In June 2001 42-year-old Diane Pretty, happily married with two children, made a public appeal for the right to ask a doctor to help her die. Diane had Motor Neuron Disease. In two years the fatal illness had taken away her ability to walk, she was tube-fed and was starting to lose her speech. Her intellect however, was unaffected and she communicated by way of a ‘light writer’. She felt she should legally be allowed to choose how and when she died, rather than have to endure a long drawn-out death. Following the Government’s refusal of her request, Diane turned to the courts. The case was the first of its kind, brought under the Human Rights Act, which came into effect in October 2000.

The case began at the High Court in August 2001, went through the House of Lords, to the final decision in the European Court of Human Rights in April 2002. Although Diane lost her appeal, the European Court conceded that the Government was not respecting Diane’s right to dignity, protected by Article 8 of the European Convention on Human Rights. Days after the decision, Diane died the death she had feared. The petition she launched calling for the Government to act and change the law remains the largest online petition ever received by Downing Street.

How changing the law can improve human rights at the end of life

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If you think you know everything there is to know about ‘the euthanasia debate’, think again! Euthanasia is one of those old chestnuts philosophers have been debating for years, but events of the past 2 years have challenged many assumptions.

A series of high-profile ‘right to die’ cases has increased public pressure for a change in the law: Diane Pretty, Miss B and more recently Reginald Crew, who was one of several British people to have an ‘assisted suicide’ in Switzerland. Now human rights lawyer Lord Joffe is promoting a Patient (Assisted Dying) Bill in the House of Lords in the UK. The Bill would allow a competent adult who is suffering unbearably from a terminal illness to make a considered request for medical assistance to die.

Every day the Voluntary Euthanasia Society (VES) receives emails, letters and phone calls from people seeking help to die because of unbearable suffering. Individuals with Huntingdon’s or Motor Neuron Disease tell us the law puts them
in an impossible position: they are forced to end their lives sooner than they really want to, because they cannot request medical assistance once they become too weak to act alone.

So what is standing in the way of the Bill – and why has it not yet received Government backing? In an increasingly secular society the social taboo on ending your life in cases of unbearable suffering has all but disappeared. 81% of the British public support a change in the law (NOP 2002). Among medical professionals the majority in favour of change is slimmer – 55% of doctors (Medixuk.com 2003) support the patient’s right to choose and 59% of nurses (Nursing Times 2003). Still, a majority support change – and Lord Joffe’s Bill has an opt-out clause for those who feel they cannot help a patient for reasons of conscience.

The real obstacle is the understandable concern that a law allowing assisted dying could be abused. Also, some argue, developments in palliative care mean that most pain is now treatable. Only a few difficult cases such as Diane Pretty, are impossible to refute. Assistance might be justified on an individual basis, the argument goes, but it would be at the expense of other more vulnerable people.

But stop to consider what happens now. You need to ask this question to decide if a change in the law would bring more or less abuse? Under the current law we know some patients who want active help to end their lives do not get it – and suffer as a result. Others do find people willing to help them. 15% of doctors (The Sunday Times 1998) say they have helped a patient to die. At least one in 20 nurses (Nursing Times 2003) think colleagues are helping patients end their lives. Relatives assist and are not punished by the courts.

In short, people are helped to die in spite of the law, but it is hard to determine how many, how often, and in what circumstances. Because there is no regulation and no independent witnessing, it is impossible to establish whether there was ever a competent, informed request from the patient. Research from other countries suggests that in many cases there was not.

The Netherlands, Belgium and Australia have all conducted research into the frequency of requests for, and the occurrence of, voluntary euthanasia and nonvoluntary euthanasia (Deliens 2000). The research suggests that without regulation, there is four to five times the rate of non-voluntary euthanasia. It is no coincidence that Belgium and the Netherlands went on to introduce statutory legislation to regulate assisted dying. Unfortunately the British Government has steadfastly refused to carry out research in this area.

The VES campaign is motivated by the belief that we should respect the human rights and autonomy of people like Diane Pretty. People with terminal illnesses want the reassurance of knowing that if all else fails, they have the option of requesting medical help to die. This, they say, would give them greater peace of mind. It would also stop many premature suicides. A change in the law would also help remove the conditions that give rise to nonvoluntary euthanasia, ‘suicide tourism’ and ‘mercy killings’. If end-of-life decision-making were open, honest and patient-led there would be more, not less protection for vulnerable people.

The Patient (Assisted Dying) Bill has already been approved by the Joint Committee of Human Rights. Their report concluded that the Bill’s safeguards, ‘would be adequate to protect the interests and rights of vulnerable patients. These safeguards would ensure that nobody could lawfully be subjected to assisted dying without his or her fully informed consent.’

You can support the VES campaign by emailing info@ves.org.uk or phoning +44 (0)20 79377770. Our website http://www.ves.org.uk has more information.

OPINION POLLS

NOP public opinion poll (2002) 28 October
NOP asked: ‘Do you think that a person who is suffering unbearably from a terminal illness should be allowed by law to receive medical help to die, if this is what they want, or should the law not allow them to receive this medical help to die?’
• 81% said that ‘Yes, the law should allow them to receive medical help to die.’
• 12% said that ‘No, the law should not allow them to receive medical help to die.’
• 6% said they don’t know.

Medixuk.com (2003) Friday 24 January
A survey of 1002 UK doctors from all specialties. 55% thought physician-assisted suicide should be permitted when a person has a terminal illness with uncontrollable physical suffering

REFERENCES

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