

## The Reverend Dr James Woodward

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### Helping people to die with dignity

from the Birmingham Post, 1 December 2006

#### Perspective

*Dying has long been a taboo subject, discussed in hushed tones or half-truths. Here the **Rev Dr James Woodward**, Director of The Leveson Centre, explains why palliative care should help people to live their last days - rather than simply waiting for the end - and asks when the humanity will be put back into medicine*

Life is full of interesting gaps. I doubt whether many of us have really come to terms with our mortality.

There is a gap between head and heart; between what we say and how we act. We know that we will all eventually die. In our work of care we may regularly come across death, but somehow our fears can take hold.

Our own fears can then leave us failing to grasp the questions that take shape in those who are closer to death than us. The map of dying and death remains foreign, an un-negotiable land remaining strange.

If we as individuals have a contradictory relationship with death then it is hardly surprising that our society and the health systems we construct often fail those they serve at this crucial time in their lives. A wide cross section of people will gather today in Birmingham to discuss Living Well to the End of Life. We want to change the map of life and death – to enable people and systems to ensure that everyone is given the opportunity to live well and die well in the place and manner of their choosing.

The Pan Birmingham Palliative care Network has a clear vision that seeks to increase choice, reduce inequality (especially for women and older people) and through better planning and intervention to enable us all to travel safely through this fearful geography. Working together across professional boundaries we want to raise standards of care and give the person and patient a voice.

This ambition is inspired by many who have wanted to help others to live life by dying well.

In the early 1980s after University, I worked with Cicely Saunders, a pioneer in the modern Hospice Movement who said this to those she cared for: ‘...we will do all we can not only to help you die peacefully, but also to live until you die’.

Dame Cicely created a place where this could happen and I learnt the value of watching and waiting with those who were dying. This vision has gained widespread acceptance but has yet to be fully realized in

our practice.

Three issues emerge for me as I reflect on the gaps in both theory and practice: firstly a failure of imagination that, secondly, shapes our humanity which can result, thirdly, in the depth of compassion that we can communicate.

Only human beings have the capacity to imagine a future that could be different from the present. Can we imagine what it might be like to be in someone else's shoes – to see and feel what life looks like for those who are in pain? Imagining what it is like to be someone else is at the core of our humanity. It is the essence of compassion and the beginning of morality.

Can health care professionals and our structures of care demonstrate the imagination of the sheer fragility and preciousness of life in the face of death? This has political implications for the use of resources, our investment in staff training and support, and our desire to organise systems with the constant reminder that it is the patients that pay our wages. Our public ethic is one of service. Cruelty is a failure of imagination!

None of us can prepare for our birth but we can prepare for death. The way we grow old and get ready for death is a key part of the quality of our humanity.

We each have our own story, like and unlike anyone else's. We have to discern what is good, how to make choices that set us free and marvel at the sheer wonder and beauty of it.

Making mistakes and learning lessons are part of deepening our life enabling our humanity to be rounded so we can see how our experience can be harvested at the end. We can become more human if we attend to these opportunities to affirm, value and celebrate the parts of our experience that are fearful.

I once asked someone what they most needed at the end. 'People who try to understand, that's all,' he said. 'It's not possible to completely understand – just effort to grasp a bit of these last weeks'.

I remember sitting with a person who was dying in a busy acute hospital ward – the whole culture of that place failed to engage with these last moments. This failure was more than just the inevitable task! Focussed activity of the place, the attitudes of staff, showed little effort to understand and support.

I have been present when doctors wanting to protect a patient have offered half truths about diagnosis; nurses who cannot allow their protecting defences to shift towards a deeper respect for the vulnerability of another human being.

The foundation of a good heart is kindness, affection, honesty, warmth and careful listening. Surely this is not a subject for complicated theorising but a matter of common sense!

Failures of humanity will always happen and there are many wonderful people who care with enthusiasm, but we should be brave

enough to challenge inadequate care. Medicine is both art and science: the exercise of head and heart.

The poet John Donne expressed it in this way: "This is a melting heart, and a troubled heart, and a wounded heart, and a contrite heart; and by the powerful work of thy piercing spirit such a heart I have."

There is a fundamental need for virtue that can shape compassion – a confidence that those we trust with our bodies can demonstrate that there is more to the practice of medicine, nursing and social work than the pursuit of money and status.

Love and compassion can enhance the value of those we work with beyond the reductionism economic categories we confine life within.

So how do we mind the gap and improve our practice? How might we put humanity back into health care? What is the heart and soul of medicine? Is it possible to inspire compassionate care rather than just adequate care?

I believe it can be possible but this change will need courage to ask questions and challenge both ourselves and others to redraw the map of death and dying.

Some of these questions will be opened up at today's conference – I hope that we can stimulate public involvement and debate so that we can all play a part in the development of quality services at a time in our life when we are most in need of them.

- The Living Well to the End of Life campaign is launched today at 9.30am at Birmingham's Botanical Gardens.

James Woodward

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