

DAVID ALBERT JONES

# Sleepwalking into euthanasia

While not changing the law, last week's judgment on the Purdy case gives a filip to the euthanasia movement. Here, a professor of bioethics warns that it should be a wake-up call to opponents of assisted suicide, as legislation could find its way onto the statute books by stealth

**O**n 30 July, the law lords decided in favour of Debbie Purdy, representing an important legal victory for the euthanasia movement in this country. However, it is important to recognise what the decision did not do. It did not legalise euthanasia in this country. It did not legalise assisting suicide in this country. It did not legalise accompanying someone to another country for the purpose of committing suicide there. The law has not changed. Assisting suicide remains illegal.

Debbie Purdy did not win the right to immunity for her partner if he assisted her suicide. Rather, she won the right to information about how the Director of Public Prosecutions (DPP) decides whether to prosecute in cases of assisted suicide. The DPP has discretion as to whether a criminal case should be referred for prosecution.

Sometimes there is not enough evidence. Sometimes there is enough evidence but the DPP decides that a jury would be extremely unlikely to convict or would be likely only to impose only a nominal sentence. What Ms Purdy sought was information about whether the DPP was likely to prosecute a companion who accompanied someone to commit suicide in another country. The law lords upheld her right to this information – a decision that is a thin end of a thin euthanasia wedge.

This legal landmark means that the DPP, Keir Starmer, now has to write guidance, explaining how decisions are made about whether or not to prosecute someone for assisting suicide. The guidance will not give strict rules or blanket immunity but will state the kind of factors taken into account when weighing up whether to prosecute. For example, if there were a history of abuse between the assister and person committing suicide, this would clearly weigh in favour of prosecution, whereas if the assister had tried hard to dissuade the person from committing suicide this might weigh against legal action being taken.

The Purdy case made its way through the courts because Ms Purdy particularly wanted to know whether her husband would be prosecuted if he helped her end her life at the

Dignitas clinic in Switzerland. Since its establishment, Dignitas has enabled 115 Britons to die. These cases have generated a massive amount of publicity, but it is important to note how exceptional they are, given the number of deaths in the United Kingdom – 574,687 in 2007, of which 5,377 were suicides.

In eight of the Dignitas cases, the police referred the matter to the DPP. In all but two of them, the DPP declined to prosecute because of lack of evidence. Of the two remaining, one was the injured rugby player Daniel James. In his case, in a very unusual move, the DPP published his reasons for not prosecuting. He did not refer to the fact that Daniel James was disabled as a reason for non-prosecution. Instead he pointed to the way in which the young man's parents had tried to dissuade him and noted that they had no financial gain from his death.

Mr Starmer intends to bring out his draft

guidance as early as September and then have a period of consultation before finalising it. He made clear in an interview this week that although Ms Purdy was concerned with travelling abroad, his guidelines will apply domestically.

It is to be hoped that Mr Starmer will include factors such as prior domestic abuse or coercion, encouragement of suicide, the degree of determination of the person committing suicide and the prospects of financial gain for the person assisting. These circumstances all affect the degree of criminality involved.

On the other hand, the DPP should resist reference to illness, disability, or chronic conditions as reasons not to prosecute assisting suicide. There must be no suggestion that some people have lives that are less worthy of protection, less worthy to be lived. When the DPP comes to consult on these guidelines,

## 'Last days in the company of chosen companions in familiar surroundings and with some assurance of tranquillity is an alternative worth pondering'

SUFFERERS OF motor neuron disease feature prominently among the 100 or so Britons who have travelled to the Dignitas Clinic in Switzerland to end their lives, writes Joyce Prince. The first Briton to go publicly to Dignitas to commit suicide, Reginald Crew, had the disease and died there in 2003. Another sufferer, Craig Ewert, who died at the clinic three years later, allowed his death to be filmed for a television documentary.

In 1973 my husband was diagnosed with motor neuron disease. The neurologist's evasive manner and averted, shifty gaze raised our suspicions and sent us scurrying to the nearest medical library. Our reading was not reassuring: "No known cause, no treatment, no cure, rapidly increasing muscular paralysis, particularly affecting breathing and swallowing, cognitive functions remain unimpaired with an average expectation of life

from diagnosis of three years." The medical textbook advice centred on the administration of hefty quantities of opiates.

In 1973 the debate about assisted suicide had not been joined, but we were shocked and resistant to the implication that recourse might be made to involuntary euthanasia. There was no self-help group. Our general practitioner was unsparing with his time and consideration but readily acknowledged his ignorance of "this rare disease". We had two young children and the future looked grimly precarious. My husband was a Catholic by upbringing, no longer practising though claiming that being reared as a Catholic is like being vaccinated – one cannot be unvaccinated.

The anticipated rapid deterioration did not take place and three years later he had recovered somewhat from the depression that followed diagnosis and was more confident.

it will be important for as many people as possible to write and encourage him to uphold the equal status and dignity of people with disabilities or chronic health conditions.

What happens next following the guidelines and consultation will depend on a variety of factors: public opinion; the attitudes of MPs and peers; the campaigns of organisations both in favour of, and opposed, to euthanasia; and the possibility that an MP sympathetic to assisted suicide might sponsor a private member's bill (the method by which abortion was legalised in Britain). However, it is not a foregone conclusion that this is the turning point that brings euthanasia to the United Kingdom.

Although discussion of euthanasia stretches back to the ancient Greeks, today's voluntary euthanasia movement began in the 1930s. It found its horrifying nemesis in Germany in the 1940s when, allied to Nazi eugenics that encouraged the ending of "lives unworthy to be lived", euthanasia was a euphemism for murder. These dark events helped contain the euthanasia movement for a generation. However by the 1980s it had revived, its supporters now re-focusing on terminal suffering. They achieved their first major legal victory in 2002, when the Netherlands became the first country in the world to legalise euthanasia.

But in official surveys Dutch doctors admitted ending the lives of 1,000 people a year who had never explicitly asked for euthanasia, and in 2005, in the *Netherlands Journal of Medicine*, a report claimed that euthanasia had been used illegally on 22 infants with spina bifida. As a result euthanasia advocates rarely mention Holland these days. They usually commend to us the American state of Oregon, where assisted suicide was legalised 12 years ago.

The Death with Dignity Act makes assisted



suicide available for those with less than six months to live and deemed mentally capable of making such a decision by two doctors. However, researchers have found that some of the people who were prescribed lethal drugs under the act did manifest signs of depressive disorders.

In Britain, for the last three years, the euthanasia debate has been going on at two levels. The more reflective debate has resulted in a number of key victories in Parliament for the opponents of euthanasia. When the House of Lords came to consider a private member's bill in 2006, it voted decisively against legalisation. The Lords were disturbed by the evidence from the Netherlands of widespread abuse. Then, only a month ago the House of Lords voted against legalising assisted suicide.

Having failed to carry the day in Parliament, the euthanasia lobby has been trying to raise a storm outside. So in parallel with the measured arguments, there has been an intense and highly emotional media battle going on

which centres on selected "human interest" stories and opinion polls. And there has been a noticeable shift, with public opinion generally favouring a change in the law.

Without minimising the importance of careful quiet debate in medical and political circles, it is necessary for the common good for many more people to take part in the popular, public, and media debates. The law might not have changed but it will change if those who see the dangers remain silent in the popular debate.

For example, those who work in the field of end-of-life care, and who know more than most about how dying people feel, are convinced that the task of improving care will be harmed, not helped, by the introduction of assisted suicide or euthanasia. And they are well aware that there is still a great amount to be done to improve end-of-life care in the United Kingdom.

It is not inevitable that the Purdy case will lead to legalised assisted suicide. It is possible for the DPP to put forward conservative and flexible guidelines that do not involve any reference to disability and that do not bring euthanasia closer. The greatest danger at the moment is that this technical ruling gives momentum to the euthanasia movement and makes legalisation seem inevitable. If this is accepted without challenge, then the United Kingdom could sleepwalk into a change in the law.

The Purdy judgment therefore is a wake-up call for those who support end-of-life care, for those who respect the equality for people with disability and chronic illness, and for those who work in mental health.

■ Professor David Albert Jones is director of the Centre for Bioethics and Emerging Technologies at St Mary's University College, Twickenham.

He canvassed support for a patients' association through a letter in the London evening paper. About 30 people came to our house for the first meeting of what became, in 1979, the Motor Neurone Disease (MND) Association. It now has international affiliations, several care and research centres attached to teaching hospitals, and a network of professional and volunteer workers who teach, support and advise anyone affected by MND who requires it. The frustrating sea of unknowing that we faced in 1973 has given place to a more felicitous and helpful environment. But the cure for this devastating disease remains elusive.

From its early days the MND Association has allocated resources in roughly equal proportion to research (into cause and cure) and to the development of support services for people living with the disease. For this purpose local branches of the association usually provide the contact point. Trained volunteer visitors, many of whom have extensive experience of the predicaments facing patients, their families and friends, can provide invaluable friendly support and a guiding link into the professional services provided at national level by the association.

These are extensive and have been built up over 30 years in response to empirical observation and service research.

Opportunities are maximised to work with the statutory services and local hospice provision. The network of the association's care and research centres provides highly specialised neurological expertise at hospital level. Patients are often gratified to be voluntary participants in a research project knowing that their contribution may help improve the lot of their successors. These undertakings sometimes lead to national and international contacts being established – a welcome by-product.

A successful programme of graduated support in response to progressive deterioration can lead to end-of-life decisions being made, however wistfully, without the desperation that impels a person to contemplate suicide in a sombre, impersonal Swiss clinic. Last days in the company of chosen companions in familiar surroundings and with some assurance of reasonable tranquillity is an alternative worth pondering.

There is a final twist to my family story. The

reprieve of the first three years was extended to 20, with a corrected diagnosis of multiple sclerosis. With specially adapted accommodation and anxiety about potential horrors that lay ahead held in abeyance, my husband carved for himself a very different, but contented life. He both gave and received pleasure abundantly. He found eventual dependence repugnant. Curtailment of this phase of his life, however, would probably have been even more repugnant. But that was in 1992 before the legal possibility of doing so had arisen.

Palliative care occupied centre stage and great advances have been made since then. I have been a "participant observer" in some of the radical changes that have affected the management of, and attitudes to, a still incurable disease. It would be a damaging blot on our health service and public life if present concerns about assisted dying were to take our eye off developments in palliative care in both community and hospice.

■ Joyce Prince is a founder member of the MND Association.