these small professional groups there are differences of theory and personal style but all of them think in terms of therapist and client: it is a professional relationship based on the psychological needs of one person and the skilled response of another to those needs. The distance between them is integral both to the success of treatment and the survival of the carer.

Psychological work with the terminally ill has many of the features of other types of counselling and psychotherapy but the relationship is changed by two factors: the first is the shortness of the client's expected lifespan and the second is the enormity of his loss. In my experience, and I am neither psychotherapist nor trained counsellor, those facing death have a particularly urgent need of human warmth and honest straightforward communication. My personal 'style' has evolved over eight years of work in the field and is characterised by a degree of directness and informality that is unusual in ordinary medical practice. In ten years I have changed from being rather shy about physical contact to being quite at home holding patients' hands or letting them weep on my shoulder. I find that this physical aspect of comforting flows very naturally from honest communication about painful truths and is in no way dependent upon length of relationship. Perhaps I can illustrate this with a typical scenario.

It happens quite frequently that I am asked to see a patient in one of the surgical wards of our big district hospital. The referral may be to consider the patient for admission to the hospice or just to advise on his pain and symptom control.

klau ti)

Handwritten note

Not uncommonly I am asked to help out because the patient is having difficulty coming to terms with his diagnosis or because the family has forbidden the doctors to tell him the truth about his illness and tensions are arising out of the deception.

One thing I have learned is that these encounters should not be conducted when I am under severe time constraints or very tired. I now feel free to ring the ward and say, 'I'm sorry, I'm at the end of my rope tonight. Will it be OK if I come tomorrow? I'll do it much better.' If the need is urgent I will go anyway, but if not I will leave it until I am better able to work with sensitivity. When I go to the ward I always ask the nurses about the patient before I see him or her. The nurses are usually much closer to the patient than his doctors and are often more aware of his hopes and fears. But when I ask them 'does he know?' - meaning, of course, does he know he has cancer and that he is going to die - they often look at each other and say, 'I think he knows, don't you?' - but he doesn't say anything.'

Then, armed with as much information as possible, I arrange to see the person on their own. This often takes a bit of organising, but I have learned to my cost that 'heavy' conversations behind curtains can have a disturbing effect on the other patients who are inevitably sitting with their ears pricked to catch even the whispered confidences. Having the courage and authority to insist that a patient be put in a wheel-chair and taken into the office or, if bed bound, wheeled, bed and all, into a side ward is crucial, not only because of the importance of other patients not hearing but because both the interviewer and the patient are severely constrained in what they say by knowledge that someone else is listening. (One of the difficulties for nurses working in the community is that they do not feel they have the authority to insist that a relative leaves the room while they talk to the patient, so they struggle with the problems of communication in a three-cornered conversation in which an over-protective spouse often answers for a patient quite capable of speaking for himself.)

Handwritten note

Handwritten note

Once alone with a new patient I introduce myself, explain that I have come at the request of their doctor, and ask them to tell me their story. The fact that I am familiar with the history and diagnosis makes no difference to this manoeuvre

for its purpose is not to inform me of things which I already know but to establish a rapport and to elicit some of the submerged iceberg material of sadness and anger. It is in the telling of the story that I meet my patient and in my listening to him that he meets me. This first meeting is a pivotal one in establishing a therapeutic relationship and it may take up to an hour - sometimes longer. But it is time well spent for in that hour one can establish bonds of trust and confidence which are the practical tools for later 'work'. Everything depends on the quality of my listening: the patient must understand clearly from my verbal and non-verbal cues that I am interested in him as a person as well as in his physical problems. This means not only paying careful attention as he speaks, but asking him to clarify issues which I do not understand. As his story unfolds I make notes and if it does not emerge spontaneously, I ask not only what happened and what the doctors said to him but how he *felt* about it then - and how he *feels* now. This exploration of the emotional as well as the physical component of the cancer journey is the key to establishing a supportive relationship. It is often the first time a patient has been asked by a doctor - or indeed by anyone - how he feels about things and he may well begin to cry.

It is at this stage of the dialogue that the doctor, or other worker, may further affirm the patient's worth and forge bonds between them. Patients are nearly always embarrassed and ashamed if they cry in front of the doctor - and many doctors find it hard to cope with. I well remember a surgical colleague who, when a patient began to weep in a clinic, put his finger on her nose in a jocular fashion, 'now, now Iris, we don't want any of *that*, do we?' When a patient weeps with me, I draw a little closer to them and perhaps put a hand on their shoulder. I tell them that they must feel free to cry - that they have every right to be sad or angry or confused. This 'permission' to cry is only a permission to be a human person and *indulge* in what is a very normal and therapeutic release of emotion. When the tears have passed, and they usually do in a few minutes, the person nearly always feels better and somehow comforted, *albeit* by a stranger.

It sometimes happens during the course of such an interview, that a patient asks me if his illness can be cured. This is *the question* - feared by so many carers and so often answered

1. Soluchy  
 2. He...?  
 3. ...  
 4. ...  
 5. ...  
 6. ...  
 7. ...  
 8. ...  
 9. ...  
 10. ...

achali  
 [abict]

with *evasive platitudes* or *outright lies*. I prefer to leave the issue of telling the truth about diagnosis until later; but I may say at this juncture that clear, direct questions about a patient's diagnosis and future *always* deserve an honest answer. It is never right to lie. This does not mean that one should ever be brutal with the truth. One must listen carefully to what the patient is asking and respond slowly, one step at a time, monitoring the response and stopping when it appears that they have enough to absorb for the moment. The 'art' of breaking bad news is one we all need to learn and it should be adequately taught to all doctors and nurses in training.

As always we return to the two essential components of good caring: competence and compassion. Well meant kindness is not enough, nor are the most carefully learned communication skills: but the two together can transform despair into hope, neurotic demanding behaviour into marvellous dignity and courage.

It is curious how this phrase 'dying with dignity' has crept into modern language about the care of the dying. I find it rather tiresome, *conjuring* up stereotyped images of people breathing their last in calm *hushed* surroundings, with nurses and family tiptoeing in and out of darkened rooms. I now understand dignity in a rather different way which has more to do with integrity of personality than external order and serenity. One of the most important aspects of my work is helping people cope with *impending* death by *exploring* their fears, *debunking* the myths and facing the real ones truthfully with them. It is ironic that most 'undignified' or 'neurotic' behaviour in those facing death is the result of the way they have been handled by their carers.

A short time ago, while working with a colleague in the hospital outpatients department, I saw two middle-aged women who were behaving in a very undignified fashion, being aggressive, demanding and apparently unreasonable. Each was like a bomb on point of detonation, possessed by anger and discontent with the world in general and their doctors in particular. By coincidence we had had a run of deaths at the hospice and I had several empty beds so I offered to take the ladies in to 'sort them out'. My colleague was a little surprised as neither of them could be considered 'terminal', but was grateful to have the problem taken off his hands. I admitted both women directly from the clinic and

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 [ylyhau]  
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 melhat  
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 2 emora  
 dny  
 fist  
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 puor  
 vycarova  
 tichy  
 }  
 distola  
 vana'at e  
 woosbr  
 prthama  
 }  
 zrejue  
 outcauy  
 }  
 wrougt

stop limit

stood back to watch the sparks fly. By the time I arrived back at the hospice they were in and already there was trouble. Kate's daughter met me at the top of the stairs to say that Mary had not stopped talking since she arrived and was driving her mother mad. I looked in the neat three-bedded ward and there was a very tense Kate perched miserably on the edge of her chair while Mary gave vent to her feelings from the adjacent bed. Luckily the bed in our single ward was temporarily empty while its occupant was at home for a couple of days; and so, lying in my teeth, I asked Kate if she would do me a great favour by changing to another room, and taking her gently by the arm I steered her out of earshot of Mary's diatribe.

redet usolo  
valley  
p  
p  
p

Over the next two weeks the nurses, my fellow doctors and I 'worked' with Kate and Mary. Ninety per cent of this consisted of being a sounding board, listening patiently and attentively while they told and retold the tale of their illnesses. These were all too familiar stories of fear and anxiety, magnified out of all proportion by medical collusion. Kate was the angriest. She was a chronic bronchitic who had nursed several of her elder sisters through terminal illness and then fallen sick herself. Suspecting the worst, she had asked her doctors (at St Elsewhere's, not Plymouth, I hasten to add) outright whether she had cancer. 'They patted me on the head, like a little girl,' she said, 'and told me not to worry.' But Kate did worry. Her 'bronchitis' did not seem to be getting any better and she was not responding to antibiotics in the way she used to. Eventually she was unable to cope alone and decided to go and stay with her daughter in Plymouth. The consultant gave her a sealed letter to give to the doctor who would be taking over her care. Safely at home Kate looked at the envelope and then, no doubt looking furtively to right and left, she opened it. Inside she found a letter which spoke of an elderly woman with an advanced incurable lung cancer who would soon need terminal care. 'The daughter knows, but we decided it would be better not to tell the patient,' she read. Kate was not only furious but humiliated. It was her body and her life - and yet here were these people considering to keep her in the dark, treating her as if she were a child or already totally incompetent. It is little wonder that when she came to our clinic she was not the archetypal polite, deferential, grateful patient. Poor Kate! It was her carers who had

zvt  
tajne  
sahode  
jasni  
zula'dat  
tajne  
pokořene  
actiy

robbed her of her dignity. Two days later, it was a very different woman who sat on the hospice lawn stroking Trudy, my assistant Michael's dog, and posing with a smile for the TV cameras who happened to be filming the hospice that day. By now Kate knew she had cancer and that she was going to die - but she had control of her life again. It was her decision to stay in the hospice - and her decision two weeks later to spend £300 and risk shortening her life by going to London in a taxi to say goodbye to her friends.

kladit

The hard part for Kate will be the gradual relinquishing of her independence. Fiery spirits like hers find it very difficult to accept the loss of their freedom to move about unaided and ultimately the weakness that makes it impossible even to change position in bed. As Kate becomes weaker the burden upon her daughter will increase. She will need enormous patience to cope with the frustration of not being able to help and the sadness of seeing her mother fail. If only for her daughter's sake I hope that when Kate's time does come she is in ours or some other hospice, for her daughter will need all the help she can get to cope with her mother's anger and her own impotence and guilt.\*

opustit  
duvny

I do not pretend, of course, that the hospice world has a monopoly on skilled and loving care. One can find the same quality of care in many different situations: in a general hospital, in homes for the mentally handicapped, units for drug addiction or in services for the treatment of patients with AIDS. I think in particular of L'Arche communities or of my friends Benedict and Lila who share their home with a number of young schizophrenics. Benedict is an Orthodox priest and he and his wife Lila have eight children. For twenty years they have opened their home to people in need and for the past ten years this has meant young schizophrenics from the locked wards of psychiatric hospitals. Patients apparently uncontainable in a traditional institution become somehow tamed in their home, joining in the life of the family and watching the miracle of lambs being born. Lest we get carried away with sentimentality and the beauty of this vision, however, let me quote the conversation that I had with Benedict when I first spoke to him on the telephone. 'Today'

troucaj

\* Kate returned to her home in London and died peacefully in the local hospice.

he said 'is my fiftieth birthday, and I have spent it scraping  
shit off the bedroom wall!'

[kin]  
pibury

I knew then that we were kindred spirits, for the only kind  
of holiness I can cope with is that which is firmly grounded  
in reality. As I said before, loving is a costly business and  
one needs an earthly sense of humour to survive. This poem  
by an English Benedictine monk is one of my favourites, for  
it has no illusions about the pain of discipleship:

balz'lon

fichol

kim'el

huda

oz de'm'el

zaps'el  
Eav

pat'chal  
q'ly'net

Anoint the wounds  
of my spirit  
with the balm  
of forgiveness.  
Pour the oil  
of your calm  
upon the waters  
of my heart.  
Take the squeal  
of frustration  
from the wheels of my passion  
that the power  
of your tenderness  
may smooth  
the way I love.  
That the tedium  
of giving  
in the risk of surrender  
and the reaching  
out naked  
to a world  
that must wound  
may be kindled fresh daily  
in a blaze of compassion  
- that the grain may fall gladly  
to burst in the ground  
- and the harvest abound.

Ralph Wright

### A New Commandment

My little children . . .  
I give you a new commandment:  
love one another . . .

John 13:33-34

In the next few chapters I will be exploring the manner of  
Jesus' loving as shown in some of the familiar gospel stories.  
But before I embark upon the New Testament teaching, I  
would like to look back for a moment to the Old Testament  
understanding of love. Why, I wonder, did Jesus say that his  
command to love was new? He and his disciples were steeped  
in the Jewish scriptures and must have been deeply familiar  
with theology of the tenderness of God and his predilection  
for the poor, the suffering and the oppressed. Throughout the  
Old Testament runs the theme of Hesed, the faithful covenant  
love of God for his people. We meet it first in Exodus, in the  
marvellous stories of Moses' encounters with God on Mount  
Sinai. True, God tells Moses that he may neither know his  
name nor see his face, but in amazing, scary moments in the  
cloud, when all the Israelites are cowering in their tents, God  
reveals himself. 'Yahweh, Yahweh, a God of tenderness and  
compassion, slow to anger, rich in kindness and faithfulness'  
(Exod. 34:6). I love the rich counterpoint between images of  
the mysterious unknowable God of Sinai and the God who is  
tender and full of compassion. In Hosea we find the same  
message expressed in different, more poetic imagery. The  
prophet likens God to a father besotted with love for his child,  
loving him unconditionally, in spite of neglect and rejection:

new'el  
(nab'el &)

prose'el

no'el'el  
el'el'el

er'el'el

h'el'el

ve'm'el

el'el'el  
(k'el'el'el)

el'el'el

el'el'el

When Israel was a child I loved him,  
and I called my son out of Egypt.