

Moving beyond the medical model

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I have attended many deaths in hospitals, in people's homes as a Marie Curie nurse and as a hospice nurse. Some have left very powerful memories – good and bad. Alongside this my health counselling and coaching work has been greatly influenced by the holistic approach pioneered at the Bristol Cancer Help Centre (now Penny Brohn Cancer Centre) where I worked in the 1980s. My personal and professional development have always run in tandem and in recent years, prompted by three deaths more close to home, I have been drawing together all the threads of my life in response to a need I see all around me: a more human, respectful, enlightened and empowered approach to supporting people at the end of life. This has culminated in the development of a course for Doulas, or companions for the dying.

Summary

Hospitals don't do death well, and there is high presume on the services of hospices. A new level of emotional, psychological and spiritual support for people who are dying, and their families could empower individuals and society. Death and dying is about more than medicine and there is an important role for an amicus mortis, a friend in death – a guide, mentor and facilitator.

To learn really to help those who are dying is to begin to become fearless and responsible about our own dying, and to find in ourselves the beginnings of an unbounded compassion that we may have never suspected.

Sogyal Rinpoche¹

A disempowered society

As a society we have never been more alienated from death and dying. We fear it and it remains taboo. Our increasing separation from it has led us to become inwardly unprepared and outwardly unskilled at dealing with it. We have handed over the responsibility for care to health professionals and death arrangements to funeral directors. This state of affairs could be justified if the quality of services were impeccable and if it were a true reflection of the wishes people have for themselves at the end of life. Sadly it is not.

Of the 500,000 or so annual deaths looked at between 2005 and 2007, it is surprising that only 4% on average died in a hospice. We have bought-in to the story that we are skilled at dealing with death in the UK, because of the high standards that, in general, are achieved in hospices. But this has

given us a distorted view of the whole picture and a false sense of security. It is a more random experience for the 58% of people who die in hospital and the remaining 19% who die at home plus the 19% in nursing homes and elsewhere.² Importantly 70% of us would like to die at home and yet the place of death figures demonstrate a considerable gap between the wish and the reality.³

Taking a historical viewpoint Professor Mike Richards says: 'Around 1900 about 85% of people died in their own homes, with workhouses accounting for most other deaths. By the mid-twentieth century around 50% of people died at home. In the early twenty-first century acute hospitals have become the most common place of death.'⁴

Long-term projections by Gomes and Higginson suggest that if current trends continue unchecked, fewer than one in 10 people will die at home by 2030 while deaths in other institutions will rise by over 20%.⁵ If you consider death is rightly placed in the medical arena this trend will lift your heart. However the evidence is to the contrary.

There is growing concern that hospitals don't do death well. The experience isn't good for patient or family, with 54% of complaints being

related to care of the dying and bereavement care in acute hospitals.⁶ A recent report from the Health Service Ombudsman Ann Abraham on the care of the elderly is in a long line of criticisms about the way older people are often badly treated in hospital. She cited appalling examples of neglect, pain and lack of dignity.

*'These stories, the results of investigations concluded by my office in 2009 and 2010, are not easy to read. They illuminate the gulf between the principles and values of the NHS constitution and the felt reality of being an older person in the care of the NHS in England. The investigations reveal an attitude – both personal and institutional – which fails to recognise the humanity and individuality of the people concerned and to respond to them with sensitivity, compassion and professionalism. The reasonable expectation that an older person or their family may have of dignified, pain-free end of life care, in clean surroundings in hospital is not being fulfilled. Instead, these accounts present a picture of NHS provision that is failing to meet even the most basic standards of care.'*⁷

It is easy to criticise services when presented with such a sorry picture. Most nurses and carers work exceptionally hard and genuinely care about the people they look after. The National Council for Palliative Care believes that the most critical issue for the elderly and palliative care is that frontline staff often lack training in delivering basic end of life care. A survey of 900 nurses carried out in November 2010 by Nursing Times revealed that 69% of nurses felt they did not have sufficient skills or time to talk to patients about dying, and 72% that their anxiety around end of life care was due to a lack of training. A quarter of those surveyed described themselves as acute sector staff nurses. Only 29% of doctors and 18% of nurses received pre-registration training in end of life care, and there is a lack of formal training for staff working in care homes. Something isn't working. The important question is what do we do about it?

Why move beyond the medical model?

Medicine has to some extent become a victim of its own 'life-saving' success and as a result it presents us with uncomfortable moral and ethical dilemmas. In practice we see doctors criticised from all sides, on the one hand for carrying out interventions that keep dying patients alive, and on the other when they decide to discontinue ineffective or distressing treatment, to allow nature to take its course. In the current climate everyone loses. Oh for the days when death was so much simpler, when it was accepted as a hard fact of life, a natural progression and not a failure!

Change won't be easy. Among the public, very few people have encountered anyone who is dying, witnessed a death or seen a dead body, so uncertainty, fear and ignorance pervade. Not only that, as death becomes more and more medicalised, professionals regard themselves as

the keepers of 'best practice' and yet as we see above that view is flawed. When such professional conviction embeds in any organisation, new initiatives can be perceived as a threat. We cannot underestimate the enormity of change that is afoot, in professional circles and in society, as the realisation dawns: we must make improvements in how we care for the dying. The North East Strategic Health Authority, in developing its services, has begun to think laterally, perhaps influenced by Allan Kellehear's work related to compassionate cities.⁸ In a brave gesture, in response to local surveys, it has created a charter which states: *'It is neither desirable nor cost-effective to see death as the province of clinical medicine. [The Good Death charter will] stress the need to 'normalise' death, build public health capacity and aim to create a compassionate community approach to end of life.'*⁹

This is an excellent beginning and quite a remarkable turn of events. Are we witnessing an important shift in awareness about the importance of death, perhaps even a return to the values – although hopefully not the conditions – that existed in our communities only a few generations ago?

Much to be done

Examples of holistic practice are rare. For example very few doctors or nurses feel comfortable enough to enter the emotional or spiritual terrain required to engage people in preparation for death, or to help create the best conditions possible for a good death. For example we have seen, along with the rise of science and increasing levels of knowledge and skill, a divergence of medicine and spirituality. Where the priest and physician were once one, it is rarely acceptable to openly call upon our intuitive, prayerful, or healing capacities in our work. It is even less likely that health practitioners feel safe enough to admit they might hold the life and death of their patients in the context of a spiritual journey. Yet when we deal with death and dying, how can we not?

Coming to terms with death is a lifetime's work

In response to the report from the Ombudsman, Reverend Angela Tilby expressed a similar perspective on the BBC's Thought for the Day: *'There's something deeper going on at an emotional level which needs to be addressed. What is needed here is praeparatio mortis: preparation for death, a spiritual education in coming to terms with our mortality. This is a task, not for the last weeks of life – it is often too late by then – but for much younger people and especially for those who care for the frail elderly. What happens to them may happen to us; if we care for our own souls and bodies we should treat the infirm with love. It may sound brutal but there's no point in caring for such people if you have not learnt to accept and then to overcome your own fear and revulsion.'*¹⁰

When, as health practitioners, we start to consider death, we cannot escape the fact that it will come to us all. As Jung says '*Death is psychologically as important as birth. Shrinking away from it is something unhealthy and abnormal which robs the second half of life of its purpose.*'¹¹ If we have never spent time reflecting and coming to terms with the certainty of our own aging and death, how can we feel at ease enough to share the journey with someone who is terminally ill, or know the best way to commiserate with someone who has just lost a loved one? It is all too emotionally charged and unfamiliar.

If we have such no-go areas in our personal lives, it will inevitably impact upon decision-making in our practice. As a consequence it is difficult to engage fully with the importance of the dying process and to value it as the most profound of physical, emotional and spiritual experiences and a sacred transition.

Pain and suffering

Where does it leave us if we start to consider that death is more than the province of medicine? Michael Kearney gives a clinical perspective when he distinguishes between pain and suffering in palliative care patients. '*... what we have seen is that pain affects parts of people. Using the principles of the medical model, pain can be assessed, treated and in the vast majority of instances be brought under control.*' The aim is to restore individuals to a pain-free existence. He goes on to suggest: '*In contrast to pain, suffering can be understood as the experience that results from damage to the whole person Pharmacological interventions do little to ease the intensity of this distress and make no impact whatsoever on the raw open wound at the core of the experience.*' His key point is: '*We may speak of curing another's pain, but it is more appropriate to speak of individuals themselves finding healing within their suffering, for when healing comes to someone in suffering it does so from within the depths of his or her own psyche.*'¹²

To witness another's suffering and yet be powerless to ameliorate it is one of the most emotionally demanding experiences in health care practice. When medication is not an effective route, it requires us to call upon all our inner resources of love, compassion, sensitivity, intuition, presence, strength, kindness or quiet prayerfulness to be able to walk alongside in support. Sadly these qualities are less and less valued as central to health care and are a bit of an embarrassment. This erosion of values, in our culture over the last 30 years, has led us to the point where we believe doing a good job means we have to be 'administering to' as opposed to 'being with'. In palliative care especially, we need both.

Radical transformation

*'To allow people the deaths they want, end of life care must be radically transformed ...'*¹³ When we do think laterally and consider medicine as one resource among

many and not the only story, whole layers of complexity fall away. Instead, if we approach it by placing the person who is dying, their family, friends and social network at the centre, along with the kind of support that gives the family confidence to care, a different picture begins to emerge – one of simplicity, empowerment, respect and responsiveness to need. We begin to restore death and dying to its rightful place, as a human event not a medical one.

There are calls for radical change coming from many quarters, this recent Demos report takes an innovative look at end of life care: '*People want solutions that allow them to die at home. Yet big society-style community solutions will not emerge from thin air. Volunteers can at best carry a small share of the burden. Most families cannot be expected to cope on their own with dying relatives. We need a serious and properly funded government strategy to support the creation of the local, social and cooperative solutions people want.*'¹²

Amicus mortis

One of the aims of *Living well, dying well* is to foster communities of people who feel comfortable around the subject of death and are more prepared for it, ultimately to make sure those who would like to die at home can have that wish fulfilled. When families decide to look after loved ones at home it is a complex decision. When we are preparing to welcome a new baby to the world we have an expected date of delivery). Our growing alienation from the process means we have lost our intuitive-knowing of our expected date of death. When we have no means of predicting it, it is not easy for a family to press the pause button on life for an indeterminate period of time. Not only that, even with good community nursing and medical resources, it is a frightening prospect for most families. It requires a level of confidence, trust and know-how to commit to this journey. The missing piece of the jigsaw is a person who 'holds' the situation with the family. An *amicus mortis*, or a friend in death. The closest analogy is the birth Doula, or birth educator/ birthing companion.

Walking alongside

We can't forget that death is a process, always unknown and unique to each individual. Even in our secular society, the mystery and awe that surrounds it is ever-present. The role of a Doula for the dying is that of companion, someone who has been there before and even though they might not know which route the journey will take, they aren't afraid of the territory, they feel at home in the unknown. In whatever way is needed, they support the family, give information, leave room for conversation, facilitate sharing, discuss practical requirements, create an environment that is conducive, liaise with professionals, are an advocate for the dying person, and with respect of and sensitivity to the religious and spiritual beliefs of the family, hold a compassionate space, be as a guide into the next world. Many nurses working in palliative care do this

to some extent, often covertly, but because their job is pressured and task-orientated, 'spending time' or 'being with' is necessarily, though regrettably low priority.

The role of a Doula is a non-medical one. Think back only two or three generations when there was always someone (generally a woman) in the neighbourhood, who was called in by families to help out at a death – she was often the same woman who was summoned to help with birth. When we lost this role, death gradually became removed from everyday life and hence our relationship with it. Doulas do not replace medical or nursing expertise, but rather, they add a missing layer, acting as an expert family member, a mentor or facilitator and a source of information or guidance.

*'Dying is an intimate and sacred journey, best done in its own time, in a tranquil and peaceful way. When it goes well, it's an honouring of life well lived and an important rite of passage.'*¹⁴ If we are to support people at the end of life in a whole and integrated way, in addition to good symptom control and nursing care we need to draw more on our human qualities and be able to:

- know when death is approaching
- develop relationships that are meaningful
- empower people and instil confidence so that death can happen in a natural, timely way
- work together to create the best conditions for a fulfilling life right to the end
- support people to feel whole, healed or complete
- prepare people for the transition from this world to the next
- create supportive environments
- have courageous conversations
- bring a lightness and awareness, and the ability to 'hold the space', so that souls can leave with a clear sense of direction
- engage families so they feel fulfilled by the experience of having cared for a loved one in the way they wanted
- stay in touch with our humanness as we work with death and dying
- be psychologically and spiritually at peace with our own mortality
- develop our capacity to remain centred and compassionate in the face of suffering
- be prepared to walk alongside where ever the journey goes.

Conclusion

The demographics on aging are terrifying. Coping with the numbers of people who will be facing death in the next 20 years becomes an overwhelmingly difficult problem to solve, if we try and do it through existing

models of health care. But when we take a moment to bring it back to ourselves – yes, to personalise it, to ask: what would I like for my mother, father, wife, husband or lover at the end of their life? What do I want to have happen when I am dying? Who do I want around me? Where would I like to spend my last months, weeks or hours? What kind of care would I like to have? The solutions become simpler somehow, and it is doubtful that many of us would sign up for the interventionist approach of the hospital. Most people say they would like to be free of pain and be surrounded by family and friends. Anxiety levels drop in such a safe environment and that can facilitate a deeper process of inner healing, resolution and readiness for death. In practice this happens when a combination of effective care and human companionship helps to establish secure inner space for that person to be in.¹² Home and hospice are undoubtedly the most conducive places. When the pressure of demand on hospices is so high, creating a way for ourselves and our communities to feel empowered enough to bring death back home whenever possible, is the only sensible way to go. Drawing on new non-medical resources, such as Doulas, mentors or trained volunteers are key to making it happen.

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