



**MORLAN'S ANNUAL LECTURE 2011**

# **Dying Well Matters**

**Professor the Baroness  
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**Morlan**

Canolfan ffydd a diwylliant  
Centre for faith and culture



## Background

Morlan is a centre that aims to promote community life – culturally and spiritually, locally and further afield. It was established in April 2005 to create a bridge between the church and the local community and has developed into an important centre in the area.

But Morlan is so much more than just a building ...

It's a meeting-place – to create and discuss, to perform, to learn, to promote and encourage, to understand one another, to share and contribute ... a common ground between the church and all who live in our multicultural society.

Morlan is a welcoming and friendly place that reflects those principles that bind the human race and all races and creeds together. The trustees of Capel y Morfa, the Welsh Presbyterian Church that owns the centre, consider the establishment and support of Morlan as central to their mission.

Its various rooms – a large hall, two committee rooms and a coffee bar – can be hired for all sorts of events and activities, and it has the facilities for musical and dramatical performances. And it's a busy place! Prayer meetings, Welsh classes, dance classes, a lip reading group and youth club take place there on a weekly basis, and several local groups use Morlan as their 'home', holding regular meetings there. The place is used by both local groups and national organisations.

In addition, Morlan has its own programme of activities and events that it organises and hosts throughout the year on a wide range of themes – social, political, religious and cultural themes.

Between this programme of events and the activities of the hirers, all sorts of events take place at Morlan – committee meetings, conferences, plays, concerts, all sorts of fairs, public meetings, social events, lectures, debates and art exhibitions.

Morlan's first Annual Lecture was held in April 2010 during the celebrations to mark Morlan's 5<sup>th</sup> anniversary (*Religion and Politics: The Most Reverend Doctor Barry Morgan, Archbishop of Wales*). This is therefore the second and was delivered by Baroness Finlay on 7 May 2011.

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## Dying Well Matters

Dying Well has implications to the individual and to those left behind. Because of that I intend to deal with the political dimension from the UK and, quite specifically, for Wales.

End of Life Care is a political issue. There are about half a million deaths each year in Britain and, currently, over a third of those are in people aged 85 years and over. However, Gomez and Higginson have predicted that by 2030 this will rise to over 44% of all deaths occurring in people aged 85 years and over. This has become a political issue; both because of the cost of healthcare and the absence of family who are often away abroad or live at a distance or who may themselves be ill, and who are therefore unable to care. But there is an additional dimension; these people belong to the baby boomer generation who have always 'had it good', have never lived through war or famine and have high expectations from life. They are controllers, control freaks in many ways and, above all, they are voters. And the increasing 'grey' vote will mean that the balance of power will be held by these people.

Death is in the news a lot. The media, particularly radio, television and newspapers, are full of stories about assisted suicide; this has become a well-funded and very active campaign. In addition, there are complaints about care, with some terrible examples of care in the media recently. The Ombudsman's reports make salutary reading. For any story to grab people's imagination it has to have a few elements to it: one is instant emotion and the other is that it reflects society. But media stories also nudge society's thinking.

It is often said that the big issue in our society now is autonomy, using the term as if autonomy means 'I want therefore I get'. But autonomy means self-governance; it is relational. Our living and our dying have an effect on those around us. Indeed, everything we do affects those around us.

There are some very specific concerns about dying. At a personal level, people are frightened of symptoms and have often witnessed bad deaths in the past. Society hears about the demographic time bomb, which in many ways is a denigratory term for the growing numbers of the elderly. The media raise concerns about disturbed children and adolescents in our society, yet rarely recognise that multiple losses and bereavements may be a key factor in behavioural disturbance. With the publicity around assisted suicide, with organisations such as the Society for Old Age Rational Suicide, some people have been coerced into believing that this should be the new norm. There is also much misunderstanding around living wills and advance directives. You cannot direct in advance that somebody does something to you. By contrast, properly written advance decisions to refuse treatment are legally binding as laid out in the Mental Capacity Act.

Palliative care has failed in some ways to get its message across. The palliative care approach to a patient is to look at their physical problems in the context of social, emotional and spiritual distress, all of which impinge on their perception of their

physical problems and greatly exacerbate the distress that they experience. But palliative care needs to be involved in the care of patients from the time of diagnosis onwards, possibly into grief and bereavement.

It is sometimes said that death was easier in the old days and that doctors used to help patients on their way, but actually this is a misunderstanding of the role of drugs such as morphine. It often reflects the situation where patients were left with unrelieved pain for a very long time. It was only when pain was relieved that the patient was actually comfortable enough to be able to let go of life and die of their disease, as pain itself is a powerful stimulus to respiration and to consciousness. Given the enormous misunderstandings in many people's mind around pain control, it is hardly surprising that one of the big issues in our society remains pain and its management. Poor care has driven calls for dignity, choice and control in the way that we are looked after. It was Cicely Saunders who said that dignity is having a sense of personal worth and Harvey Chochinov has shown, through good research, that care is the key to patient's dignity. To quote from his article in *The Lancet* in 2002: *"Care that confers honour, recognises the deservedness of respect and esteem of every individual – despite their dependence, infirmity and frugality – could lie at the heart of care that concerns dignity."*

So if patients are not being killed off by pain relief, are they being killed off by having interventions withdrawn? I hope to demonstrate quite clearly that they are not and that the continuation of an intervention which is not achieving any therapeutic aim and has in itself become futile, is often more of a burden than a benefit to the patient. Stopping such interventions has no impact; the disease continues to run its course. But if the intervention was in fact preventing deterioration, then it should not be stopped unless, of course, the patient refuses consent for the intervention to continue. This was what occurred in the case of Miss B when Miss B was on a ventilator, it was keeping her alive, but she wanted to refuse to continue to have the treatment; that decision was upheld by the Court.

Much of the time the clinicians agonise over whether to stop an intervention or not, they stop the intervention and the patient dies fairly soon afterwards, but sometimes the patient gets dramatically better and the clinicians realise that their treatment, rather than the disease, was doing more harm than good. But for the vast majority of patients, stopping the intervention that seems to be having no benefit does not make any difference and the patients die at the time that they would have died anyway as the disease takes its course. This is fundamentally different to a lethal overdose of drugs, either taken by mouth or given by injection, with the express intention of killing the patient as rapidly as possible. This bringing forward of death, foreclosing a life long before a normal death would have occurred, may mean that the patient dies months or even years before they would have done so from their disease.

So why do people ask for assisted suicide or euthanasia? It seems that they do so because they fear the future is worse than today. They fear that pain will come back again or will start, they fear that in the future they may lose their dignity, lose control of their mind and their body, and somehow lose their ability to express their wishes.

They often fear becoming a burden. But the patient who is currently in pain is desperate for pain relief not death, and the patient who was confused wants that confusion sorted out, not death. The perception of the future that is very bleak calls for a very different response, but with no less urgency than a symptom problem that should be managed with immediacy.

Andrew Lansley's NHS reforms have had one good phrase in them: "*nothing about me without me*"; patients should be involved in decisions about them and their management, about having some choice in decision making and having control within the process, rather than feeling they're swept along on a conveyor belt. This is very different to the image of people being made to feel that they are a burden. Some local proponents of assisted suicide are clear that they feel that people become a burden on society and a waste of resources. Baroness Warnock, in her article in *The Times* on 10 October 2008, said: "*If you are demented, you are wasting people's lives – your family's lives –and you are wasting the resources of the NHS*" so the utilitarian ethic does have an influence towards assisted suicide and euthanasia. So let's look for a moment at how people make decisions and also examine the role of the clinician and the information flow between a clinician and a patient.

Decisions are made based on information, but the way any information is interpreted is strongly influenced by a person's past experience, memories, and an interpretation of the current situation. Such interpretation may come from formal information given, but often it is influenced by the media. A powerful influence though is the reactions of those around; when people are ill they become particularly sensitive to such reactions, sensing feelings and atmospheres with a heightened perception; it is worth remembering that 90% of communication is non-verbal.

The person who says that he just want to die may not be asking for death at all, but is very easily influenced by the way that he is responded to. He may pick up a subliminal message that he is right to think he would be better off dead. Or he may detect a subliminal message: "*you are worth me working hard to improve things*". And within that context, patients wishes to die fluctuate as they go between the very strong drive to live and an acceptance of the situation that they are in.

In looking to legislate around assisted suicide and euthanasia, it is important to differentiate between euthanasia – where the doctor injects the patient with a lethal overdose using a cocktail which is similar to that used in US executions – and physician-assisted suicide – which is where the doctor gives the patient the lethal medication that the patient takes unaided. And then there is assisted suicide which is where assistance with suicide is outside the patient's healthcare provision.

In the debate over whether the law should be changed to legalise euthanasia/assisted suicide, there is compassion and morality on both sides. But the real debate has to be about public safety and the question is whether these actions to deliberately take life can be licensed safely. It is noticeable that the Scottish Parliament Committee looked at assisted suicide recently and commented that the Courts have to temper the individual's right to respect of his private life with the interest of wider society. In the

balance between an individual's right to exercise autonomy and the interest of society as a whole, the Scottish Parliamentary Committee felt that the wider societal concerns should prevail in the context of the law.

Safeguards, whatever they are, have to be proportionate to the risk, have to be realistic and must work in difficult circumstances of the real world. Thus the tension in the debate is always between safeguards and how these restrict such actions, or a process of death on demand in which the safeguards are recognised to simply be window dressing but not to be truly rigorous. Even when strict safeguards are thought about, there are difficulties.

Attempts to restrict assisted suicide to just the terminally ill are fraught with difficulty because medicine is a probabilistic art. As well as diagnostic errors, which are demonstrated at about 5% of post mortems, prognostication is notoriously inaccurate. Even when a patient is clinically diagnosed as being within the last 48 hours of life, 3% improve again. One only has to look at some notable prognostic errors, such as Abuset al Megrahi, to see clearly the problems of trying to predict how long someone has to live. Oregon's Death with Dignity Act requires the patient to be in the last 6 months of life; their data shows that from the time of request for assisted suicide to death, the range is between 15 days (the minimum in their law) and 1009 days (equivalent to about 2 years and 9 months).

The decision to end one's life must be an informed decision, but it is cognitively demanding in that it is the most complex decision a person can take. Oregon's experience is worth examining here; one in eight physician-assisted suicides in Oregon had Motor Neurone Disease (MND) and, as a neurologist informed the House of Lords Committee on Assisted Dying for the Terminally Ill Bill, 30% of patients with MND are cognitively impaired. A study by Ganzini, published in the British Medical Journal in 2008, followed 18 Oregon patients who requested physician-assisted suicide. Nine of these died from physician-assisted suicides; three of whom had undiagnosed and untreated depression. In the conclusion of the article, the author states: "*the current practice of the Death with Dignity Act may not adequately protect all terminally ill patients*".

It is also difficult to detect whether a decision is truly voluntary or taken under a degree of coercion. Assessment has to be rigorous, with neither doctor nor patient nor relative taking the process lightly. It is worrying that Oregon's data has shown that last year one doctor wrote eleven prescriptions, which raises some questions about this doctor's practice. Indeed, in Oregon, the pro-assisted suicide campaign group (Compassion and Choices) view themselves as guardians of the law and, at times, act as brokers to help patients find somebody who will write a prescription for the lethal drugs. Worryingly, in Belgium, an anonymous survey shows that almost half of their euthanasias are outside their law.

But where is the doctor's duty in all this? Suffering may be unbearable, but the key question is whether it is relievable. The doctor's duty must be to help relieve suffering,

and to know the limits of his/her competence, seeking help from others when failing to provide the relief needed.

It is often said that patients trust their doctors, and indeed they do. It is this trust that makes patients particularly vulnerable, but society is comforted by trusting doctors: *“if the doctors think it is alright, then it must be”*. The difficulty is that a law framed for a very small minority of highly resolute, strong-minded individuals, can negatively impact on the equality of the whole population.

In conclusion, I would like to quote from Onora O’Neill who, in arguing that there are great dangers with attempts to change the law, pointed out that we do not live in an idealised world. As she said: *“in a world of idealised, wholly autonomous patients, and of wholly selfless and compassionate families and professionals, legislation providing for assisted dying might, if ethically acceptable, not be risky. But we do not live in that world.”* And she went on to point out that: *“we should not put too much weight on the fragile structure of the voluntary”*.

### **The Welsh Dimension**

So what have we been doing in Wales to try to improve the care of the dying? We have had a strategy since 2008, which sets out a fundamental principal of fairness of provision across Wales, with fair access of specialist palliative care. Specialist palliative care aims to improve the reality of the individual’s experience, while helping patients reset their hopes and aspirations to within the limits that disease now imposes.

The Palliative Care Implementation Board was set up in 2008 and has achieved a seven day service across the whole of Wales. This has been through partnership working amongst the Clinical Nurse Specialists, which has revolutionised the access that patients have to specialist advice at weekends and on Bank Holidays.

In addition, the Implementation Board has defined a core service that should be available across the whole of Wales, calculating what is needed on both a population basis in terms of staff and hospice beds, and on the basis of the number of hospital beds locally, which are the centres to which sick people are brought.

The Board has also invested in Primary Care with Hospice at Home services with a Gold Standard Framework being rolled out to General Practices, short courses for GPs in Palliative Care and District Nurse training. There are out of hours links and guidelines on palliative care issued to every GP across Wales. The Implementation Board has also launched a programme called *Dying Well Matters*. In this programme, people are invited to share their experiences of what went well and what went badly. They are invited to put pen to paper and write in to say what their experience was like, so that the Board can look at areas where care is not good, improvements can be focussed and targeted, as well as giving information to reinforce good practice.

In addition, the Board has been listening to the patient voice through a programme called *iWantGreatCare*. In this, patients are invited to fill out a user evaluation,

providing a score against their experience of care and asking them for free text comments as well. But another really important piece of work has been that the Board has recognised that children are relatives and often carers. In this world of fragmented families, a grandparent can provide security and unconditional love. They can provide guidance, wisdom and be the child's confidante. In modern society, when a grandparent is dying the child is often as devastated as they would be if it was the parent dying, if not more so. They are losing the one fixed point in their world.

We know that there are huge numbers of bereaved young people and children in Wales of school age. Across Wales there are almost 22,000 children who have been bereaved of a parent or sibling and almost twice as many bereaved of a close family member or friend. Amongst children in care, their experience of bereavement and loss is even higher. We know that these children do not do well if they do not have support and so we are building in a network across Wales working with Cruse to provide bereavement support specifically for school age children because bereavement care is the most effective form of preventive medicine. Without adequate support, these children are at higher risk of teenage pregnancy, abuse, drug and alcohol misuse and of developing a criminal record. And even if the child does well, they still remain at risk of underperforming academically, potentially blighting their life chances.

So if there is only one message that I want you to take away from this lecture, it is to think about the children. Remember the children whenever you come across somebody who is ill and dying. Ask whether there are children and who is providing them with support, who has explained to them what is happening, who is giving them the choice as to whether they want to be with the person who is ill, want to go to the funeral, how they want to remember the person who has died. Please do not forget them.

*Professor the Baroness Finlay of Llandaf*  
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