

Assisted Suicide

How the chattering classes have got it wrong

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1. INTRODUCTION

A painless and speedy death, resulting from a hygienic medical procedure that leaves no mess: assisted suicide is the final consumer fantasy. Although illegal in Britain, it is already available to the determined and comfortably-off, who can buy (at £10,000 a shot) an appointment with death at the Dignitas clinic in Switzerland. Here, completely legally, a physician will inject them with a fatal poison. Why can't, argue the distinguished and articulate advocates of assisted suicide and voluntary euthanasia, this choice be available to all?¹

The simple answer is that, if we legalise assisted suicide, we risk having a strident élite condemning the less fortunate to a premature death. For it is the marginalised, the disabled, the less articulate and the poor who are most likely to be under pressure to accelerate their death. The NHS hospital or care

¹ "Assisted suicide" means providing someone with the means to end his or her own life prematurely. Ending another person's life at his or her own request is called "voluntary euthanasia". In Britain, both assisting suicide and voluntary euthanasia are criminal offences, the former punishable with a maximum 14 years and the latter, as murder, with life imprisonment.

home, engulfed by a rising tide of elderly people, and starved of funds, will feel the burden of the “bed-blocker” – and fill the insecure and vulnerable patient with guilt for taxing a system that is already under severe strain. Above all, the disadvantaged, fearful of authorities and lost in bureaucracy, may not know how to manipulate the system and may, in comparison to the confident members of the choice-obsessed consumerist élite, be more subject to manipulation by others.

A well-organised lobby of euthanasia supporters, led by Dignity in Dying, have tried to convince us that legalising assisted suicide is the most humane solution for everyone’s final exit. Their campaign draws its force not only from the worried well, but also from new, and alarming, demographic forecasts: by 2033, 23% of the population will be over the age of 65.² Research undertaken by Barbara Gomes and Professor Irene Higginson suggests that the annual number of deaths is expected to rise by 17% between 2012 and 2030.³

This huge new pressure on our health and support systems risks turning our last stage of life, and our death, into a nightmare. There are two dangers: the first is that the needs of those too old and weak to look after themselves may be ignored; the other is that when everyone is competing for limited resources, the aged may feel guilty because they are diverting investments from everyone else.

The legalisation of assisted suicide and voluntary euthanasia was once thought unthinkable in this country, where it was

² Office of National Statistics, 2009.

³ *Delivering Better Care at the End of Life*, King’s Fund, January 2010.

associated with the Nazis' secret euthanasia programme. Yet public demand for what is being euphemistically called the 'right to die' has grown hugely (to 74%, according to a poll last year by *The Times*).⁴ Cases such as Lynne Gilderdale's, who had suffered with a paralysing form of ME for 17 years, until her mother, Bridget Kathleen Gilderdale, helped her to die by giving her an overdose, have triggered sympathetic reactions; their prosecution has met with huge opposition.

The issue has been debated in Parliament four times over the past six years. Debbie Purdy, who has MS, last year won the right to have the prosecution guidelines affecting those who assist suicide clarified. Keir Starmer QC, the Director of Public Prosecutions (DPP), published his guidelines in February 2010.

The new guidelines have not paved the way for assisted suicide; they call for each case to be judged on its own merits. But those working with the elderly, the disabled, and the terminally ill worry that, once introduced on compassionate grounds, assisted suicide will lead to death on request or euthanasia without consent.

In particular, they contend that any change in the law will expose the vulnerable to coercion by their family or other interested parties, such as a doctor, or a nursing home director. They are concerned that too many could be talked or pressured into giving up their lives for the convenience of younger, healthier individuals.

For the real battle over assisted suicide and euthanasia is between the haves and have-nots. Euthanasia enthusiasts such

⁴ *The Times*, 25 July 2009.

as Lord Joffe and Lord Falconer (both of whom have attempted in Parliament to legalise assisted suicide) and Dignity in Dying patrons such as Terry Pratchett, AN Wilson and Patricia Hewitt need not fear coercion if assisted suicide becomes legal: articulate, determined and well-connected, they would know how to protect themselves in any situation. But for millions of others, too anxious, inarticulate, or fragile to clearly defend their needs, their disadvantage may cost them their lives. As Dr Carol J Gill has written:⁵

“Viewing the world from a position of privilege may limit one’s insight into the consequences of a policy change whose greatest impact could fall on socially marginalised groups.”

The debate about assisted suicide and euthanasia has been portrayed as a battle between religious and anti-religious groups. It is not. Many secularists view assisted suicide and euthanasia with horror; while there are believers who regard assisting someone to end their lives to be an act of charity. Out of the 93 speeches dedicated to this issue in Hansard, only 6 are by bishops; the rest are by parliamentarians concerned that a change in the law carries with it the potential for coercion.

If this is to be resolved, it should be on the basis of facts, not faith. Legalising assisted suicide risks harming the most vulnerable. It should be rejected on grounds of public safety, not personal morality.

⁵ “No, we don’t think doctors are out to get us: Responding to the straw men distortions of disability rights arguments against assisted suicide”, Dr Carol Gill, *Disability and Health Journal*, 2010.

The dangers inherent in the legalisation of assisted suicide can be grouped in four categories:

Second class human beings

The danger is that less-than-perfect citizens will be deemed expendable. Not only will those who require a great deal of care and assistance, including the elderly, feel that in the new hierarchy promoted by euthanasia they stand at the bottom rung; they may feel guilty, seeing themselves reduced to a burden on their families or the state. This will be all the truer of the socially marginalised.

Doctor Death

When the doctor prescribes a fatal potion or administers a lethal injection, rather than battling to save you from disease and or death, trust in doctor-patient relationships risks being destroyed. It is precisely because we trust our doctors always to act in our best interests that what is being euphemistically called 'assisted dying' is so dangerous: a doctor who agreed to a patient's request to 'end it all' could all too easily send a signal, however unintended, that the doctor considered death was the best course of action in the patient's circumstances.

The death squad

Who will regulate these deaths, if we don't adopt the physician-assisted suicide model? Assuming we allow for conscientious objectors, a self-selecting cadre of "death regulators" will take charge of assisted suicide. Who will be able to check this all-powerful death squad? Who can be sure that at the last minute the patient does not undergo a change of heart yet is pushed to go ahead with suicide anyway by those present? None of the scenarios put forward by the euthanasia lobby offer any insurance that coercion will not take place once official approval for an assisted suicide has been given.

Slippery slope

Once assisted suicide becomes legal, it will slide into voluntary euthanasia which in turn will lead to involuntary euthanasia. Physician-assisted suicide is, after all, simply physician-administered euthanasia. Once the principle is breached that a doctor may act knowingly to bring about a patient's death, the way to full-scale euthanasia lies open.

In short, legalising euthanasia will change our lives, forever. Our world will become a harder, more selfish place, where the weak will have no voice and no value. The Government must therefore resist calls for the legalisation of assisted suicide and voluntary euthanasia.

2. DEATH AS A CONSUMER CHOICE

Douglas Sinclair, 76, a widower suffering from multiple system atrophy, left his care home in South Tyneside last July. With the help of two friends, he flew to an apartment rented for assisted suicides by the Swiss group, Dignitas. There, on 28 July, he swallowed a fatal draught and died. On 2 September Northumbria police arrested Sinclair's two friends on suspicion of assisting his suicide. Keir Starmer, the Director of Public Prosecutions, will decide whether they should be charged.

Daniel James was a 23-year-old undergraduate who became paralysed from the neck down in a rugby accident in March 2008. He needed 24 hour care: he could not move from the chest down and lost the use of all his limbs. Unable to make the adjustment from robust athlete to tetraplegic, he became convinced that he wanted to end his life and tried to commit suicide three times. 18 months after his accident, his parents took him to Dignitas to die. Mercia police questioned Daniel's parents after their return from Switzerland, but no charges were brought against them.

Lynn Gilderdale, 31, who had battled with ME for 17 years, was found dead of a morphine overdose at her home on 4

December 2008. Her mother Bridget Kathleen Gilderdale was cleared of attempting to murder her by jurors at Lewes Crown Court. Another count, of aiding and abetting suicide, had been admitted by Gilderdale and for this she received a 12-month conditional discharge, among the most lenient sentences the judge could impose. Mr Justice Bean said: "I do not normally comment on the verdicts of juries but in this case their decision, if I may say, shows common sense, decency and humanity which makes jury trials so important in a case of this kind."

Sir Edward Downes, 85, and his wife, Joan, 74, died at Dignitas, their two children in attendance, in 2009. Lady Joan was suffering with cancer, though it is unclear what was her likely prognosis. Sir Edward was visually impaired and had lost his hearing but he was not terminally ill. Keir Starmer, the Director of Public Prosecutions, issued a statement noting that, although there was sufficient evidence to charge their son, Caractacus Downes, who booked their flights and hotel and flew with his parents, it was not in the public interest to do so.

Debbie Purdy, 47, has Multiple Sclerosis which has robbed her of mobility and is affecting her sight and hearing. After hearing her doctor's diagnosis, Purdy claimed that she and her partner Omar Puente wanted to fly to Switzerland and opt for a Dignitas end. Purdy then faced a dilemma: she would need her partner's assistance to carry out her wishes, but worried lest, once back in Britain, Puente would face prosecution.

These cases have generated huge public sympathy. The despair of the elderly and disabled widower; the horror of a youth being struck down by a severe disability; the sadness of a talented man losing the one faculty crucial to his art; the grief of a woman disabled in her prime: in any era, these events would

seem tragic. But in today's culture they are worse than tragic – they are unbearable.

We worship youth, health, achievement. Advertisers, the media, movie and fashion industries promote and confirm, each day, a carefully defined template of human perfection. The ideal has become the norm: although employment laws protect the elderly and disabled against discrimination, prejudice against those who fall short of “the norm” surfaces from the school playground to the news room. The move to legalise assisted suicide is rooted in this concept: that not all of us are of equal value.

Thanks to our understanding of medicine and technology we are also now more in control of our existence than ever before; diseases and setbacks that once caused us to stumble, fail or die, are easily overcome by popping a pill or pressing a button. Religious traditions are being sidelined by a secularism that places the all-powerful self at the centre of the universe. Politicians (“You, the voter, will decide”) and self-help books (“You can do anything”) help propagate the myth that we are totally in charge.

Recent attempts to legalise assisted suicide and euthanasia focus on “control” and “choice”. The current “End of Life Assistance” Bill, which MSP Margo MacDonald has recently introduced to the Scottish Parliament, is concerned with “Providing persons with a choice at the end of life”. She echoes Lord Joffe's statement to the House of Lords Select Committee about his second (of three) Assisted Dying for the Terminally Ill Bills: it was, he told the Select Committee, based on “the principle of personal autonomy and patient choice, the right of each individual to decide for themselves how best he or she should lead their lives.” Dignity in Dying, the group which

campaigns for the legalisation of assisted suicide, has adopted the catch phrase “your life, your choice”.

Notions of “choice” and “control” appeal to our consumer culture. We are encouraged to think that we can buy anything – even, through the purchase of a lethal drug, a room in a Dignitas-style apartment, a ticket to Switzerland, a good death.

But death is not an individual step, carried out in isolation. Rather, it is an act that places us in relationship with others – family, the local community, anyone with whom we must share our limited social and health service resources. Committing suicide is a liberty that does not require others to play an active role in what is universally considered a moral wrong (ie killing); but assisted suicide, by definition, relies on your being entitled to co-opt someone else to do the work for you. You are morally compromising another person to become the agent of your death; it also means that, far from enjoying total autonomy, you are at the mercy of someone else.

3. BE AFRAID

Public support for assisted suicide is boosted by demographic trends. The population is ageing. Over the last 25 years the number of people aged 65 and over increased by 1.5 million. The number of deaths in England and Wales is predicted to rise by 17% over the next 20 years from about 503,000 (2006) to about 586,000 (2030).⁶

Experts have identified a £6 billion funding gap in care of the elderly opening up over the next 20 years.⁷ At present, most of this care is still provided by relatives and friends, while state-financed care is available only for those with low incomes. As a result, many pensioners are forced into selling their houses if they move into a nursing home, where the average cost is £800 a week. Some 2.5 million elderly live below the poverty line.⁸

⁶ King's Fund, *Delivering Better Care at the End of Life*, January 2010.

⁷ Ibid.

⁸ The Centre for Social Justice briefing, 8 February 2010.

People are living longer, but with longer periods of ill-health at the end of life. According to the Alzheimer's Society, the number of people with dementia will rise from 700,000 to over 1 million by 2025.

These trends will be cause for concern. Those elderly and infirm who must rely on family and friends for care feel particularly guilty about placing an extra financial burden on their loved ones. Paving the way for the early and speedy exit of the elderly and the infirm can suddenly seem a practical and inexpensive solution.

Hierarchy of beings

The elderly are not the only group who need to fear the implementation of an assisted suicide scheme in Britain.

Baroness Campbell has suffered from spinal muscular atrophy since birth. She has argued that a change in the law:⁹

“...wouldn't just apply to the terminally ill, no matter what the campaigners may say. It would affect disabled people too, not to mention the elderly. A change in the law... would alter the mindset of the medical and social care professions, persuading more and more people that actually the prospect of an 'easy' way out is what people such as me really want. Well, the vast majority of us do not.”

Dr Carol J Gill has written about the “pervasiveness of social devaluation based on class, age and disability”, which fuels the response to assisted suicide by people with disability.¹⁰ Because

⁹ *The Daily Mail*, 10 July 2009.

¹⁰ Gill, *op. cit.*

of this devaluation, people with disability fear that the able-bodied see no reason to share (already limited) resources with them.

Baroness Finlay is Professor of Palliative Medicine at Cardiff University and a Consultant at the Velindre Cancer Hospital in Cardiff. In her view:¹¹

“A law permitting assisted suicide or euthanasia... would create a facility for these actions to be taken subject to a procedural checklist and would send the clear message that, if you are seriously ill or incapacitated, ending your life is a reasonable course of action for you to contemplate.”

The slippery slope

Once assisted suicide is legal on compassionate grounds, how can we protect the vulnerable from being coerced into dying?

Baroness Warnock put it crudely:¹²

“Pensioners in mental decline are ‘wasting people’s lives’ because of the care they require and should be allowed to opt for euthanasia even if they are not in pain.”

This approach assumes that the death of a patient will no longer be an unavoidable necessity but a morally acceptable

¹¹ In correspondence with the author.

¹² *Life and Work*, September 2008.

form of therapy. But Dr Rob George, a Consultant in Palliative Care at University College London has explained:¹³

“From a law that, at present, forgives those who act *in extremis* we would slip to licensing a process in advance.”

Pressure will grow for euthanasia to be applied more widely: if it is in the best interest of competent patients, why should it not be foisted upon the elderly, who might be persuaded that they were a burden? Or on minors, who also cannot speak for their best interest? Or on the mentally incompetent who cannot know what is their best interest?

Financial pressures

The disadvantaged are also hit by today's recession, when euthanasia may be seen as a cost-effective way to treat not only the terminally ill but all those who require extra care and assistance, including the elderly. The Department of Health acknowledges that “overall cost of end of life care is large (measured in billions of pounds)” and in addition, “there are costs met by other government departments”¹⁴ such as the Attendance Allowance and Disability Living Allowance.

“We should not be having this debate in a situation where resources are limited and stretched” argues Dr David Jeffrey, Honorary Senior Lecturer in Palliative Medicine at the University of Edinburgh, “Assisted suicide should never be a resource issue.”

¹³ In correspondence with the author.

¹⁴ Department of Health, *End of Life Care Strategy*, 2008.

And yet, it cannot fail to be. “I have heard an elderly widow tell me that ‘I don’t want to go into the nursing home. I want to give all my money to my grandson so he can go to University,’” reports a consultant in palliative care.¹⁵ “There are all kinds of family pressures, spoken and unspoken, and all kinds of feelings of guilt that would push someone to take the wrong decision when it comes to the end of their lives.”

It is because it is impossible to determine how a patient has come to his or her decision that coercion is a concern in the debate on assisted suicide. This is especially true of those at the mercy of individuals and institutions bent on cost-cutting measures. As the philosopher Onora O’Neill has written:¹⁶

“How are we to distinguish requests to be killed that express individual autonomy, from requests that express compliance with the (unspoken) desires of burdened carers and relatives, not to mention expectant heirs?”

¹⁵ Palliative care co-ordinates the different disciplines needed by the terminally ill patient and their family. It includes not only managing the symptoms of illness or extreme old age but all the various challenges facing the dying: dignity, attentive care, the presence of family, emotional and spiritual health.

¹⁶ Onora O’Neill, *The Lancet*, 11 October 2008.

4. EVIDENCE FROM ABROAD

In The Netherlands, where voluntary euthanasia and assisted dying were legalised in 2001, euthanasia has been available for the terminally ill in cases of 'hopeless and unbearable suffering' certified by two doctors. (Euthanasia is not limited to adults, nor does an applicant need to be terminally ill.) Euthanasia for cases of dementia has been officially recorded since 2003. 16 year olds are allowed to be assisted to die, without their parents' involvement. Later this year, the Dutch Parliament is set to debate a measure that would allow assisted suicide for anyone over 70. Supporters of this measure have already collected 112,500 signatures in a month.

Around 2,500 euthanasia cases were reported in The Netherlands in 2009. This is 200 more euthanasia deaths than in 2008, according to *Telegraaf* which also reports that only around 80% of instances of mercy killing are registered with the monitoring body.¹⁷ Euthanasia training has become part of both medical and nursing school curricula. Indeed, such is the pro-euthanasia atmosphere in

¹⁷ 3 January 2010.

The Netherlands that the Dutch Patients' Association, a disability rights organization, has developed wallet-size cards which state that if the signer is admitted to a hospital "no treatment be administered with the intention to terminate life." Many in The Netherlands see the card as a necessity to help prevent involuntary euthanasia being performed on those who do not want their lives ended. Indeed, when the House of Lords Select Committee visited The Netherlands in 2004 to investigate how euthanasia was regulated, they were told that one aim of the campaigners was to have an 'end of life pill' on sale in all pharmacies.¹⁸

Oregon: the dangers for the disadvantaged

In Oregon, with Washington one of two US states that have legalised assisted suicide, the Department of Human Services (DHS) annual reports show that there has been a fourfold increase in the number of reported deaths from assisted suicide since the legislation was approved in 1997. In 2009, there were 59 reported deaths, which is ten more than in 2007 and 43 more than in 1998.¹⁹

The numbers seem low. But Oregon has a very small population: its 59 cases of assisted suicide in 2009 would be equivalent to nearly 1,000 such cases a year in the UK. Especially worrying for our older citizens is the age profile of those opting for assisted suicide: the median age in 2009 was 76 and the most common age group (40.7%) was in the 75 to 84 age group. The number of applicants for assisted suicide listing "not wanting to be a

¹⁸ House of Lords, *Assisted Dying for the Terminally Ill Bill*, 2005.

¹⁹ Department of Human Services, *Death with Dignity Act Annual Report*, March 2010.

burden on family, friends and caregivers” has also risen steadily. In 1998, this was given as a reason by only one in eight of those who died by assisted suicide, whereas in 2008 one third of those who took their lives listed this as a reason.²⁰

The slippery slope is not only about licensing assisted deaths; it is about according tremendous power to those who regulate these deaths. As one spokesperson for the Oregon-based Compassion and Choices told the Lords’ Select Committee, her organisation was acting as “stewards of the law”.²¹ This sense of omnipotence is, alarmingly, justified. In Oregon, licence is effectively given to the assistant rather than the patient. Once approval of assisted suicide has been granted, should the patient at any point change his or her mind about carrying on with the procedure, it can only be hoped that they manage to convince their assistant as well.

Most worrying of all is the danger posed to the most disadvantaged, as shown by the cases of Barbara Wagner and Randy Stroup. Wagner, a 64 year old Oregon woman, was told in 2008 that her lung cancer had returned, and her one hope lay in a \$4,000 a month drug that her doctor prescribed for her, but for which her insurance refused to pay. The Oregon Health Plan did agree, instead, to pay for drugs necessary for a physician-assisted death. Those drugs would cost \$50.²²

²⁰ G Pitcher, *A Time to Live: the case against assisted suicide and euthanasia*, Monarch, July 2010.

²¹ House of Lords, op. cit.

²² ABC News, 6 August 2008.

In a similar case in Oregon, Randy Stroup, a 53 year old, was diagnosed with prostate cancer. Uninsured and unable to pay for expensive chemotherapy, Stroup applied to Oregon's state-run health plan for help. Lane Individual Practice Association, which administers the Oregon Health Plan in Lane County, wrote to Stroup to say the state would not cover Stroup's pricey treatment, but would pay for the cost of physician-assisted suicide.²³

Little wonder that research carried out in Oregon showed the poor and uneducated have only a limited enthusiasm in applying for assisted suicide.²⁴ Oregon requires that two physicians sign an application for assisted suicide. But as Dr David Jeffrey has argued many doctors refuse to assist suicide, which leads the applicant to shop around for a doctor to administer the lethal dose.²⁵ This is tricky, however, as the list of those willing to participate remains unpublished – as, indeed, does almost all information relating to assisted suicide in Oregon: once they've committed suicide, the patients' records are destroyed. Doctor-shopping is all the more demanding in a state where, unlike in the UK, there is no tradition of a personal GP who has grown familiar with a patient's case over the years. Only a very determined, articulate and well-connected citizen will find two physicians willing to help them die in this way.

²³ *The Washington Times*, 29 July 2009.

²⁴ "Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups", Margaret P Battin, et al, *Journal of Medical Ethics*, October 2007.

²⁵ David Jeffrey, *Against Physician-Assisted Suicide: a palliative care perspective*, Radcliffe Publishing, August 2009.

Switzerland

In Switzerland assisted suicide has been legal since 1941. Suicide is now nearly three times as common there as in the UK.²⁶ Organisations such as Exit and Exit International claim to have 70,000 members. They rely on lethal prescriptions from doctors who have known their patients for years, and are familiar with their medical histories, and often their family.²⁷

But it is another Swiss organisation that in Britain has become synonymous with assisted suicide: Dignitas. The group, founded in 1998 by Dr Ludwig Minelli (who in an interview with the BBC in April 2008 described the act of suicide as a “a marvellous possibility given to a human being”²⁸) serves a mainly foreign clientele. For about £10,000 per person, clients are assisted in suicide on the basis of a single consultation with a Swiss doctor. (As a result, in December 2007 Zurich’s chief physician required that two doctors’ consent would be needed henceforth.) Until 2007 Minelli had used flats in a small residential building in Zurich for the purpose; but a local politician forced them out. Dignitas has also been known to use hotel rooms and, in one incident which provoked a national outcry, a car by the side of the road. Swiss authorities have not welcomed the international coverage that has dubbed Zurich the capital of death tourism.

²⁶ According to the World Health Organisation, there were 17.5 suicides per 100,000 people in Switzerland in 2006, compared to 6.4 in the UK (2007). In The Netherlands, the ratio was 8.3 (2007). See http://www.who.int/mental_health/prevention/suicide/country_reports/en/index.html

²⁷ “Death Becomes Him”, *The Atlantic*, March 2010.

²⁸ “The Report”, BBC Radio 4, 2 April 2008.

5. THE LAW

The guidelines set by the Director of Public Prosecutions (DPP) state clearly that the presence in the victim of a terminal illness, a severe and incurable disability, or a severe degenerative physical condition from which there is no possibility of recovery do not constitute grounds for leniency towards the assister.

In law, there is no hierarchy of beings. Assisting the death of someone who is severely disabled, or has been diagnosed with a terminal illness, is an offence, just as assisting the death of someone in perfect health is. Police are expected to investigate all such cases, and anyone found guilty faces a maximum 14 year sentence.

That no one who assists a suicide can be sure of immunity from prosecution is a crucial safeguard, according to Lord Carlile QC, the Government's former independent assessor of anti-terrorism legislation. He points out that:²⁹

²⁹ In conversation with the author.

“We need legal protection for the vulnerable. I have seen care home matrons coming into a little legacy from their patient; families where the greed motive is definitely present. Coming across these cases in the course of my work, I can see that it is extremely difficult to ever secure a law that protects the vulnerable from undue pressure.”

Lord Carlile goes on to argue that sometimes patients need the law to protect them not only from their family, or their carers, but also from themselves.

“My case load has persuaded me beyond any doubt that there are people who make statements about their case (“I’m suffering so much I wish to die”) and these statements are relied upon – but when the patients reach that position they no longer feel that way.”

The law judges each case individually on the evidence, and has shown compassion for those who, in assisting a loved one to die, have acted *in extremis*. The DPP’s guidelines make clear, however, that the focus of attention in deciding whether to prosecute is not on the circumstances of the person asking for assisted suicide but on the motives of those doing the assisting. No one who has accompanied a loved one to die in the Dignitas suicide facility in Switzerland, for example, has been charged in Britain.

When Dr Anne Turner’s three children accompanied her to the Swiss apartment in January 2006, the Crown Prosecution Service concluded that her children simply pushing her wheelchair onto a plane bound for Switzerland didn’t constitute an act of “encouraging or assisting” a suicide in the sense of

Section 2 of the Suicide Act. Lesley Close, who helped her brother fly to Dignitas to kill himself in 2008, worried that she would face arrest when she returned to Britain.³⁰

“Coming through the airport, Lesley felt apprehensive. But no contact was made. Eventually she asked her local police whether they were going to take any action and used the Freedom of Information Act to find out if there was a file on her. She received a courteous letter saying that to prosecute would not be in the public interest.”

Recent attempts at legalisation

The law has been trying to navigate the right course on the issues of assisted suicide and euthanasia since 1936, when the first bill to legalise euthanasia was debated in the House of Lords, but rejected 35 to 14. The discovery, during World War II, that euthanasia was being carried out by German physicians on the disabled and mentally unstable, made the issue unpalatable and pushed it off the public agenda – for more than 30 years.

In 1961, the Suicide Act decriminalised suicide, so that those who failed in their attempts to take their own lives would not face prosecution. 1969 saw another unsuccessful attempt to legalise euthanasia, with a bill introduced into Parliament. The House of Lords Select Committee on Medical Ethics reviewed the law on euthanasia in 1993/4 and concluded that the procedure should not be legalised.

But recently the issue has come to the fore of the public agenda: extraordinary cases such as the ones involving Anne

³⁰ *The Times*, 9 December 2008.

Turner and Kay Gilderdale have generated tremendous public sympathy for the those committing suicide and their assistants. Parliament has had to address the issue four times in the last six years. The Scottish Parliament now has before it a Bill tabled by Scottish Nationalist MSP Margo MacDonald which is seeking to legalise both assisted suicide and voluntary euthanasia for terminally ill people and for others who are “permanently physically incapacitated to such an extent as not to be able to live independently”.

In 2003 Lord Joffe introduced a Private Member’s bill, the Patient (Assisted Dying) Bill, based on Oregon’s Death with Dignity Act, which allows a doctor to prescribe a fatal medication to qualifying individuals. The Bill was drafted “to enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from a terminal illness to receive pain relief medication.” This Bill, which would have legalised both assisted suicide and voluntary euthanasia, progressed only to second reading. In March of the following year Lord Joffe introduced another Private Member’s bill (Assisted Dying for the Terminally Ill). It was referred to a House of Lords committee for detailed examination. The committee was prevented from completing its work by the Dissolution of Parliament before the 2005 General Election, but it presented a three-volume report, which summarised the extensive evidence that it had collected in four countries (Britain, Oregon, The Netherlands and Switzerland) and presented clearly the arguments for and against a change in the law.

Not content, at the end of 2005 Lord Joffe presented a third bill, this one limited to assisted suicide. It was the subject of an

eight hour debate at Second Reading in the House of Lords on 12 May 2006, when over 90 Peers spoke on the one side or the other. The bill was put to a vote and defeated by 148 votes to 100.

In 2009, Lord Falconer proposed an amendment to the Coroners and Justice Bill. This was a wide-ranging bill with a variety of objects, but certain clauses of it sought to tighten up the 1961 Suicide Act so as to strengthen the protection of those vulnerable to a growing number of websites encouraging people to kill themselves. (Only last June, a former US nurse, William Melchert Dinkel, was charged with using an internet chat room to persuade a 32 year old English man, Mark Diver, to hang himself.) Lord Falconer's amendment sought to lift the risk of prosecution from those taking their loved ones to a country where assisted suicide is lawful. The amendment required two doctors to be "of the opinion in good faith" that the person was terminally ill and had the "capacity to make a declaration". Concerns were raised over the failure of the amendment to require that the doctors acting "in good faith" should have any knowledge of the "patient". It gave patients no safeguards against coercion or abuse by others which could have been applied at an earlier stage, and would be difficult to detect for a doctor with no prior knowledge of the family. The amendment was defeated by 194 votes to 141.

Also last year, Debbie Purdy who had tried unsuccessfully in 2008 to seek a guarantee of immunity from prosecution for her husband in the event that, at some future date, he should accompany her to Switzerland for assisted suicide, took her appeal to the Law Lords. On 30 July 2009, in their final ruling as Law Lords (now they are the Supreme Court), the Law Lords unanimously agreed that Ms Purdy had the right to know

whether her partner would face prosecution if he helped her end her life. The current lack of clarity, they ruled, was a violation of the right to a private and family life under Article 8 of the European Convention on Human Rights (incorporated into English law with the Human Rights Act of 1998). The Law Lords relied on an earlier finding, at the European Court in Strasbourg in 2002:

“The very essence of the Convention is the respect for human dignity and human freedom... In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.”

The Law Lords, like the Justices at the European Court, were pitting the principle of the sanctity of life (Article 2 of the European Convention on Human Rights) against that of the quality of life (Article 8 of the same). But the exact scope of these rights and how they may be balanced against one another was uncertain – to be clarified as and when new relevant cases arose.

The DPP guidelines

The Law Lords therefore ordered the DPP Keir Starmer, QC, to draw up a policy that would spell out when prosecutions would and would not be pursued. The DPP, having drawn up an interim policy as a basis for a consultation that attracted nearly 5,000 responses, issued revised policy guidelines in February this year. This “Policy for Prosecutors in respect of cases of Encouraging or Assisting Suicide” was “more focused on the

motivation of the suspect rather than the characteristics of the victim.” But Starmer stressed that:

“The policy does not change the law on assisted suicide. It does not open the door for euthanasia. It does not override the will of Parliament. What it does is to provide a clear framework for prosecutors to decide which cases should proceed to court and which should not.

“Assessing whether a case should go to court is not simply a question of adding up the public interest factors for and against prosecution and seeing which has the greater number. It is not a tick box exercise. Each case has to be considered on its own facts and merits.

“As a result of the consultation exercise there have been changes to the policy. But that does not mean prosecutions are more or less likely. The policy has not been relaxed or tightened but there has been a change of focus.”

The policy sets out that prosecutors have to take into account whether the evidence supports the charge – the suspect did an act that could encourage or assist the suicide or attempted suicide of another person, and the suspect’s act was intended to encourage or assist suicide or an attempt at suicide.

Prosecution is less likely to be required if: the suspect was wholly motivated by compassion; the actions of the suspect, although sufficient to come within the definition of the offence, were of only minor encouragement or assistance; the victim had reached a voluntary, clear, settled and informed decision to

commit suicide; the suspect had sought to dissuade the victim from taking the course of action which resulted in his or her suicide; the actions of the suspect may be characterised as reluctant encouragement or assistance in the face of a determined wish on the part of the victim to commit suicide; the suspect reported the victim's suicide to the police and fully assisted them in their enquiries into the circumstances of the suicide or the attempt and his or her part in providing encouragement or assistance.

Hence the present law provides safeguards for the vulnerable and compassion for those who, *in extremis* and moved by the purest motives, help someone whose suffering has become unbearable carry out a settled wish to die. Yet still there are calls to change the law, to license assisted suicide in advance of the act rather than to accept it in retrospect in appropriate cases.

6. END OF LIFE AND PALLIATIVE CARE

A modern, light-filled building set amidst lush gardens and overlooking the Bristol Channel, the Marie Curie Hospice in Penarth, Wales, bustles with activity. Nurses, hair-dressers, yoga teachers, consultants and cleaning staff criss-cross one another in the corridors. Their multi-disciplinary efforts aim to cater for the 600 cancer patients' every need, from pain relief to psychological counselling to prepare them for their death. For most of the patients here, the large shared wards will be their last home.

Yet the atmosphere at the hospice is not funereal; rather it is like a doctor's waiting room: an air of quiet expectation fills the neat and comfortable rooms, where flowers and glossy magazines adorn tables, and efficient and courteous staff bustle in the background. The high tech machinery and hospital beds do not inspire dread but confidence. You are in good hands, here.

A young family sit in a corner room whose bay windows look out onto the garden and the Channel beyond. The hospice caters not only for the needs of the dying, but assists family members with bereavement counselling. Some relatives, in particular

widows and widowers, continue to come to the hospice well beyond their loved one's demise.

Although situated on a quiet road above the town, the Marie Curie hospice is far from isolated: local volunteers come to read to patients, and the entrance lobby and staff room are filled with photos and brochures of local volunteer groups that have raised funds through marathons, bicycling trips, a trek to Mount Sinai in Egypt. Like the majority of UK hospices, government subsidies only cover part of the running costs; the rest must be raised through charitable donations.

I meet with Betty, a cancer patient who has been here for about a fortnight. She sits up in bed, surrounded by family photos, cheerfully telling me of the marvellous care she has been receiving from hospice staff. (One nurse has just helped her fix her hair for our interview.) Betty's good humour shines through her frailty, dispelling the fears and squeamishness of someone brought up in a culture that has cordoned off death from daily existence. Her family visit regularly, and thanks to the morphine being administered intravenously, Betty is not in any pain. One of the other women in the ward has a persistent hacking cough, and Betty looks at me, eyebrow raised: I'm not sure if this is to say, "I have to put up with that all day" or rather, "Poor thing, not long for this world." We don't discuss Betty's own imminent death. Whether out of weariness or because her powers of concentration are not what they once were, Betty is not interested in engaging in a long conversation. She lies back against her pillow after ten minutes, and looks relieved when a nurse comes in to draw my visit to an end.

"How people die remains in the memory of those who live on" wrote Dame Cicely Saunders, pioneer of the hospice movement. For many Britons, that memory will be painful: few are lucky

enough to die at home, or in the quietly dignified surroundings of the Marie Curie Hospice in Penarth. Most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere.³¹ If the trend in home death proportions observed over the last five years continues, fewer than one in ten people would die at home by 2030. Institutional deaths would increase by over 20%. Deaths in institutions would rise from around 440,000 to around 530,000 a year. People will die increasingly at older ages, with the percentage of deaths amongst those aged 85 and over rising from 32% in 2004 to 44% in 2030.

Most deaths in hospital do not occur in acute situations (during an operation) but when the patient is lingering in the hospital ward, considered too fragile to be moved home or to a nursing home. Acute care units are inhospitable places for any patient. As one consultant in internal medicine in a UK teaching hospital points out, they are “brightly-lit 24/7, noisy as a railway station, and with a turn-over of 70 patients per day.” The Department of Health goes further:³²

“Several observational studies have shown that a proportion of patients dying in hospital experience very poor care. They may not receive optimal symptom control, communication may be poor and patient and family involvement in end of life decision making may be lacking...”

³¹ B Gomes et al, “Where people die: past trends (1974–2030), future projections and implications for care,” *Palliative Medicine*, 2008.

³² Department of Health, *End of Life Care Programme*, 2009.

Hospital deaths are not just unpleasant. They are expensive. A night in an acute hospital bed costs about £600 to £700; in an intensive care unit, it can cost up to £2,000 in a London hospital. The highly supportive service that has to be in place when a patient is admitted for, say, cardiac arrest, is also expensive, as Seymour points out: “You’d have to have four junior doctors, a medical registrar, a resuscitation nurse, an anaesthetic doctor... This is a huge investment of resources.”

The growing number of elderly people will place a huge burden on the NHS. “Does the 83 year old with dementia really need a bed here? These are the kinds of questions that we’ll be asking,” a leading consultant contends. “Given the cost of acute care and intensive care, there will, most likely, be a stratification of the health system.” For the NHS, treating those whose care is expensive and whose expected longevity is low, assisted suicide could become an easy way out. For a government pressed for resources, the realisation that the elderly patient with dementia who costs tens of thousands to the NHS could instead be led to accept assisted suicide with a £10 tablet, will also be tempting.

For almost one in five of us, death will come in a care home. Staff here are sometimes inadequately trained in end of life care and access to community palliative care teams can be limited. A consultant says that in his experience nursing home staff often fail to diagnose that someone is dying, turn to any GP – even a locum unfamiliar with the patient – and rush into unnecessary hospitalisation of residents. Some care homes have a high turn-over of staff, who may have no prior knowledge of the patient’s particular case history; some care home staff do not have a good command of the English language and fail to communicate with the patient; and finally some care homes

push patients into hospital, according to the Department of Health, fearful for their reputation if too many residents die within the home.³³ All too often, the frail octogenarian who is just suffering from a temporary dip in his condition, finds himself hauled into an ambulance and then pushed into the alien environment of a hospital, where he is surrounded by strip lights and noisy strangers.

Palliative care

But death doesn't need to be painful, terrifying and humiliating; and it doesn't need to occur in a hospital, after a hugely distressing (and expensive) admission via the accident and emergency service, or a long stay in an acute care unit. Britain was a pioneer in palliative care. Dame Cicely Saunders, who founded St Christopher's hospice in 1967, understood "end of life care" as the treatment of what she called "total pain" – suffering in body, mind and soul. The carer had to focus on the individual's mental as well as physical needs; the carer also had to take into account the suffering of the patient's family as they faced the issues raised by the patient's condition.

Palliative care has been a recognised clinical specialism since the 1980s. Most major hospitals offer specialist palliative care services. In addition, voluntary sector hospices and community teams offer palliative care – including at home.

Britain spends £1.4 million on hospice care every day. In 2009, there were 217 hospice and palliative care inpatient units; 3,194 hospice and palliative care beds; 308 home care services; 105

³³ Department of Health, *End of Life Programme*, 2009.

Hospice at Home services; 279 day care centres; 345 hospital support services.³⁴

Yet this is not enough. There are approximately 2.5 million staff within health and social care. Of these, only 5,500 work – roughly two in every thousand – in specialist palliative care services.³⁵ A consultant in palliative medicine explains how our current arrangements are not enough:

“Access to palliative care is open to huge geographical variation and depends on what’s wrong with you. If you have cancer you have access to a gold-plated hospice service: many hospices rely on support from cancer charities. But, if you suffer from heart problems, it can be a very different picture.”

Equally frustrating, according to John Wiley, who set up the Teeside Hospice Care Foundation in the early 1980s and has just retired after 30 years as consultant in palliative care, is the way that the quality of your palliative care will depend on the day of your admission to hospital: “We run our hospitals on a five day rather than seven day a week schedule. Woe to you if you’re admitted on a Friday evening. You may not see the appropriate team until Monday morning. For someone who is dying, that could be too late.”

Despite such frustrations, Wiley reports that in his 30 years of practice, only a small number of people have ever asked for euthanasia. “I would guess there were no more than 3% – and

³⁴ Help the Hospices website.

³⁵ Department of Health, *End of Life Programme*, 2009.

of those who did ask me about it, about half were asking because they knew I wouldn't be able to grant their wish.”

The last Government committed £88 million in 2009/10, £198 million in 2010/11 to implement an improved end of life care strategy. It launched the first comprehensive framework aimed at promoting quality end of life care across the country, the Liverpool Care Pathway for the Dying Patient, (LCPDP) in 2007. The LCPDP offers a map for people recognised to be dying, and for the doctors and specialists caring for them. The patient's comfort is the priority and certain medical routines are suspended: in the last 72 hours, some systems are pointless, medicine might be stopped, there may be no need to monitor the patient's heart beat. As palliative care specialist John Wiley points out, the Pathway has ensured that dying patients are seen and reviewed every four hours, and are not deceived as to their condition.

But Wiley fears that all this investment would stop with the legalisation of assisted suicide: “Change the law and there will be no incentive to improve our end of life care system.”

Countries where euthanasia is legal are also countries where the palliative care is not up to British standards, argues Baroness Finlay.³⁶

“Specialist palliative care does not exist in the Netherlands, nor in Oregon. It is far less advanced in Belgium than it is in the UK and in Belgium the formal training programme for doctors to become

³⁶ In correspondence with the author.

an accredited specialist in palliative care does not exist in the same way as in the UK.”

The Netherlands, Belgium, Luxembourg and two US states support the legalisation of assisted suicide/euthanasia because there is, simply, no adequate alternative. This was borne out by Dr Susan Tolle, of the Oregon Health Sciences University Center for Ethics in Health Care, who told the Lords Select Committee that many people had voted for the “Oregon Death with Dignity Act”, because of a tragic experience which a loved one had had in end-of-life care:

“In some ways, it [the Act] was a vote of no-confidence about some aspects of end-of-life care in Oregon.”

Dr David Jeffrey, a consultant in Palliative Medicine at the University of Edinburgh, has visited Oregon several times to study the consequences of its assisted suicide legislation. He reports that doctors there are “amazed when I say that there is a move to replicate their system here in Britain. ‘But the context is totally different’, they argue, ‘we don’t have the same kind of specialist care, hospices are run differently, and only 17% of our population has health insurance.’³⁷

Death: the final taboo

Despite its relative high standard in end of life care, the UK suffers from a cultural silence surrounding any discussion of death. In one recent survey conducted by Marie Curie Cancer Care, almost four out of five respondents felt that death is a

³⁷ Dr David Jeffrey in conversation with the author.

taboo subject for the majority of people in this country.³⁸ This allows for all kinds of myths about death and dying: that it is always painful, that how they die is completely out of the patient's hands, that pain relieving drugs only work in highly toxic doses. These myths generate fear among the wider public, and are often exploited by pro-euthanasia campaigners.

Doctors and nurses in the palliative and end-of-life care practices can dispel some commonly held myths about the process of dying. Baroness Finlay explains:³⁹

“The vast majority of deaths are peaceful. Those of us working in specialist palliative care are always striving to ensure that death is peaceful and dignified, without unrelieved pain or other difficulties. Small doses of pain relief can keep people comfortable when they are lying in bed and feeling stiff. Morphine does not shorten life when given at appropriate pain relieving doses, but it does ease any discomfort and can be reassuring to both the person who is dying and for the family to know that morphine or similar medication is available.”

As a report on the last year of life in the *New England Journal of Medicine* shows, the passage from no disability to complete dependence in the last year of life is unpredictable.⁴⁰ Any law

³⁸ Department of Health, *End of Life Programme*, 2009.

³⁹ In correspondence with the author.

⁴⁰ Thomas M. Gill et al, “Trajectories of Disability in the Last Year of Life”, *New England Journal of Medicine*, April 2010.

which facilitates suicide as soon as we are diagnosed with a fatal illness will ignore the fact that for many, the majority, the last months of our lives are not usually associated with overwhelming disability and the hopelessness that this might engender.

Even in the case of motor neurone disease (MND), which afflicts two people per 100,000 in the United Kingdom, and is regularly described by the media in its most horrific forms, many of the symptoms can be relieved or reduced – the more so if patients are treated in a specialist MND Centre with access to experienced physicians, nurses, physiotherapists and palliative care experts. It is rare for MND sufferers to choke on their own saliva, as is commonly reported. Most MND sufferers die of respiratory failure in their sleep.⁴¹

⁴¹ House of Lords, *op. cit.*

7. DOCTORS

Two thirds of doctors oppose the legalisation of euthanasia and physician-assisted suicide. Opposition to euthanasia and physician-assisted suicide was higher among specialists in palliative care and care of the elderly: fewer than one in 10 palliative care specialists believed euthanasia or physician-assisted suicide should be legalised.⁴² All the Medical Royal Colleges and the British Medical Association, after consultation with their members, have declared their opposition to assisted suicide. As Professor Tim Evans, Academic Vice President of the Royal College of Physicians, warns:⁴³

“Allowing for the practices of euthanasia and assisted suicide in our health care system would put the relationship between doctor and patient on a very different footing.”

⁴² Professor Clive Seale, *Palliative Medicine*, March 2009. The survey of 3,700 doctors found that 66% opposed any change in the law.

⁴³ Professor Tim Evans, in conversation with the author.

Far from ensuring the patient's autonomy, bringing the practice of assisted suicide into the health care system means giving doctors power over how and when you die. Although Harold Shipman was a rare psychopath, many among the medical profession will be uneasy with the potential for abuse in this area. A review of the medical and psychiatric literature as to the potential effects of legalised physician-assisted suicide found that:⁴⁴

“Medicine, a profession dedicated to helping others, can provide an ideal opportunity to conceal sadism... Patients are generally protected from doctors acting on urges to kill by the ethical and legal boundaries prohibiting killing, to the extent that this is considered a non-issue in medicine apart from rare, deviant cases. The legal sanctioning of doctors to assist patients in killing themselves may create a new, undesirable conduit for the expression of hostile countertransference.”

Given that most physicians in this country oppose the legalisation of the practice, and would have conscientious objections to taking part in it, applicants would have to shop around for a doctor willing to collaborate. The small number of doctors who agreed to go along with prescribing lethal injections would be relied upon, by clients whose medical history they will not be familiar with. But how objective is an assessment carried out by a doctor who is not the patient's

⁴⁴ Madelyn Hicks, *Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors*, BMC Family Practice, 2006.

regular practitioner and who has been selected precisely because he sees no problem with physician-assisted suicide?

An elderly patient, or a severely disabled one, would feel wary of a physician known to have been the agent of suicide and/or voluntary euthanasia. Such a doctor becomes Dr Death, the one who will deliver the fatal potion or injection, rather than the champion of life. This would be a grotesque reversal of the doctor's role, according to one consultant in palliative care.⁴⁵

“We have an obligation to share our therapy options with our patients: will the time come when I'll be saying to patients in the outpatient clinic ‘there is this cancer drug, this supportive system, or this lethal injection’?”

Baroness Finlay also warns that:⁴⁶

“Doctors are all too well aware how vulnerable seriously ill patients can be, how they worry about the course of their illness and its impact on their families and how, not infrequently, they will talk of wanting to ‘end it all’ out of depression or despair or a desire to spare others. An experienced physician recognises such statements as a flag that the patient needs help and reassurance. But a doctor who responded by processing ‘assisted dying’ would be sending to the patient a signal, however unintended, that that was the best course of action in the patient's circumstances.”

⁴⁵ In conversation with the author.

⁴⁶ In correspondence with the author.

New dilemmas

The advance of modern medical techniques has raised a new set of dilemmas for doctors, patients and their families – and ironically has given a new lease of life to the pro-euthanasia movement. Through artificial ventilation, cardiopulmonary resuscitation, and other new procedures doctors have been able to extend their patients' lives well beyond their expected lifespan.

In many cases, this is welcome: heart attack victims, for instance, can now recover and live many more years of a full and active life. There are some cases, though, where the extension of life simply means more years spent under constant medical supervision, either in hospital or care home, with many of the patient's faculties impaired.

“Thou shalt not kill; but do not strive officiously to keep alive”: recognising that sustaining life artificially can compromise a patient's best interest, physicians will at times refuse life-prolonging treatment or discontinue supportive systems such as a liver machine or a heart machine in some cases. This is not “euthanasia by the back door”: doctors foresee that their refusal of a life-prolonging treatment may result in the death of the patient, but this is not their intention; whereas in the case of assisted suicide and voluntary euthanasia the patient's death is indisputably the intent. Similarly, when physicians discontinue futile supportive systems, they do so not to end the patient's life but because they recognise that death cannot be prevented by such a system.

Almost one in five doctors admit they use drugs (mainly midazolam) to relieve pain and induce a state of deep sedation in

patients.⁴⁷ The practice, known as “double effect”, came under scrutiny in May 1999 with the acquittal of Dr David Moor, who had given a dying patient a lethal dose of diamorphine. His defence, which was accepted, was that his intention had been simply to ease the patient’s pain.⁴⁸ As the Professor of medical ethics at Imperial College School of Medicine at St Mary’s, has written:

“In the UK, as in many other countries, doctors may give as much pain relief as is necessary to relieve the patient’s pain and suffering where this is judged to be in the patient’s interests and has not been refused by the patient, even though the doctor knows that the patient’s life may be shortened as a result.”

This is not to say, Dr Rob George stresses, that doctors “can only treat pain, breathlessness and distress at the expense of shortening life... The treatments we use in palliative care categorically do not kill.”⁴⁹

Doctors who do assist suicide find this role confusing – and worse. 58% of doctors who had assisted a suicide reported feeling very comfortable with having taken that role, yet only 39% would definitely do it again. Among oncologists, 24% regretted having performed assisted suicide. A third felt that the emotional burden associated with assisting suicide had

⁴⁷ *The Journal of Pain and Symptom Management*, October 2009.

⁴⁸ Professor R Gillion, “And the difference is crucial for patients and their doctors”, *BMJ*, 1999,

⁴⁹ R George and C Regnard, *Palliative Medicine*, 2007.

affected their practice of medicine. A Dutch doctor who had carried out euthanasia many times said:⁵⁰

“The price of any dubious act is doubt... I don’t sleep for the week after... The idea that each case gets easier and easier is just rubbish.”

The limits of medical knowledge

Diagnosis and prognosis of depression is notoriously tricky. Many people who seek assisted suicide do so because they are depressed. Psychiatrists claim that 98% to 99% of these cases can be treated, and once treated change their mind about assisted suicide.⁵¹ Christine Kalus, a Macmillan consultant clinical psychologist, agrees that:

“A significant proportion of people with life-threatening conditions have depression which could successfully be treated with anti-depressants, and/or psychological therapies, such as family, cognitive or others which have proved effective.”

The majority of cases of depressed patients, however, go undetected. Nationwide, there are only 50 to 60 clinical psychologists working in palliative care – with some more who work in oncology. Assessment is difficult for those who are not fully trained in this area. Even GPs who have been trained find depression very difficult to recognise: they manage only 39% of all depressed patients. Some patients’ depression can be

⁵⁰ M Hicks, op. cit.

⁵¹ Royal College of Psychiatrists, noted in evidence to DPP, 2010.

brought on by the chemotherapy, steroids, and radiotherapy treatments they may be undergoing:⁵²

“Oncologists recognise 33% of mild-to-moderate cases of depression and only 13% of severe depression cases in their cancer patients... Recognising depression in suicidal patients can be complicated by the phenomenon that having decided on suicide, some individuals appear far from incompetent to make treatment decisions.”

Faced with a serious, debilitating illness, many patients understandably become depressed. Incontinence, paralysis and breathlessness impact on quality of life, but psychological factors including exhaustion, loss of control and dignity, loss of hope and feeling a burden are also to be expected. A weakened and depressed person may be highly susceptible to the hint that maybe everyone would be better off if he or she took the “easy way out”.

This has happened in Oregon. Out of a sample of deaths from physician assisted suicide, one in six had been suffering from treatable depression that had not been picked up by the prescribing physicians.⁵³

But depression is not the only issue that can confound doctors. Earlier this year, researchers at the University of Liège and the Medical Research Council’s Cognition and Brain Sciences Unit in Cambridge discovered that a car crash victim, presumed by

⁵² M Hicks, op. cit.

⁵³ G. Pitcher, op. cit.

them to be in a persistent vegetative state (PVS), could answer simple questions through a new brain scanning technique.

The unnamed patient is one of 54 people with severe brain injury who took part in the three-year Cambridge-Liège study. Four of the vegetative patients, who gave no signs of consciousness or responsiveness on conventional measures, showed “brain activation that reflected some awareness and cognition” when the researchers asked them to imagine doing certain things.

Helen Gill, a consultant in low awareness at the Royal Hospital for Neurodisability in London, told the BBC that:

“We discovered that 43% of patients assessed [by us] had [also] been wrongly diagnosed as being in a PVS, with serious implications for their care, including the removal of life support.”

The Cambridge-Liege study should remind us that medicine is not an exact science, nor are physicians all-knowing. The Royal College of Pathologists told a House of Lords select committee in 2004 that post-mortem research indicated that as many as one in 20 diagnoses of terminal illness were wrong. Even where diagnosis is correct, how accurately can a doctor predict that a terminally ill patient will die “within a few months at most”?

Prognoses, like diagnoses, are not infallible. We should recognise that patients, and those close to them, risk making decisions about their end of life care on an inaccurate premise.

8. THE REGULATOR

"I and others have suggested some kind of strictly non-aggressive tribunal that would establish the facts of the case well before the assisted death takes place.

The members of the tribunal would be acting for the good of society as well as that of the applicant to ensure they are of sound and informed mind, firm in their purpose, suffering from a life-threatening and incurable disease and not under the influence of a third party... I would suggest there should be a lawyer, one with expertise in dynastic family affairs who has become good at recognising what somebody really means and indeed, if there is outside pressure. And a medical practitioner experienced in dealing with the complexities of serious long-term illnesses.

I would also suggest that all those on the tribunal are over 45, by which time they may have acquired the rare gift of wisdom, because wisdom and compassion should, in this tribunal, stand side-by-side with the law. The tribunal would also have to be a check on those seeking death for reasons that reasonable people may consider trivial or transient distress. I dare say that quite a few people have contemplated death for reasons that

much later seemed to them to be quite minor. If we are to live in a world where a socially acceptable “early death” can be allowed, it must be allowed as a result of careful consideration.”⁵⁴

The author Terry Pratchett, diagnosed with Alzheimer’s two years ago, has become a vocal pro-euthanasia campaigner. His tribunal is an attempt to regulate assisted suicide, once it is legalised. He proposes that a family lawyer and a medical practitioner with experience in long term illness should sit on his tribunal. Given that so many in the medical profession, and almost 90% of physicians dealing in palliative care, do not want to legalise assisted suicide; and assuming we allow for conscientious objectors; this leaves only a tiny, self-selecting cadre, who would again and again send people to their death. What kind of doctor would want to spend their life administering fatal injections?

The rest of the over-45s on the tribunal would, one supposes, come from all walks of life. But our cultural taboo surrounding death and the way the dying are partitioned from the rest, would make it difficult for those not in the caring professions to assess who should be allowed to have a so-called “early death”. If a condition such as depression can pass undetected by even a trained GP, what hope is there for a tribunal of untrained non-medics?

Crucially, would an illiterate, unemployed citizen be offered a seat on the Tribunal – or indeed, on any other regulatory body set up for the express purpose of monitoring assisted suicide?

⁵⁴ Terry Pratchett, *The Guardian*, 2 February 2010.

If not, this would mean that the educated élite will be in charge of assisted suicide. We will have the unpalatable scenario of some articulate professionals pulling the plug on the socially marginalised.

The establishment of such a body – whether a Pratchett Tribunal or a similar decision-making entity – raises some interesting philosophical questions, too. How to weigh the merits of a particular “application”? If an applicant has young children, would this count against assisted suicide? If an applicant is extremely talented and still active, would anyone wish to cut short their lives? Would an “application” be reviewed in a one hour “session”, or would it merit half a day?

Whatever the regulatory model, it would not secure the control and choice that euthanasia supporters lay claim to. Hand a government-sanctioned group the power to decide when you die, and you are not autonomous, but subject to its decisions.

9. LIVING WILLS AND ADVANCE DECISIONS

In May 2010, the General Medical Council warned doctors they could be struck off if they fail to respect the wishes of terminally ill patients who want to refuse food and water and support systems that prolong their life. Doctors must abide by “living wills” in which patients specify in advance that they do not want to be resuscitated. The guidance makes clear that advance decisions can be ignored only where there is evidence that a patient may have changed his or her mind.

“Advance decisions” or “living wills” have been recognised as legally binding as of April 2007.⁵⁵ The statements are made by

⁵⁵ This is the wording of an Advance Decision: “Should I be unable to communicate, please note that I have signed, in the presence of two witnesses the following Declaration: if the time comes when I can no longer take part in decisions for my own future, let this Declaration stand as the testament to my wishes; if there is no reasonable prospect of my recovery from physical illness or impairment expected to cause me severe distress or to render me incapable of rational existence, I request that I be allowed to die and not be kept alive by artificial means and that I receive whatever quantity of drugs may be required to keep me free from pain or distress even if the moment of death is hastened.

adults judged to be fully competent to decide about the life-sustaining measures (oxygen, food, water) they wish to accept or refuse, when they reach a point where they are no longer able to make decisions or communicate their preferences. (An advance statement cannot authorise a doctor to do anything illegal. Doctors are not bound, either, to provide a specific treatment if in their professional view it is clinically inappropriate.)

Patients who make an advance decision are rare. “If I walk through my acute unit,” a consultant in internal medicine in a UK teaching hospital, explains, “where we have a turnover of 70 people per day, only about 1% will have an advance directive written up.” Even in the US, where advance decisions have been in force for the last 20 years, only 5% to 11% of patients with an unanticipated critical illness have one.⁵⁶

Patients remain wary of advance decisions – with reason. To decide today, when you are a healthy 50-year-old, what you will want in terms of therapy and intervention when you are a frail and ailing 85 year old, is impossible: advance decisions would have to be reviewed constantly. Even then, the patient risks miscalculating what his or her attitude will be in the event: happiness for a dementia patient strikes the healthy of mind and body as inconceivable; yet it is possible.

An extraordinary example of this took place at the Addenbrook Hospital in Cambridge, last year. Richard Rudd, 43, was paralysed as a result of a motorcycle accident. As Mr Rudd had always been adamant that if ever he were to find himself in such circumstances, he would wish to die, doctors were ready to switch off his life-support machine – when suddenly he blinked,

⁵⁶ A Tillyard, “Advance Decisions: the American Experience”, *Critical Care*, 2007.

to show that he wanted to live. Nine months on, he still needed round-the-clock medical care, but was able to communicate with his family.⁵⁷

Andrew Tillyard, Consultant in intensive care medicine at Derriford Hospital, argues that, rather than expect a patient, when healthy, to accurately predict his or her desire to stop life support some 20 years later, the onus should be on GPs to ask patients when they are towards the end of their life where and how they envisage their dying days – in hospital or at home/hospice/nursing home.

“We should encourage GPs to have these conversations. We’ve had the allocation of smoking cessation money directed to Primary Care Trusts, which in essence meant GPs would get money for telling a patient to stop smoking; now we should have money for the doctor who raises the subject of ‘where do you want to die?’”

Acute physicians, confronted with a terminally ill patient, are having to decide their patient’s best interests without any real knowledge of the patient’s circumstances or wishes. Conversely, with regards to Richard Rudd, advance decisions made by patients prior to a sudden and unexpected event need to be interpreted with caution.

⁵⁷ BBC One, *Between Life and Death*, 13 July 2010.

10. TOWARDS A DIGNIFIED DEATH

To erode support for assisted suicide, government policy needs to change. In particular, we should recognise that more needs to be done to make a dignified death possible for all.

Improve our access to palliative care

Palliative care in Britain, unlike in those few countries that have legalised ‘assisted dying’, is outstanding.⁵⁸ Its palliative care and network of hospices put this country top of the list of 40 countries – including the Netherlands, Belgium and the US, which have all legalised assisted suicide.

In the British health care system, palliative care is a recognised clinical speciality, like paediatrics or oncology, with demanding four-year training for those who specialize. Its distribution, however, both around the country and within the health care system is uneven.

⁵⁸ According to a global report published by *The Economist*, Britain is the best place in the world to die. Best Death Index, Economist Intelligence Unit, 14 July 2010.

Training in palliative care should be made compulsory for all hospital and nursing home staff. Such training can be done in apprenticeship form, so that trainees learn on the job from specialists. We need better inter-disciplinary co-ordination along the lines of the hospice model, bringing together GPs, district nurses, social workers, hospital staff, and staff in care homes. More psychologists are required to assess patients suffering from depression.

Equip care homes and nursing homes to cope with the dying

There are over 18,000 care homes in England. Too many are ill-equipped to cater for the dying. Too many care home managers worry that a death on the premises will damage their reputation: their reflex action, when a patient is taken ill, is to rush them to hospital. Hospitals at present have no feed-back mechanism to let care homes know when a case is an inappropriate referral.

The hospice experience shows that death need not be hospitalised and compartmentalised – nor can it be avoided. Death needs discussion and careful examination: for only then, can the experience of dying be improved for all.

Family and carers

Many elderly and infirm people rely on relatives as carers. The relationship may be close and loving, and the carers will speak of the pleasure that they experience in caring for their loved one. But carers, especially when their services are required over a period of years, or when they themselves are frail or elderly, need support. They have the right to have their own needs assessed and reviewed and to have a carer's care plan.

Respite care is crucial to support family and carers. This is particularly true among the disadvantaged. GPs and social services should direct carers to free services such as Hospice

at Home (a service which can provide qualified nurses and nursing auxiliaries, trained in specialist and supportive palliative care).⁵⁹

Reduce inappropriate referrals

Too many elderly and disabled people end up in hospital when they don't need to. These inappropriate referrals are incompatible with limited resources in the health care system, an explosion in the numbers of elderly patients, and above all, with what most patients want.

As one consultant puts it:

“We had an elderly nursing home patient who was dying, but she was brought into A & E in the middle of the night, where she died behind the curtain. This kind of inappropriate referral is an every day occurrence. It's inappropriate in that this is not what the patient would wish; and because many of the patients who end up (literally) in acute hospitals could as well have been kept in their nursing home or brought to a non-acute hospital.

The National Beds Inquiry found that 20% of bed days for people over 65 would be inappropriate if alternative services were in place.⁶⁰ Considering that older people are high users of health care – roughly 4.5 times higher, for those 65 and over,

⁵⁹ Hospice at Home is funded by voluntary donations, carers grants from Local Authorities (LAs), and PCT and Marie Curie Cancer Care matched funding.

⁶⁰ Sir Derek Wanless, *Securing Good Care for Older People*, The King's Fund, 2006.

than for those under 65 – filtering the inappropriate referral would constitute a huge saving.

Communication

Medical practitioners can debunk the myths surrounding death by communicating with their patients about the choices before them for end of life care. We already have Advance Care Planning (ACP), a process in which health professionals discuss with patients how best to plan for their end-of-life care (including the individual's concerns and their understanding about their illness and prognosis). But at present few patients seem to know about, or take advantage of, this opportunity.

Encouraging GPs to discuss with healthy patients where they would prefer to die would relieve the immense pressure on hospital resources, as well as restoring death to its status as a natural and familiar event.

Innovation

Two recent initiatives – one in Bath and North East Somerset, the other in the US – have also shown how more can be done to help the dying within existing budgets. In Bath and North East Somerset, a joint NHS-Local Authority initiative provided a dedicated nursing and physiotherapy team for three residential care homes to show how dedicated nursing and physiotherapy can save money as well as improve the quality of care in these homes.⁶¹ The research found that residents were likely to benefit from improved quality of life as early detection of illness, and subsequent early intervention, was a major part of the team's work; overall, estimates of costs and savings ranged from a

⁶¹ Deidre Wild and Sara Nelson, *Providing Nursing Support within residential care homes* Joseph Roundtree Foundation, April 2008.

'worst case' scenario of £2.70 extra to a more likely scenario of £36.90 saved (mainly in NHS costs) per resident per week.

In the US, a substantial project in telehealth carried out by the Veterans' Health Administration showed that monitoring patients with chronic conditions through appropriate technology (anything from video phones and telemonitoring devices to biometric devices and digital cameras) significantly reduced hospital admissions (by 20%) and bed days (by more than a quarter) of care for these patients. Moreover, the cost of the programme was significantly lower than other forms of care – \$1,600 per patient a year, compared with \$13,121 for the direct cost of home-based primary services and an average of \$77,745 for nursing home care rates. Care co-ordinators worked with the patient's doctor, monitoring risk against set thresholds (eg blood pressure upper levels) and intervening, usually by telephone, in case of risk. In this way, co-ordinators typically managed 100-150 patients.⁶²

⁶² See Department of Health Care Network, Newsletter, July 2010.

11. CONCLUSIONS

Legalising assisted suicide and euthanasia will put the socially marginalised at serious risk. Attempts to change the law should be resisted.

The elderly, people with severe disabilities, the mentally unstable, and those with terminal illnesses will be presented with self-inflicted death as a natural, normal and expected final solution.

As Britain readies itself for a rapid growth in the number of over 80 year olds, the pressure to consider assisted suicide as a utilitarian solution will grow. But we should preserve the status quo. At present, the law shows compassion to those, in extraordinary cases, acting *in extremis*; it does not license a process in advance. We must not change the law to cover a few hard cases, but must protect the great majority. The best way to do so is to improve our access to the palliative care already available to a section of the population.

The chattering classes who support legalising assisted suicide claim that they want to protect our right to die as and when we wish. It is true that few in Britain today die as they would choose

to. The impediment, however, does not lie in our law against assisted suicide, but rather in our culture. Obsessed with health, youth and success, we make assumptions about the poor quality of life that people with disabilities suffer from, and shrink altogether from addressing the issues surrounding death and dying. This culture, found also within our health and social care systems, has allowed fearful myths about the pain and indignities of various disabilities to take hold of the public imagination; health professionals to misdiagnose dying patients; unskilled carers to push elderly or disabled patients into hospital the minute they fall ill.

The hospice experience shows that death cannot be hospitalised and compartmentalised, an ugly incident that we self-consciously rush past, averting our eyes. A few key changes in the training of medical professionals and co-ordinating multi-disciplinary services in end of life care could ensure that, as happens now in hospices, all the patient's needs are met. Palliative care and preventive systems are far cheaper than intensive care. They also relieve the over-stretched health and social services, and dispel the image of a painful, lonely and undignified death. They would dispel, too, the image of a painful, lonely and undignified death.

The hospice experience shows that death cannot be hospitalised and compartmentalised, an ugly incident that we self-consciously rush past, averting our eyes; it is, in fact, part of the human condition and of our society.

Even this transformation will not satisfy the handful of determined men and women, who, regardless of the legal implications, will always want to control every aspect of their death. They will continue to clamour for the legalisation of assisted suicide as a fundamental right.

But for the vulnerable, once it becomes enshrined in the law, this “right” might turn into an obligation. They may feel that, once over a certain age, or grown too dependent on others, or too fed up with life, or too ill, they should opt for death rather than life. Worse, many may be coerced, actively or subtly, by cost-conscious hospitals, or by intended heirs with an eye to a legacy, or by exhausted carers.

As assisted suicide becomes embedded in our culture, investing resources in caring for these vulnerable groups will be seen as a waste: they'll soon be gone. The Big Society will be just wishful thinking; Britain will be a collection of individualists in the prime of life and good health. Anyone else will have felt compelled to end their miserable existence.

A society cleansed of the feeble, the infirm, the imperfect: it is a template others, in history, have sought. We should remember at what cost.

A strident consumerist élite is playing on our fears of death and dying to call for the legalisation of assisted suicide.

Euthanasia enthusiasts among the chattering classes have nothing to fear from a change in the law: articulate, determined and well-connected, they are unlikely to be bullied into an early death.

But millions of others are less fortunate. Many ill and elderly people will fail to represent their own best interests or those of their loved ones. Fearful of authorities and confused by bureaucracy, they may be subject to manipulation by others.

Legalising assisted suicide would create a new category of second class human beings. It must be resisted.

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