

## Hospice as Community

*Have mercy on us Lord, have mercy.  
You are the potter and we are the clay.  
Somehow or other we have held together until now.  
We are still carried by your mighty hand  
and we are still clinging to your three fingers,  
Faith, Hope and Charity  
with which you support the whole great bulk of the earth,  
that is to say, the whole weight of your people.  
Cleanse our reins and hearts by the fire  
of your holy spirit and establish the work  
that you have wrought in us, lest we return  
again to clay and nothingness.*

William of St Thierry

Twelfth-century Cistercian abbot of Rievaulx Abbey.

It is only in the last year or so that I have come to see St Luke's Hospice as a community. Before that it was just the place where I worked, a bit like the hospital but smaller and less formal. Then one day I was listening to one of Jean Vanier's tapes while driving my car and I heard a talk he had given to a group of people who work in L'Arche. He spoke of people called together because of their desire to serve a particular group of the poor or disadvantaged and how what united them was not the natural bonds of family, friendship or common interest but their calling to serve. This means that life in community will almost always be difficult because such people have not chosen each other but have in a very real sense been *chosen* by their calling to serve.

I would not have *chosen* to live or work with many of my present 'community' at St Luke's and I doubt if many would have chosen me! We have been called together to work as a team because of our desire to work with the dying and our

gifts to do that work. As in religious life, there are many who are inspired by the hospice ideal and would like to work in the field but find, when they try their 'vocation', that the reality is very different from what they had imagined. Work with the dying requires not only great sensitivity and patience but a robust and earthy sense of humour, for when you are in the business of caring for those whose bodies and minds are literally disintegrating, tragedy and farce are inexorably intertwined. There is too a deeply contemplative aspect to the work for it demands not just that we *do* things for people but that we *be* with them. It is a ministry of presence, a being alongside the suffering, impotent as they are impotent, mute as they are mute, sharing their darkness. As I described in an earlier chapter, this foot of the cross ministry is enormously demanding because not only does it expose us to the pain of others, but it turns the spotlight upon our own weaknesses. The hardest thing for me about this work is not the contact with the patients and the exposure to their pain but my own recognition of the gulf between what I preach and what I practise. It is not so much that I teach a way of caring which I do not practise but that I can only sustain that level of caring for a limited period. There are days on which I know I am working really well: that my sensitivity to people's pain and needs is finely tuned and I am using all my professional and spiritual skills. There are other days however when I find that I am distancing myself from the patients and their relatives, providing only the statutory level of physical care that ordinary medical practice requires. These are the days when I am tired or my mind is preoccupied or when I have just had enough and want out.

Most of the time, of course, one cannot take time out when one needs it or would like it. To be economically viable a caring service has to be organised in such a way that there is little overlap of staff, and that means that, unless one is really ill, one must press on as best one can, battle fatigued or not. This means that inevitably there will be days when people are irritable or bitchy and not only less sensitive to patients' needs, but less available to each other. I am personally acutely aware that I am not as friendly to junior nurses, domestic staff and volunteer helpers as I should be and not only do I appear distant, but sometimes, quite unwittingly, I hurt people. This is partly thoughtlessness but much more



117

the fact that I have only a given amount of emotional energy to spend on being nice to people and sometimes, when I have spent a lot of this on patients, there is precious little left over for anyone else.

One of the lovely things about the hospice is the way in which we are learning to cope with each other's bad humour. In the early days there was a good deal of friction between various senior members of the staff, myself included. There were cliques and counter-cliques, jealousies and feuds and the occasional battle for supremacy. The ward office door was frequently closed and one could walk in upon what was clearly a private discussion about another member of staff. I was as guilty as anyone for I would flounce up to the office in a fury, shut the door and pour out my rage to one or another of the nurses. I know, in hindsight, that I was partly responsible for a good deal of the unrest at that time.

Conscious that all was not well between us and that stress levels were high, we made a number of attempts at 'support groups' in which an outsider would meet with members of staff to discuss recent events and air any grievances. Both of the attempts foundered after a few weeks. In one group we met with a local clergyman who was experienced in working with junior hospital nurses. At first we would sit in silence and then someone would mention a recent 'demanding' case and we would all agree that, yes it had been very hard and we had found it very difficult. It took me a while to realise that these sessions were for me not only not helpful, but actually very frustrating. Here we were desperately dredging up problems in order to please the group facilitator who was generously giving up his time for us, and at the same time, quite unable to speak openly about the source of our pain.

It was not only he who was giving up his time: but those who were on duty were desperate to get back to their work while those who had come in during their off duty were equally keen to escape. I felt particularly frustrated because I knew that we needed help and yet there was no way I could reveal to the junior nurses the feuds I was engaged upon with their seniors. Eventually the group foundered because too few people came and we all breathed a sigh of relief and reverted to our natural support strategies: letting off steam to the people whom *we* chose, when and where we felt like it!

Now, several years later, I can examine the situation with

greater calm and observe where the *natural* support groups have formed. An important breakthrough for me personally, and I think for the hospice as a whole, was when I began to receive professional support outside the hospice. The fact of having an impartial skilled person to whom I could legitimately unload my anger and distress meant that I no longer wanted or needed to unburden inappropriately to the nurses or other members of staff.

One of the difficulties in a small unit is the loneliness of those in positions of responsibility. In a hospital the consultants can moan to each other about the ward sisters or the administrators, and vice versa, but in a small unit the matron, the doctor and the administrator are particularly alone, especially if they do not have a good working relationship with each other. I imagine it is the same in other specialities. I have gossiped to enough colleagues at hospice conferences over the last five years to know that inter-personal difficulties in management are almost par for the course. In some units the clash has been of such a magnitude that senior staff had to leave, and in some units matron, medical director and administrator have all gone. This is not the place to go into the causes of conflict between these particular offices in the hospice movement, but it is worth noting that it exists, and that it is the cause of a huge burden of distress in dedicated professional people whose only conscious agenda is to relieve suffering.

In the five years that we have worked together a number of natural groupings and support strategies have emerged within our unit. One such grouping is those who have lunch together in the dining room. I should clarify this by saying that although in theory any member of staff is free to order a cooked lunch and eat it at the dining room table, in practice only a few senior staff do; the remainder, nurses and secretaries, prefer to carry soup and sandwiches off to their desks or wherever they can find to be alone with their peers. For the senior staff, however, matron, doctors, social worker and administrator, this meeting over the lunch table is vital daily communication. It is a time when we talk shop and let off steam, teasing, arguing and getting to know each other as people. It has been a rich experience for me to grow in love and respect for people for whom, at first, I had no natural affinity and to realise that they, like me, are a very human



amalgam of strengths and frailties. It is not just a question of accepting others' frailties, but realising that often these frailties are irrevocably bound up with who they are and therefore with their strengths and gifts. Humbling too has been the realisation of how my own weaknesses are patiently accepted by the nursing and other staff because they, in their turn, value me not just for the work that I do, but for the person that I am.

The other very important grouping is those of us 'at the coal face', those most closely involved with the patients. It has been a real delight for me to work with the same group of nurses over a period of six years. Without any facilitation or outside help we have bonded together as a team which functions as a single person. True, there are differences and friendships within the grouping, but there is a genuine respect for each other's expertise and personality that is quite special in the medical world. It is this team work which is the basis of hospice care, for no one person has the medical or personal resources to meet all the needs of any given patient. Out of the mutual respect there has flowered a genuine friendship between the members of the team so that we are able to share the darker side of our feelings about the work. This freedom to share is the essence of support, for if I feel 'safe' enough in the group to admit that I feel badly about the way I have handled something or that I dislike a particular patient, then I open the way for others to speak of how *they* feel. It is in such circumstances that there emerges the most helpful and healing knowledge: that others also do things badly or become irritated by patients and their relatives, or feel guilty because they cannot give as much as they think they should.

This freedom to be yourself in the work situation is a very precious gift but, like all liberties, it must be respected and cherished. Where there is no such freedom relationships are stilted and unresponsive but where there is no respect for boundaries you have anarchy. Discovering where the boundaries lie in any given relationship takes time, and trust between people is something which must be earned, not demanded by right.

There is a fine balance too, between how much personal distress should be shared in a work situation. An attempt to find this balance is important for two very different reasons. The first is that too great a degree of sharing of personal

problems can lay an unfair burden upon other carers who are already under strain from an emotionally demanding job. It is one thing to reveal that one has a difficulty, another to talk about it repeatedly and at length. The second reason is one that I have learned to my cost: if those in positions of leadership reveal too much of their frailty, the people who depend on them may feel threatened and insecure.. This has been for me one of the hardest things to bear in my present job. At the very time that I have been most in need of personal support – when I have been overtired or anxious or depressed – I have had to struggle to keep a brave and serene face because if I did not, the word would be passed around that I 'had problems' or could not cope and my job would be in jeopardy.

That I have found it necessary to keep up appearances in this way is, of course, a sign that relationships in the hospice are not perfect. But *of course* they are not perfect, for we are all wounded people and, as I wrote earlier, we are all groaning in a great travail as we are being fashioned into a community. It does, however, highlight a particular area of disharmony which I have found to be common in hospice circles and that is between the carers and their council of management.

It may be that this disharmony is a characteristic of charities, a clash between dedicated lay and professional people with different visions or approaches to the same problem.

Perhaps it is worth exploring for a moment the causes of this friction for it is a major cause of distress for a number of senior hospice staff. Perhaps the first and simplest thing to say is that doctors and nurses do not like being told what to do by lay men! I certainly find myself bristling like a hedgehog when solicitors or businessmen or clergymen appear to question the way I conduct my professional life. They in turn, I suspect, find themselves irritated beyond measure by what they perceive as the arrogance of clinicians who will not listen to advice from those with managerial skills.

One absurd but important cause of misunderstanding in my own situation has been a difference of vision between professionals and lay advisers of what the hospice should be doing. I do not doubt that similar problems exist in units for drug abuse, alcoholism or the care of the mentally handicapped. When the idea of a hospice for Plymouth was first conceived, a small nucleus of people dedicated themselves to



making the dream a reality. They gave generously of their time and energy in meetings and fund-raising in order to set up a place where dying men and women would be cared for with love and skill. After five years their dream came true – and their real problems began, for their ‘baby’ took on a life and will of its own and began to develop in ways they had not bargained for. What had started life as a cosy ten-bed hospice where people would ‘die in dignity’ became a bustling professional centre whose members were called upon to visit patients in the community and in the hospital and to teach. The work of the hospice spread far beyond the four walls of its building and with this rapidly expanding endeavour came what businessmen call ‘revenue consequences’. A core staff which had been adequate in the early days became ever more thinly spread until they demanded that their numbers be increased. Another factor that the founding fathers of the charity had not bargained for was that professionals who, in the early days of their dedication and enthusiasm, would work long hours for little money would not always be willing or able to keep up such a pace for months or years. I recall with some sadness the bitterness that I felt after nine months of my present job when I realised that my very considerable overtime work was not only not remunerated but not acknowledged.

How difficult it is for brothers to live in unity! In those early days, when I complained about my colleagues and managers I was told that I must communicate better with them. This, at a time when we were barely on speaking terms, seemed like an impossible counsel of perfection. And now when I am able to live in relative peace with both peers and governors, I find myself giving exactly the same advice to colleagues who feel ill used and misunderstood. But even as I say it, I see the same look in their eyes which says ‘What me, talk to *them* – you must be joking, you just don’t understand!’

Enough of division! Let us return to the idea of hospice as community and focus upon what our naval administrator calls the engine room: the people without whom the ship could not sail. One of the fascinating features of the hospice movement is what has come to be known as role overlap. This is just a jargon way of saying that where hierarchical barriers are not too rigid and a team is working well, different members will feel free to adapt to meet needs as they arise.

It is not unusual in our situation to find the cook comforting grieving relatives, or the pastoral co-ordinator feeding a patient or sitting with someone who is restless. In the same way the secretary and receptionist in our front office provide warmth and a listening ear to the motley of visitors to the hospice. It is they who are the frontline of the endless droppers in: the old ladies with their knitted knee blankets; the marathon runner with sponsor forms and the shy diffident widows and widowers who have plucked up courage to visit the hospice on the anniversary of the death of their spouse.

I am always fascinated by the ministry of these ladies in our front office and I hate to think of the nurse or doctor hours that would be needed to replace them if it was decreed that secretaries should confine themselves to typing and the taking of dictation.

And lastly, of course, are those who should be first in a hospice community, the patients. As in any community which cares for wounded people, they are the heart, the core, the reason for our existence. It is for them that we have come painfully together and they are the cement that binds us, despite our wounds and our ‘differences,’ into one body.

Like the carers, they bring their own gifts and wounds, their own idiosyncratic needs which we must strive to meet. Some ask no more of us than our kindness and our competence, a place of safety in our house. They are pilgrims, travellers who need a bed for a few nights before they continue their journey. Others, however, come yearning for love and acceptance, searching for a sense of belonging that has somehow eluded them. These are the people to whom we have something special to give: a renewed understanding of their worth as people, of their unique value as individuals. I am reminded today of a gentleman who was with us for a couple of weeks recently. I was asked to see him on the haematology ward where he was a patient. It had been decided that further treatment for his blood condition would not be in his best interests and that he would benefit from hospice care. At first he seemed a sad and rather pathetic figure, demoralised by his illness and unable to accept his impending death. During the course of our conversation he spoke wistfully of his home and of his electric organ, which he knew he would never play again. Gambling on the goodwill off the matron and the administrator at St Luke’s I said that



this was nonsense and that he must come *with* his organ and play it for us. Never will I forget the way that man's face changed. When he realised that I was serious, his eyes lit up and he seemed to sit straighter and taller. From being useless, he was suddenly wanted again, his sense of dignity restored. Two days later he came to us and the day after that the administrator went home with him to collect the organ in the hospice van. It was only a week or so that he was well enough to play for us, but those days could have been a lifetime for the joy they brought him. It is a rare happiness and privilege for us to provide a home and family for people such as this and reward enough when they mutter in disbelief, 'I never knew places like this existed.'

## A Time of the Olive Press

*It is a time of fear, of apprehension,  
a fear of pain and disfigurement,  
a fear of hateful eyes and deeds of violence,  
a fear of the power of those who want  
to quarantine, to imprison,  
to tattoo with identity marks  
(shades of Auschwitz),  
a fear of the death dealing.  
There is a tightening,  
a pressure on the chest,  
a desire for air, for space  
beyond the narrow constricted gate.  
There is cold fear in time of tribulation,  
a time of the olive press, the wine press,  
the crushing of grapes,  
and no guarantee of a good vintage.*

Jim Cotter  
from *Healing More or Less*

It happens from time to time that people ask me if I will stay in Plymouth or go somewhere else, perhaps even return to Chile. I usually smile and say I don't really know; but I have no immediate plans to move on. It is difficult to explain that working day by day with the dying makes one acutely conscious that life is a gift and one cannot count on receiving it tomorrow, let alone in a year's time. At a more personal level, I have a deep sense of having been chosen to do this work and I remain ever open to the possibility that I might 'burnout' or be sent somewhere else. Like many people, I wonder very much if the present AIDS epidemic will change my life, if we at the hospice will be drawn into caring for a quite different group of dying people. This chapter is a