

FACING DEATH

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'You know, doctor, I never really thought that I was going to die, I suppose we none of us do. But there does come a time when you are ready to lay it down' — (Lily, a patient in a hospice).

WE MAY FACE death intellectually, plan for insurance and other practical matters, meditate on the death and resurrection of Jesus and know well the christian teachings. We may (especially if we live in the USA), attend classes in 'Death and dying', but all this is likely to fall short of a true facing of its reality for ourselves. Even a ready facing of the little 'deaths' that we meet in life is different in quality from its ending. Like Lily, who had been disabled all her life, we do not really imagine that *we* will die.

A true facing of death is not done once for all, it is an individual journey for each person, a journey between those two statements. However, though each one is unique, it takes place across a broadly similar map. This journey is seen many times over by those who work in hospice teams and from time to time by all those in the caring professions. It implies work, often hard work, on the part of all involved, the patient, his family and friends and all the staff who are trying to help them. There may be many problems to face but there are also achievements to be made before the final letting go.

The modern Voluntary Euthanasia Movement, now established in different forms around the world, aims to make a legalized shortening of this time available to all who choose. While understanding such a desire when good care is not available and other priorities make it seem a distant dream, there are fundamental objections to this solution. The existence of a legal option for a quick way into death implies that there is little value any longer in the person who is dying and in the journey that he is making. Those who work close to people in this situation would affirm how much the dying person and his family would lose if time were to be cut short. Psychiatrists report that suicide is the most devastating of bereavements, leaving intolerable feelings of rejection and guilt for those left behind. But those who believe a legal right to end life would undermine the peace of mind and freedom from fear of many vulnerable people ('I am no better than a burden, I should not expect people to look after me'), have a responsibility to help people who are in such need. They may

do this by active care, by neighbourly and social concern or by trying to encourage others to find how much may be gained by living until death comes. The 'sanctity of life' lies in each unique person.

Many deaths are sudden and give no opportunity for facing and coming to terms with what is happening. Such an unprepared entry into another world, and a judgment to face there, has been greatly feared in the past. Many people today seem to have lost this concern and give little thought to the idea of living each day in readiness. A lack of belief in anything beyond this world is now common, even though hospice workers frequently meet among families and friends a tentative hope that death is not the end of a loved person. They may express a vague expectation of 'a better world' or feel like Wandor, who wrote 'On reflection, I'm not sure I would be better off believing in God. But when my mother died, I found that I was glad that some people still do'.¹ But even where there is no belief in another life that demands some preparation, there is surely still a place for completing work in this one. Time is often needed for a final summing up of what a life has meant, and for reconciliations and meetings that can make a major difference to the family's journey through bereavement.

Violent deaths are sadly common, and shock and the absence of any time in which to begin to come to terms with loss make for difficult bereavements, especially when a child is killed by accident or even murder. The poignant contributions of the parents who share their experiences in the Compassionate Friends Newsletters show how much they need each other's understanding and help in a world where they are so frequently avoided and isolated by those around. And what of torture, disappearance, starvation and the many deprivations of a world so full of 'darkness and cruel habitations' (Ps 74,20)? Suffering and death face us with much sorrow and many questions.

Death from cancer still seems to arouse a unique fear. Some consideration of its process and the ways of handling it that are seen in the hospices may be a helpful starting point from which to consider facing death more generally. Physical pain and other symptoms, decisions concerning appropriate aims of treatment, the frequently vexed question of whether to tell a patient the truth of his condition, the emotional responses of the family and even of some professionals to this particular diagnosis show many common problems in particularly sharp focus. Alongside the special threat of cancer we may consider the effects of some other progressive illness, the paralysis

and loss of communication coupled with an alert mind of motor neurone disease and some strokes, the gradual loss of faculties of the organic dementias and of movement and independence in some rheumatic and similar painful disorders. In all these situations, the person concerned is facing a whole series of endings, of physical independence, of relationships, of hopes and future plans and of confidence in the meaning of his life. How can he be helped to endure them and to use the time that is left?

The progress of cancer is not as inexorable as some of the other diseases mentioned above. The development of treatments that may halt its progress or palliate its symptoms will lead the patient to 'hope against hope'. This may be tantalizingly unrealistic and merely bring the pain of hope deferred and it also poses the dilemma of when to cease fighting for life and accept the approach of death. Teilhard de Chardin presents this dilemma from a christian point of view:

We have come a long way, christianly speaking, from the justly criticized notion of 'submission to the will of God' which is in danger of weakening and softening the fine steel of the human will, brandished against all the powers of darkness and diminishment . . . I can only unite myself to the will of God (as endured passively) when all my strength is spent. . . . Unless I do everything I can to advance or resist, I shall not find myself at the required point — I shall not submit to God as much as I might have done or as much as he wishes. If on the contrary, I persevere courageously, I shall rejoice in God across evil, deeper down than evil; I shall draw close to him.²

Many are afraid that the side effects of treatment will be worse than the disease itself, but yet feel guilty if they refuse it. Such decisions are never easy and patients do not always have the support they need in facing them. But once it has been decided that nothing more can be done to halt the progress of the disease there is a great deal that can be offered to ease its physical manifestations. The aim of pain control and the relief of other symptoms is that the patient should find his body and its needs less obtrusive, even when his activities are more and more curtailed by disease. Our bodies can have their essential integrity affirmed even in weakness and dependence and when careful attention is given to the analysis and treatment of its problems we can still feel that it is well regarded by others. A changing body image can be faced and accepted and a sense of personal worth be maintained even in the face of great physical loss.³

The successful control of terminal pain and other symptoms achieved during the past two decades, largely by the members of the Hospice Movement, has proved to be transferable to different settings, including the patient's own home. 'No patient should be allowed to die suffering, for pain can be relieved entirely in the majority and controlled satisfactorily in the rest'.⁴ The public's preconceptions that all strong pain killing drugs will lose their effect after inevitable increases in dose, and that at best patients will be sleepy and confused if pain is to be eased, have been shown to be untrue; and the teaching on how to use such drugs effectively is finally spreading widely into the general field.

The greatest sorrow of a dying patient is the ending of relationships and responsibilities. We live in our interchange with others and as encroaching weakness leads to the change of roles, as the wage earner can no longer work or the housewife has to hand all her activities in caring for the family to others, it is hard not to feel useless and humiliated. The family often takes readily the opportunity to repay debts of love and care but it is not easy to be perpetually at the receiving end of other people's concern and this must be given with sensitivity. This time can be used to heal bitterness and find reconciliation and as at any time of crisis, this may take place at surprising speed. ('We lived a lifetime in three weeks'.) But in order to do this well at least some of the truth of the situation has to be shared. Families often feel they must protect the dying person, but this is almost always misguided. The patient comes to know by other means and is then left even more isolated, unable to share his concern for others as well as for himself. To dissemble continually is inhibiting and exhausting for both sides. However hard it may be to face the approaching parting it helps to stay with as much truth as possible to work through the anxiety and grief it brings. Some families have shared little during their life together, some people have spent their lives avoiding unpleasant realities and not every group will be successful. No one should be hurried through stark disclosures and we may have to wait while partial truths are gradually absorbed, but some shared awareness has again and again been seen to facilitate often surprising family growth. Patients (and families) may continue to hope against hope, to take a 'day off' from truth by concentrating on a trip or a celebration, and still meet in depth at one and the same time. Nearly all of the many families who leave St Christopher's Hospice with new strengths after a patient's death are those who have been able to face

their parting together. Bereavement will still be hard to come to terms with, but such memories will help to make this a creative process. The hospice team is ready to work singly or in groups with those who need special help for this long journey of sorrow.

To face death means to face the ending of hopes and plans. Pain is not only physical and social, it is also deeply emotional. Indeed, mental pain may be the most intractable of all. The anxiety over the disease and its treatments merges with the depression evoked by dwindling capacities. Most of us have reason to feel shame as we look back over our lives, but this is often confused and confounded with vague and irrational feelings of guilt among the very ill. Some people find themselves attacked by bouts of understandable anger or devastating despair. Yet clinical depression is comparatively rare among cancer patients and suicide uncommon.

Sadness is appropriate and should be faced and shared. It calls for a listener, rather than for drugs, although a combination of the two may help to lift an inhibiting load and enable a patient to tackle problems that had seemed unmanageable. When such treatment is carefully assessed and reviewed, this is not to manipulate the mind but to give it greater freedom and strength in facing reality. Sacraments announcing God's forgiveness may bring peace, or the acceptance of those around confirm this without words.

The greatest fear is of loss of control; yet even with an encroaching brain tumour or with failing mental powers the person may be helped to focus his attention and to respond in character to reality as he sees it. A daughter who described her father's slow disintegration of mind with loving yet scientific perception ended her moving description of his final achievement — 'Mind and body are inseparable, so far as we can tell, but experience suggests that they are no more than tools, and of much less account than the spirit whose purposes they serve'. The ending of that story was peaceful and once her father, in a remarkable moment of lucidity, had committed to others the welfare of the wife he loved 'he subsided afterwards into a quiet dementia which was like a rambling dream; vivid consciousness and depth of feeling were no longer present and I never felt another pang on his behalf'.⁵

To face the increasing dementia of one much loved, often over years, is one of the hardest ways of facing their deaths. The carer, when the patient is at home, as so many are, or the relative who has handed care to often hurried and overworked professionals, faces a long, slow loss and frequently fails to receive needed support.

Anxiety, depression, anger and despair will also attack them and be exacerbated by exhaustion. The loss can gradually be accepted intellectually, emotionally, and socially and the agony of separation gradually lessened, but when death finally comes there will almost certainly still be much 'grief work' to do. Like the patient who is losing control and feels he is no longer his accustomed self, the bereaved have a new world to discover and accept. They cannot be hurried through the numbness, the emotional pain, the gradual realization of the emptiness of loss and the final learning to live again. Some need much help in expressing their feelings all through this time and may finally need permission to stop grieving and allow other commitments to come around the gap.

Coming to terms with loss intensifies the ever present search for meaning.⁶ The following extract from a diary dictated by Ramsey, who became blind and inhibited in speech from an inoperable brain tumour, shows how new vistas and even new faith can open up in the accepting surroundings of a hospice and how dying, like bereavement, can finally lead to new growth:

26.8.78: Amazingly enough, I believe I'm going to find a God. I don't know how it will happen precisely, but the sense that Jesus will find me and make me all that I am and more is not too far away, and the fact that he is coming at the time that I need him most is amazing. To think that in such a short time and in my own way is coming to me Jesus Christ, that is, I hope, going to look after me, seems a most important thing, but I know it's going to be true. Annie is writing again, Jill is writing, people who know me, love me and will stay with me forever, all will amaze me. Only now am I beginning to realize by thinking of God, what he must know and think of how significant I am. I find it quite exciting to think of my future and to realize that Jesus is going to somehow make my life work and I wish I could have done it before, what does make me excited is the possibility of extending my life in this world or the next in all the ways that I now can.

Living of life and living of death was, I thought, to be a strange thing. I still think it's a strange thing. I want to try and make it a place where I am with everyone else when I am dead or alive, where it becomes a place that's not going to change. I don't know how it's going to happen, but I know it will happen. I don't know whether I'm going to die forever, but I know it doesn't really matter, because I'm going to be looked after, and everything that God wants me to do I will do to the best of my ability, and that is all that matters. I seem to be at the beginning of my life with God and that is amazing'.⁷

Ramsey's syntax has gone but what he intended to say is clear. He died two weeks later, very peacefully.

We all need meaning in our lives, and to face death seems at first to face the loss of that meaning. Most people think of themselves in terms of what they do and find in that their place in the world. As their role is lost, as Ramsey lost his as a television producer, much of the integrity of the self seems to go too. Like many others, in his response to a totally new and extremely dependent situation, Ramsey found a new self. The body seems to have a wisdom of its own. If we follow its dictates, as its powers diminish so those of the spirit can find new strength and creativity. Those who search for a new and lasting truth in their lives find as Ramsey did that life can be laid down in hope, not of something indestructible in the self, but in trust in the God whose hands hold them in death as in life. For those who feel they can no longer pray from sheer weakness there is the holding by the prayer and love of others, 'where I am with everyone else' and above all, trust in the God who knows our ability. His judgment here and hereafter is a 'setting things right' and as we believe we will live on in the memories of those who love us so we can trust that our soul is safe to live on in the invincible love of God. And so we reach trust in the whole communion of saints, the household of God.

Ramsey was unusual in being able to express this in his late discovery of God. Many who have no words, or at least none of the traditional phrases, show by their attitude, their gestures and their response to those around them that they are reaching out trustfully to what they see as true. We believe that this reaching out brings them to 'The Truth'.

Paula, young, blonde and beautiful, had the cross removed from the niche in her room and put a horny little red devil in its place. She gave friendship and entertainment to us all for weeks but had apparently no time for spiritual questions. On her last night she asked a nurse what *she* believed. On being given a simple statement of faith in Christ, Paula said 'I couldn't say I believed like that, not now, but would it be all right if I said that I hoped?' At that she took off the false eyelashes she wore night and day and gave them to the nurse to put away: 'I won't want these any more'.

But what of those who either do not have or do not take this opportunity? What of those who feel only the absence of God in their weakness or feel that they have lost their faith? Some can take Our Lord's words in the passion, the 'if it be possible' of Gethsemane

and the 'why has thou forsaken me?' from the cross and hold to them in darkness. Others who find no light in life will surely meet him in death:

In his fourth word from the cross Christ went into the lowest depths to which man comes. There he laid himself as a foundation by which we may pass over — like a man laying concrete across a swamp. . . . However great the depth of sorrow or shame you or I may be in, it is not bottomless. He went lower still — so that we might pass over.⁸

And surely we can hope that such love will be fully revealed to all as they die and pass into the Presence.

For those around, both family and staff, comes the other word of Gethsemane: 'Watch with me'. When first uttered by Jesus it could not have meant 'take away', 'explain', or even 'understand'. Its simple but costly demand was plainly no more than just 'be there':

Our most important foundation for St Christopher's is the hope that in watching we shall learn not only how to free patients from pain and distress, how to understand them and never let them down, but also how to be silent, how to listen and how just to be there. As we learn this we will also learn that the real work is not ours at all.⁹

During the two decades since that was written the Hospice Movement, a movement facing death and long-term illness and bereavement, has come a long way, and has seen its basic principles interpreted in many settings and begin to move into the general hospital and community field. It has endeavoured to remove the fact and the fear of terminal distress by a combination of tough clinical science and personal attention to detail. It has seen the whole family as the unit of care and tried to help each group to discover their own strengths as they try to share as much of the truth of the situation as they can. Its workers have opened themselves to the angers and fears that make up the anguish of some of the dying and the bereaved. They have watched many people come along the journey from disbelief through gradual realization to acceptance and offered what hospitality they could. In so doing they have often found themselves receivers rather than givers, gaining new strengths and insights from those they set out to help. To face death is to face life and to come to terms with one is to learn much about the other. In doing this the group have learnt also how much they need to share together their own experience of loss and change in this work. A hospice team needs to be some kind of a community. They have watched many people find that the God who himself died is beside them and ready to give them courage and have seen him more clearly for themselves:

When he was born a man . . . he put on the leaden shroud that's man's dying body. And on the Cross it bore him down, sore heavy, dragging against the great nails, muffling God, blinding him to the blindness of a man. But there, darkened within that shroud of mortal lead, beyond the furthest edge of hope, God had courage to trust yet in hopeless, helpless things, in gentle mercy, holiness, love crucified.

And that courage, it was too rare and keen and quick a thing for sullen lead to prison, but instead it broke through, thinning lead, fining it to purest shining glass, to be a lamp for God to burn in. So men may have courage. . . . Then they will see how bright God shines.¹⁰

The christian answer to the mystery of suffering and death is not an explanation but a Presence. Alfred the Great translated Boethius as he cried out from the suffering of the Dark Ages. Our own cry today echoes his, and the answer is the same: 'Why has thou made me thus?' He will translate it, and after many days he will translate the answer, which is no answer in logic, but in excess of light.

O Father, give the spirit power to climb
To the fountain of all light, and be purified
Break through the mists of earth, the weight of the clod,
Shine forth in splendour, Thou that art calm weather,
And quiet resting place for faithful souls.
To see Thee is the end and the beginning,
Thou carriest us, and Thou dost go before,
Thou art the journey, and the journey's end.¹¹

NOTES

¹ Wandor, M.: 'Only half the story', in *Walking on the water: women talk about spirituality*, ed. Garcia J., Maitland, S. (London, 1983), p 103.

² Teilhard de Chardin, Pierre: *Le milieu divin* (London, 1957), pp 72-73.

³ Vanderpool, H. Y.: 'The ethics of terminal care', in *Journal of the American Medical Association*, 239 (1978), pp 850-52.

⁴ Walsh, T. D.: 'Pain relief in cancer' in *Medicine in practice*, 1 (Medical Education International Ltd, 1983), pp 684-89.

⁵ Personal Papers (1960), 'Death of a mind. A study in disintegration', in *Lancet*, 1, pp 1012-15.

⁶ Frankl, V.: *Man's search for meaning* (London, 1962).

⁷ Du Boulay, S.: 'Ramsey's diary', in Cicely Saunders, *The founder of the modern Hospice Movement* (London, 1984) pp 204-05.

⁸ Clements, B.: Quoted in the *Unity book of prayers* (London, 1969), p 103.

⁹ Saunders, C.: 'Watch with me', in *Nursing Times*, Vol 61, no 48, (1965).

¹⁰ Prescott, H. F. M.: *The man on a donkey* (New York, 1952), p 1537.

¹¹ Waddell, H.: *Poetry in the Dark Ages* (Constable, London, 1948), p 26.