

Abstract

This article is a reflection of the importance and the difficulty of being present to and with terminally ill patients within a palliative care setting. It is offered as a reflective and interpretive piece on the work of a chaplain within the palliative care team. It includes an examination of the way in which the dying reminds us of our own mortality and of the often unacknowledged terror of death. Questions are asked about the distinctive role of the chaplain and what is it that the chaplain and other professionals within the palliative care team share. It is written from a Christian perspective.

Watch with me – A chaplain’s perspective.

Twenty six letters in the alphabet
Mixed together to make up words
That explain everything

So why is it so hard to find the right words?
This poem is a contradiction
Words trying to express the inexpressible

Words count for so little
In the face of this enormity
This full stop marking the end of a sentence
Which is life

Words dry up and leaving them behind
Another language is rediscovered
The forgotten language of tears, a smile,
Touch - a hand
On the shoulder, a hug, perhaps even silence
If I dare

No more words.
What is needed now is that
The Words become flesh.¹

The terror of death

John, a former professional cricketer and a keen runner, had cancer in his lower back and as a result had spinal cord compression. He had lost the use of his legs. In fact, he used to say, 'it as if my legs are the other side of the fence and I am here'. Normally a cheerful and upbeat man, he was desperately struggling to come to terms with what had happened to him, to grieve for all his losses, to begin to face what the future might hold and at the same time to try to protect his family from all that he was going through. He wanted to talk to me, to a nurse, to a doctor, in fact to anyone who could help him and give him some hope. Sitting with him was extremely difficult because what John wanted, his old life, he could no longer have. He had come to the end of active treatment and like every other patient in the hospice, the only care we could offer was palliative.

I guess most of us have either heard or been on the receiving end of the accusation, 'don't just sit there, do something'. We may have said it to our own children. In the hospice this is turned around; 'don't just do something, sit there'. Sit there and keep company. To watch with another person as they begin to lose control of their life, become increasingly dependent on others and try to come to terms with their mortality requires huge mental, psychological, spiritual and, for the chaplain at least, theological resources. Above all, as we try to watch with another person it must be that we have had to confront the same questions, to have faced our own fears and losses and begun to think about our own death. How easy that is to say and yet how difficult to do; the words 'facing my own death' trip off the tongue so easily. Yet I know from colleagues that I am not the only one working with terminally ill patients who occasionally thinks that when I get a headache it might be a brain tumour, or that

when I am feeling run down it might be leukaemia. Some sociologists suggest that all human beings carry around inside themselves a profound and usually unconscious dread of death as absolute annihilation. This awareness generates terror and is managed by most of us by developing an anxiety buffer. ⁱⁱ

There are those who suggest that belief in an afterlife developed because human beings couldn't face the fact of this life being all that there is. Yet those of us who claim to have hints of the eternal in our midst and beyond might at least admit that there are times when a patient is struggling that it is our own discomfort we can't bear, and we rush from the terror of death to the promise of eternal life all too quickly. Death is at times so fearful – it feels safer not to stay but to move quickly on before the conversation dries up and I am faced with silence and the strangeness of death and the sense of loss. Michael Kearney, a palliative care consultant of many years experience says 'the process of dying includes suffering, painful separations and unfinished business. Death cannot be tamed. Death is unknown. Death is other. Death is death'. ⁱⁱⁱ

As I said, the words 'facing my own death' trips off the tongue all too easily, but in order to be with patients I must at least have found ways of staying with and being in my own experience of suffering. It might be that the patient reminds me of someone close to me, it might be that she or he is my age but there are other times when a patient doesn't remind me of anyone in particular but somehow affects me in a way that I can't make sense of. And there are times when I simply do not want to visit or am afraid.

Being part of the team - The chaplain's role.

This piece is written from a Christian perspective. However, I find that my practice is very similar to that of my colleagues, whether we share the same beliefs or not.

In Holy Week the Christian Church hears through the reading of its scriptures, the plea of Jesus of Nazareth to his friends in the Garden of Gethsemane to 'watch with me' as he faces his impending arrest and death. For the most part pastoral care in a hospice is just that - watching with the patient, keeping them company as they face some of life's most difficult questions: 'Why me?' 'Why now?' 'Is this all there is?' 'Is there a God and if so where is God in all this?' And most common of all 'what will happen to those closest to me?' The chaplain's role like that of a nurse, is multi faceted and not easily defined. Watching with a patient and their family and friends, there are times when they give me my role and I come to understand what they need of me. At times the chaplain is a liminal person who represents the boundaries between earth and heaven, life and death, belief and unbelief. He or she may be a presence that enables a patient to respond to God either as they prepare for their death or should they need to vent their anger. I find that the clerical collar acts as a magnet and may attract or repel. The Chaplain 'keeps alive a rumour of God' and often needs to work with the projections that come his or her way. Belief systems are often threatened when a person is given a terminal diagnosis; for those in the medical profession it is often the case that a patient feels let down by the Health Service and the professional may receive some of that anger. So likewise God, who might be seen as all powerful and mighty, refuses to heal those looking for a cure. The chaplain, representing an institution that dares to speak of God and for God, needs to be sensitive to and not frightened of the anger that may be expressed. Christopher, a leading Roman Catholic layman and spiritual director, sat with a nurse in our Chapel

and as I passed the nurse called me and asked me to pray with him. Christopher simply said 'we are being angry at the moment' I replied that I could 'do' anger. 'Oh really?' he challenged, 'and how do you do that?' Knowing his religious background I suggested that perhaps we start with using some of the Psalms. 'Don't get all spiritual on me!' he said. The nurse, deeply embarrassed, asked if he would like her to leave. 'No, please stay' he replied. I asked if he would like me to leave to which he replied quietly 'Yes, please'. Later, the nurse found me and was mortified. Deeply embarrassed, she began by apologising, but I explained that I felt it was important that she call me in order that I might be rejected. The spiritual and the religious and maybe God too was of no use at such a time. Many, many times a patient asks for prayer at their bedside and listening to their story it may be possible to hold such a life in the presence of God, give thanks for all that has been given and received, to express the sense of loss being felt, say sorry where there is a need and offer a blessing as the patient faces the end stage of this life. I find the words of King Lear speak of the importance of giving thanks for the extraordinary work and care that is carried out by the whole team of staff and volunteers 'as we take upon us the mystery of things, as if we were God's spies'. So the chaplain is one who recognises and responds as one of God's spies; in a strange way he or she tells God about this place and these people.

Sometimes the hardest thing for me to do as chaplain is simply to go into a patient's room for the first time; why am I going? what do I think I am offering? I am not a nurse and let us face it, they are one of the few professions in the community that are still held in high regard. I am not a nurse offering kindness, a bed bath, some medication and a desire to make the patient as comfortable as possible. I am not a physiotherapist who might help in moving or building up certain muscles thus

enabling some freedom. I am not a complimentary therapist who can offer massage or reflexology. I have nothing to bring. Of course I have myself, I have my faith, but this is their room, their space, their disease, their pain, their precious time. What in heaven's name do I think I am doing? What on earth do the living have to say to the dying? Well, those are my anxieties – but I am almost always surprised by the welcome I receive; of course some people are polite, occasionally, but only very occasionally a patient is hostile, generally patients and their families are extraordinarily welcoming and generous. The nurses and other staff and volunteers do such a good job that by the time I arrive, patients and their visitors are expecting me to be kind and generous. I asked the question ‘what do the living have to say to the dying?’ Well perhaps not very much, but the chaplain can listen to what is being said and what is not being said. He or she must listen to the clues, metaphors and body language in order to recognise the spiritual needs of the patient.

I found one patient, who had a brain tumour turning the hospice conservatory upside down, desperately looking for something. I asked him what he had lost and he replied ‘I have lost ten minutes, I can’t find it anywhere’. He was serious and it would have been easy to put this odd remark down to the effects of his brain tumour or the medication, but I could see that he was serious and the loss of ten minutes was very important to him. As he continued to hunt high and low, I asked him what it would mean if he couldn’t find them, to which he replied, ‘But I have got to, I’ve got to!’ He was seriously distressed. Could it be that the ten minutes represented a deeper, more fundamental loss of time? Time was slipping through his hands and despite his confusion he was in touch with a deep anxiety about the way in which he could not hold back the tide of time. Is that not an anxiety that most of us share? Another

patient, a woman in her early 30s, said to me, ‘Do you know before I came in here I used to worry about whether my carpets matched my curtains?’ In the hospice the superficial is often stripped away; this is the stuff of life and death and we have to take it very seriously. Of course people will still want to talk about their allotment, the holiday they have planned, but right in the middle of them telling me of their excitement in anticipation of seeing their daughter get married next spring they will ask about the hymns for their funeral. I will say a bit about prayer and the sacraments a little later, but what I have come to see, reluctantly I think (because it seems to draw too much attention to the person) is that what is important is our presence. There are times for words; words of sorrow, words of hope; but what people need mostly is not words but for the words to become flesh, they might want company, a smile, shared tears, an ability to sit still, the willingness to listen, to watch with them often in silence.

Increasingly I discover that patients welcome prayers and a blessing and in a way this is the easiest part of a chaplain’s role. Thank goodness I have something to give, something to do. I am not saying this role isn’t important – quite the opposite, but I am aware that I can hide behind my dog collar, or I can say a prayer because there is nothing else to say or do. I can give communion rather than sit in uncomfortable silence. I can make my exit after praying with the family over the dead body of a person they have loved, rather than staying with their grief.

Multi Disciplinary Team Working

It is important to say something about the team I work with, because it is quite clear to me that much of the pastoral and spiritual care that goes on happens without the chaplain being involved. A young woman who had had the most appalling life rejected most offers of help and comfort; she was absolutely clear that she wanted nothing to do with the chaplain and seemed to hate everything I stood for. I wasn't allowed in her room. One day going home I passed by the hospice conservatory; her bed had been moved in so she could smoke and I saw a nurse making her bed and then sitting with her, holding her hand. I somehow knew at that moment that she was experiencing love, maybe for the first time in her life, and if you knew her story that might not seem an exaggeration or too sentimental a thing to say. She didn't need words about God; in fact I do not think she would ever have been in a position to entertain the idea of a loving God, she didn't need words, she needed love, she needed the word to become flesh. And the word was indeed becoming flesh in that nurse's touch. I do not believe that she would have understood it in that way and the nurse would simply thought of herself as simply doing her job. 'God it seems is happy to remain anonymous'^{iv}.

God as Presence and Absence

Watching with, staying with, being present; these are catch phrases for a faith that has at its heart the belief that God has come among us – and so being present to another person is I believe God like.

Evangelism as presence is not some new technique, a missionary method worth trying. It is nothing less than the way of God, God's own way. It is the way of the God of the cross. We live in a universe of I and Thou. To be really

and totally present, really and totally in the present, is for us to be like God. In the Eucharist Christians claim to be centred on the real presence of Christ, but the evidence suggests that we may not often manage to be really present to one another within the gathered community, let alone the wider community beyond. Presence simply as being with, presence simply as humble reverence for the other that never desires to manipulate or possess or use the other, authentic face-to-face encounter which flourishes in silence - this is very rare. Real presence is too much for us.^v

But it is not altogether surprising that being really present is too much for us. To watch with another person as they face their personal hell can leave us wanting to be elsewhere. One mother met me in the corridor and asked me to visit her young daughter. As I turned to go into the room, the mother said to me 'I can understand why my daughter has cancer, I mean, potatoes get blight, roses are attacked by greenfly, things go wrong in nature, it is when you bring God into the equation that it is hard to understand'. It has taken me twenty years to get to a position where I think bringing God into the equation might make some sense, but that mother did not want answers, she simply wanted to lash out. I said earlier that people seem to know that the chaplain represents something and in this case the chaplain represented a God who had turned his face away.

I have focussed mostly on watching and waiting with those who suffer as I believe that most people's experience in the Hospice is closer to Holy Week and Good Friday than Easter Day. But human beings are not only seeking meaning, we are also creatures of hope – we are formed by the future. So I'll finish with a story that hints at

trust in a future yet to come and seems to bring genuine comfort to some patients and those close to them.

Letting go

Mary was admitted to the hospice having suffered a great deal in the previous two years. Mary was angry with God and with life. For several days she was unable to lie flat and had her head resting on her knees and was constantly groaning. Mary didn't appear to be in any physical pain but was clearly very distressed, as were her family. Several members of staff had gently suggested to Mary that perhaps it was time to let go. Her family reluctantly agreed. In a sense family and staff were giving Mary permission to die. But she remained doubled up in obvious anguish. I was called and, after some conversation with the family, I asked if they were prepared for Mary's death and were ready to let her go. Though they were saddened, they said that they had come to the point where her dying would be a great relief to them and, they believed, to her, as none of them could bear her distress. I prayed for Mary and for the whole family and acknowledged the distress and anger that Mary felt. I quoted the text that nothing could separate her from the love of God in Christ Jesus. Mary was commended into God's safe keeping and given a blessing which included the words 'The blessing of God, the Father, the Son and the Holy Spirit rest upon you this day and for all eternity.' I left the room and within five minutes a nurse came to find me to tell me that Mary had died. Of course it must be admitted that Mary's dying in such a short time after prayers and blessing could simply be a coincidence, but I was rather shocked by the speed of the events and I was forced to reflect not on the efficacy of prayer but on the nature of hope. Hospice staff had consistently suggested that both Mary and her family might let go; but let go of what? Letting go might be understood in negative terms, letting go of life, of dreams, of family. But if she was able to let go

following prayer, might we not say that she was letting herself go into the possibility of a future? Inevitably there would be a letting go of all that had gone before, but there was a promise of more to come, a hope beyond this life.

If it is true that that all human beings carry around inside themselves a profound and usually unconscious dread of death as absolute annihilation, then we might occasionally be invited to set that terror within the context of the Christian belief expressed by St. Paul:

‘I am convinced that neither death, nor life, nor angels, nor principalities, nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God in Christ Jesus our Lord’.^{vi}

When such occasions arise it is a privilege to be on hand.

ⁱ A. Edmeads – *Hospice Language*

ⁱⁱ I am unable to find the actual source of these words, however, Robert Buckman suggests that health care professionals may carry an even greater fear of death than the general population. *Communication in palliative care : a practical guide. Palliative Medicine 2nd edition (OUP2003)*

ⁱⁱⁱ Michael Kearney, *Mortally Wounded – Stories of Soul Pain, Death and Healing p.131*

^{iv} An idea borrowed from John V. Taylor

^v Wood D. *Poet, Priest, Prophet a Biography of Bishop John V. Taylor*

^{vi} Romans 8:38-39

Key words

Watch with me

Presence

The words become flesh

Dread

Letting go

Hope