

The Practical Aspects of Theological and Spiritual Challenges in Healthcare Today: End of Life Issues

Faith in Health conference – 4th July 2008

Bill Kilgallon, Chief Executive, St Gemma's Hospice, Leeds

Rory Bremner the impressionist opened the Yorkshire International Business Conference last month and as part of his routine he did President Bush greeting Pope Benedict on the Pope's recent visit. After a few faux pas by the President such as referring to the Pope as John Paul 3 and enquiring after the health of his wife – George Bush says “well at least we agree on one thing – we are both pro-life”. The Pope however raises some difficult issues like the death penalty, illegal wars, the arms trade and gun control – well says Bush “I guess I'm pro-life till they're born then all bets are off”.

The Church is widely known for being “pro life” with a focus at each end of life.

This afternoon I want to make some comments about the last part of life and the practical and theological challenges it brings for our society, our Church and ourselves. To set the context I want to start with some words – (genuinely) of Pope Benedict. He spoke last year on a visit to Austria about life before birth and the end of life. He said this:

“It was in Europe that the notion of human rights was first formulated. The fundamental human right, the presupposition of every other right, is the right to life itself.

I wish to act as an advocate for a profoundly human need, speaking out on behalf of those unborn children who have no voice. In doing so, I do not close my eyes to the difficulties and the conflicts which many women are experiencing, and I realise that the credibility of what we say also depends on what the Church herself is doing to help women in trouble.

Another great concern of mine is the debate on what has been termed “actively assisted death”. It is to be feared that at some point the gravely ill or elderly will be subjected to tacit or even explicit pressure to request death or to administer it to themselves. The proper response to end-of-life suffering is loving care and accompaniment on the journey towards death – especially with the help of palliative care – and not “actively assisted death”. But if humane accompaniment on the journey towards death is to prevail, structural reforms would be needed in every area of the social and healthcare system, as well as organised structures of palliative care. Concrete steps would also have to be taken: in the psychological and pastoral accompaniment of the seriously ill and dying, their family members, and physicians and healthcare personnel. In this field the hospice movement has done wonders. The totality of these tasks, however, cannot be delegated to it alone”. (1)

To illustrate why we need to look radically at our health and social care system and why it is an ethical as well as a political issue – let me tell you the tale of two deaths –

the deaths of two women as described by their sons – the first is Mrs Bennett, whose son Alan Bennett gives this account in his book *Untold Stories*. After some years of mental ill health Mrs Bennett goes to live in a residential care home in Weston-Super-Mare. Bennett writes:

“That there is something not right around homes for the elderly is evident in the language associated with them: it’s swampy, terms do not quite fit and categories start to slip. A home is not a home but neither is it a hospital nor yet a hotel. What do we call the people who live (and die) there? Are they residents? Patients? Inmates? No word altogether suits. And who looks after them? Nurses? Not really since very few of them are qualified. As Mam pointed out early in her residency: “they’re not nurses these. Most of them are just lasses”.

Mam has long since ceased to wear her own clothes...these days she’s kitted out from a pool of frocks and cardigans that the home must have accumulated and put into anything that’s more or less her size. To begin with we, or rather my brother, protest about this and insist that one of her original frocks be found, so long as it isn’t actually adorning one of the other old ladies, which as often as not it is. So I’m no longer surprised when I go in to find her sitting there in a fluorescent orange cardigan she would in happier days have unhesitatingly labelled “common”.

And it isn’t only the cardigan and frock that aren’t hers. She has even acquired someone else’s name. The nurses, who are not really nurses but just jolly girls who don’t mind this kind of job, aren’t over particular about names and call her Lily.

“Hello Lily how are you today? Let’s lift you up, Lily”.

“Her name’s Lilian I venture.

“I know” says the ministering angel propping her back up, “only we call her Lily, don’t we Lily?”

The turnover of residents is quite rapid since whoever is quartered in this room is generally in the later stages of dementia. But that is not what they die of. None of these women can feed herself and to feed them properly, to spoon in sufficient mince and mashed carrot topped off with rhubarb and custard to keep them going, demands the personal attention of a helper, in effect one helper per person. Lacking such one-to-one care, these helpless creatures slowly and quite respectably starve to death. This is not something anybody acknowledges, not the matron, or the relatives (if, as is rare, they visit) and not the doctor who makes out the death certificate. But it is so”. (2)

Mrs Ferguson aged 75 with pancreatic cancer wished to die at home. Her sons and daughters wanted this to be respected, one of them Harry wrote in the *Guardian* as follows.....

“the help that she and we the carers got was a wonderful mixture of the practical and emotional. As the illness progressed and she became less mobile, more and more practical aids were provided to help her. The electric powered bed gave her great comfort. Literally, as she no longer had to use her failing body strength to sit up in the bed. Eleven days before she died a social worker visited and did a care assessment and by that afternoon a care package was in place. It sounds bureaucratic “a care package”. But it couldn’t have been more humane and person centred. Two care

workers came in 3 times a day to move her in the bed and help with attending to her personal needs. Specialist nurses came in...as with the care workers it wasn't just the range of their technical knowledge but the manner in which they applied it to mum and the relationships they developed with her that was so wonderful and deeply moving. They got on their knees to address her face to face. They caressed her hand to comfort her. They always addressed her by the name she preferred and spoke directly to her – they never spoke to her as if she wasn't in the room. They handled her weak body with respect and endeavoured at all times to allow her to make decisions about her care even toward the end when she drifted in and out of consciousness. The most crucial issue was pain control, and no matter how weak she was mum was always asked about how she was feeling and consulted about whether to increase her medication. The professionals behaved in a very human way bringing humour, rallying her spirit by telling her how much better she seemed on the few days she rallied.

They also had great skill in dealing with mum's carers – addressing our numerous daily questions with great compassion, patience and honesty. We were never given false hope but nor did they offer predictions about how long was left. They held us emotionally and comforted us especially around the issue of whether mum was in pain. It was not just the quality of care that mattered but its regularity and rhythm, and the skill and humanity with which it was carried out.

For what really mattered was the creative fusion of the practical, emotional and spiritual in everything they did, fulfilling with dignity the deeply touching possibilities of care practice". (3)

The purpose of telling those contrasting stories is not to say that Mrs Bennet's experience is shared by everyone who goes into residential care or to suggest that specialist palliative care services provided by hospices are perfect. But rather to say that we do know how to provide the care and support that people require as they grow older with disability, as they approach the end of life. But we seem to be content to aim to provide that person centred care described by Harry Ferguson only at the very end of life, and then only to a few. I think what Pope Benedict was suggesting was that the quality we aspire to and achieve for people at the end of life should be the quality we aspire to and achieve for all people who are disabled at whatever stage of life. My view is that the major political, moral, ethical, theological – from whatever perspective we want to take this presented by the end of life – is how we value and support one another as we age.

We are an ageing society and we are living longer with ill-health. Two years ago the Kings Fund published a report into services for older people – a review led by Sir Derek Wanless under the title "Securing Good Care for Older People" – the most rigorous, comprehensive and challenging examination of the subject. Wanless set out the context - the population of England is ageing - in the next twenty years the number of people aged 85 and over is set to increase by two thirds compared with a 10% growth in the overall population. Between 1981 and 2001 increases in healthy life expectancy did not keep pace with improvements in total life expectancy. Over the period to 2025 – the number of older people who do not require care will rise by 44%, those with some care needs by 53% and those with a high level of care by 54%. The review looked at the cost of providing care and the sources of funding the

care required – and set a challenge to us as a society about how much we value the lives of older people who require support and care. (4)

The review gave options about levels of care and ways to fund it – including agreeing a balance between what the community should pay and the individual – it suggested a system of co-payment.

This is a major political issue and one that all parties have to face up to. The Government has opened a consultation on this – a debate which we should contribute to because it is essentially a discussion which needs a value base.

The reality for many people currently as they grow older is of poor services. Many live in residential or nursing care homes – but this is an area of work which is under-resourced and undervalued. One of residential care’s strongest advocates wrote recently

“The culture of a care home is the key component of whether the place works well or not. This can be seen as the beliefs and expectations of staff, residents and others and the way they are translated into daily life. There is no doubt individual care homes can (and do) develop life enhancing cultures. But as long as society, and the government, holds care homes in such low esteem, the task of turning them into life enhancing establishments has little chance of success.” (5)

And for many more care is provided in their own homes – and this will increasingly be the general rule. Here again services are under-resourced. The work of providing care and support has often been reduced to tasks which are timed – how long to give a bath, prepare a meal etc and that time allocated and no more – no time to talk and build a relationship. Care work in homes and in the community is badly paid and the recruitment and retention of staff is therefore difficult.

A recent report by the Commission for Social Care Inspection set out very powerfully how we are failing older people and illustrated this by quotations from people using services –

“They have died: that is the trouble. At my time of life you find that all the friends you knew are not around”

“ That’s the trouble – you go on too long these days. You feel that you have not got much going for you, you sort of dread to be a nuisance.”

“I want to be gone! All my friends have gone.” (6)

There are, of course, some excellent services developing for older people

- which combine housing with care and support in a way which recognises, respects and sustains peoples independence
- in a way which recognises too our interdependence and tries to ensure that independence is not accompanied by loneliness
- services in which there is graduated support and care so that the individual is not obliged to move as their needs change
- services developed in such a way that they build community and build links to the wider community

The hospice movement began in this country. Gordon Brown wrote a book about courage and chose 8 people who for him were examples of courage. One was Cicely Saunders of whom he wrote

“She fought entrenched professional ignorance and indifference to the needs of the dying, but by the end of her long life she had triumphed. I have chosen her because, through the hospice movement and the new medical speciality of palliative care, Cicely Saunders life of service succeeded in changing attitudes, generating important new knowledge and transforming the care of the dying not only in Britain but across the world. In changing our view of death she changed our view of life itself.” (7)

Hospices and palliative care do not reach everyone but they have changed practice across the health service – so that in the review led by Lord Darzi end of life care is one of the key themes.

That hospice movement was brought together because people had a very strong belief in the value of each individual and a commitment to treat the whole person in the way that Harry Ferguson so powerfully described.

30 years ago a group of people in Leeds united by their faith opened a hospice – St Gemma’s where I now work. 30 years on it is an integral part of healthcare in the city. It was started by a religious order the Sisters of the Cross and Passion who still retain a role in its governance. It is open to people of all faiths and none. What the sisters did thirty years ago offers a model for how the Church could respond today to an ageing society. At the start of St Gemma’s the Church was the catalyst that enabled something to happen – and the key ingredients

- they had the vision and values
- they had a site
- they had people – the Church’s greatest resource
- they had links to the community at every level

Could the Church be the catalyst which helps develop high quality support, care and housing for older people in their last years rather than just their last weeks ?

- we have the values
- we have the sites (especially as we close churches and other institutions)
- we have the people
- we have the links to the community

BUT do we have the vision?

I am not arguing that we should aim to provide a universal service – but that we aim to emulate what the hospice movement has done for terminal care – that we show what can be achieved. To remove that anxiety and fear which leads people to want to bring their death forward.

In this morning’s session euthanasia was referred to. The development of services will not reduce the demands of those who argue for euthanasia. Indeed in a recent article in the British Medical Journal a leading Belgian proponent of euthanasia argued for a concept which he called “integral palliative care, in which euthanasia is

considered as another option at the end of a palliative care pathway and the patients' preferences come first." He argues that palliative care and the legislation to allow euthanasia, far from being antagonistic developments, could be a real synergy. He claims that the Belgian experience as the second country to introduce euthanasia and the country with the third best access to palliative care in Europe illustrates that. (8)

The development of high quality palliative care and services for older people will not take away our responsibility to vigorously debate the renewed attempts, and there undoubtedly will be renewed attempts, to introduce legislation to allow euthanasia but perhaps it will in the Pope's words give our position more credibility.

References

- (1) Pope Benedict XVI Speech at a Meeting with the Authorities and Diplomatic Service, Austria, Sept 2007
- (2) Alan Bennett, *Untold Stories*, London 2005
- (3) Harry Ferguson, Kindness amid the chaos, *Society Guardian*, 24 October 2007
- (4) Derek Wanless, *Securing Good Care for Older People*, Kings Fund 2006
- (5) Roger Clough, Positive aspects of residential care, *Society Guardian*, 9 January 2008
- (6) Henwood M and Hudson B, *Lost to the System? The Impact of Fair Access to Care*, Commission for Social Care Inspection, January 2008
- (7) Gordon Brown, *Courage – Eight Portraits*, London 2007
- (8) Jan Bernheim & colleagues, Development of palliative care and legislation of euthanasia: antagonism or synergy? *BMJ* 19 April 2008