

## **Disability Rights Commission**

### **Policy statement on voluntary euthanasia and assisted suicide**

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## 1. Executive Summary

### **Policy statement on voluntary euthanasia and assisted suicide**

The DRC is committed to the principle of autonomy for disabled people. Individual disabled people should therefore, be able to make autonomous choices, in the same way as non-disabled people, including potentially choosing the manner and time of their death. The DRC therefore does not oppose, in principle, legalisation of euthanasia for competent adults who freely choose it.

However, we believe that in the current climate of discrimination against disabled people, where a lack of access to palliative care and social support means that free choice does not really exist, the threat to the lives of disabled people posed by such legislation is real and significant. We, therefore, cannot currently support legalisation of euthanasia.

#### **Introduction**

1.1 It has been argued by the Voluntary Euthanasia Society (VES) that the DRC's holding position (that the DRC cannot support legislation at this point in time) discriminates against people with cancer and Motor Neurone Disease (MND).

1.2 The DRC exists to eliminate discrimination against disabled people. The Commission believes that disabled people should be treated equally and have equal rights to non-disabled people. However the DRC has a responsibility towards all disabled people, including people with cancer and MND who do not want to die, as well as those who want to choose the time and manner of their death but who are unable to do so. In considering the implications of such legislation the DRC is faced with a complex set of considerations.

1.3 On one hand there are disabled people such as Dianne Pretty Reginald Crew and Lisa Cook, who want to maintain their

autonomy through access to lawful assistance to die. They want to be able to receive assistance to die from somebody else without that person being liable to criminal prosecution. Dianne Pretty was living a life she found undignified, and feared her life would end painfully choking to death, and she wanted to choose assisted suicide before that point was reached. She spent the last months of her life fighting for this choice. Reginald Crew had to undertake a difficult journey away from his home and country (to Switzerland), when he was seriously ill, to get the help to die that he wanted.

1.4 On the other hand there are people such as Jane Campbell, and organisations of disabled people such as Alert and No Less Human, who say that to legalise euthanasia will lead to coercion of disabled people to seek assistance to die, and even to involuntary euthanasia for disabled people when others decide that their lives are not worth living.

**Indirect coercion to seek assistance to die due to, lack of social support to aid dignity and independent living, and social exclusion.**

1.5 There is a body of evidence to support the fact that many disabled people of all ages do not have access to good health care and adequate and properly resourced social support and this leads to indignity and lack of independence for disabled people. Many carers do not receive the help that they need to support the person they are caring for and to have a good quality of life themselves. Many disabled people and their carers face poverty and social exclusion. The strain of this does cause feelings of desperation and hopelessness and of being 'a burden' even to the extent of leading to so-called 'mercy killing'. However it is not possible to prove, or even to guess how many people in this situation would choose to seek assistance to die if euthanasia were legalised. What can be said is that there is a body of opinion among disabled people, ethicists and the legal and medical professions that there is a significant risk – so much so that they have recommended that euthanasia is not legalised.

**The influence of the media on the attitudes of disabled people, their families, and the general public.**

1.6 The media has an enormous impact on the public's perception of disability, and the evidence is that the media portrays disabled people's lives negatively in the most part. This could lead to a subtle form of coercion of disabled people and their families being persuaded that indeed their lives are inferior. This is particularly so if coupled with a lack of support and resources causing dependence and low quality of life. Again it is not possible to quantify whether or how this would affect the decision to seek assistance to die, but it does affect the climate in which decisions are made to seek and give assistance to die.

**Fear of direct coercion and fears for vulnerable people.**

1.7 There is anecdotal evidence from respected sources that direct coercion to die does already take place. It is not unrealistic to expect that there will be individuals who would similarly attempt to use any legalisation of euthanasia to further their own interests. Equally it is difficult to envisage regulation that could prevent all such incidents.

**Lack of palliative care: pain-killing medication, identification and treatment for depression, and counselling.**

1.8 Access to good palliative care including effective pain relief is essential in supporting autonomy and enabling people to live with dignity. It is accepted by the Government that good palliative care is not available to everyone who needs it in the UK. There is also evidence that people who do not receive good palliative care seek assistance to die in the UK - whether that is because of lack of effective pain relief, or depression, or both. Doctors who currently face the dilemma of being asked by patients who are suffering to help them to die, would no longer be constrained by the law. It would seem logical that if assistance to die were lawful, that those who do not have access to good quality palliative care would ask for and be given assistance to die.

**Evidence of discrimination in medical encounters leading to fear of involuntary euthanasia. Medical guidelines not being followed. Attitudes of the judiciary and court decisions**

1.9 There is considerable anecdotal evidence that decisions by medical professionals on whether disabled people live or die, are

sometimes being made against a backdrop of negative images and poorly informed assumptions of disabled people's lives. There are also incidences that have come to light, of life and death treatment decisions being made without following guidelines. Guidelines themselves risk institutionalising discriminatory attitudes. In addition there is evidence of decisions made by the courts that rely heavily on the testimony of medical practitioners and which sometimes display a devaluing of disabled people's lives. It is not possible to know how often this happens. However it does point to the difficulty of regulating legalisation of euthanasia which relies on doctors' judgements, reporting, and following of procedures, and court decisions to define the boundaries of what is acceptable.

### **Why are some disabled people calling for legalisation of euthanasia and assisted suicide?**

#### **Upholding the principle of autonomy**

1.10 The argument that legalisation of euthanasia would uphold the autonomy of disabled people is certainly a compelling one, and one that cannot be lightly put aside. There is general agreement that the only circumstance where the autonomy of one group can be overridden is where there is a real and significant threat to the lives of others. Some argue that there must be incontrovertible evidence of this threat.

1.11 The evidence from the Netherlands and Oregon over whether legalisation has threatened the lives of disabled people who do not wish to die is equivocal. As we have seen above, the evidence that legalisation in this country could threaten the lives of some disabled people is largely unprovable. However taken together the concerns raised indicate that there are many factors that could affect the safety of the legislation, and which could not be filtered out or controlled by regulation.

1.12 Supporters argue that legalisation would allow people in intolerable pain, or suffering what they would consider intolerable indignity to choose a dignified life and a peaceful, painless death at a time of their choosing. Opponents argue that with access to good palliative care, including pain relief, counselling and treatment for depression, and social support to aid independence and dignity, many disabled people could achieve a peaceful and dignified life and death; their anxieties would be relieved and their enjoyment of

life enhanced. Many who currently would choose to die would want to live.

1.13 However it is broadly believed, although unknowable, that some people would choose to die even if the best palliative care and support were available. For the few where the ability to control pain is limited, and for others, who for example, are dependent on others for intimate care, or due to pain-killing medication may be unaware of their surroundings for a large part of the time, euthanasia may continue to be the choice they want.

**Is the threat to some disabled people sufficient to override the rights of others? Can choice be denied to people who are well informed and well supported, and who make a valid decision that they wish to end their lives?**

1.14 As has been said above the argument that legalisation of euthanasia would uphold the autonomy of disabled people is certainly a compelling one, and one that cannot be lightly put aside.

1.15 However the courts in this country and in Europe have held that there is a significant risk to the lives of others that overrides the autonomy of those wishing assistance. This has been challenged on the grounds that the risk had not been sufficiently proved. It is impossible to prove the extent of such a risk, but the evidence gathered by the DRC does raise serious concerns that such a risk does indeed exist. In addition there is a considerable body of opinion internationally based on thorough investigation and robust analysis, that the risk is sufficient to deny the choice to choose assistance to die.

**Might it be possible to frame legislation and regulation to allow some disabled or terminally ill people assistance to die, whilst safeguarding the lives of others from involuntary euthanasia?**

1.16 Those who support euthanasia say that involuntary euthanasia already takes place secretly in this country, and that the courts endorse 'mercy killing'. They say that legalisation allows proper regulation of what happens and provides a better protection for vulnerable people and reduces involuntary euthanasia. In answer to this argument it is argued that if the current law is not

being adequately enforced, then legalisation of euthanasia is not the way to safeguard against involuntary euthanasia. The answer may be to improve current enforcement mechanisms - it may be that the law against euthanasia and so-called 'mercy killing' needs to be strengthened, or practice needs to change, or both.

1.17 The evidence from abroad, over whether it is possible to frame legislation that can safeguard those who do not want to die, is equivocal. However, it could be argued that whether or not regulation is working in these other countries, is immaterial as to whether legislation with sufficient safeguards could be framed in this country.

1.18 In addition, legislation works in a context. There is a body of opinion internationally, that says that it is impossible to safely legislate in the current climate of discrimination, where disabled people do not have access to good palliative care or social support to enable a good quality of life. There are questions over whether, in such a climate, disabled people will be coerced into seeking assistance to die, whether self-regulation by doctors can work, whether decisions by the courts based on advice from the medical profession will be safe, and if not what other kind of regulation can be put in place.

1.19 There is certainly a real fear among some disabled people and their organisations, and a number of authoritative individuals, that legalisation of euthanasia in the world we live in today, poses a real and substantial threat to vulnerable people. This view is endorsed by a number of influential international bodies. How real the threat is, is not currently known and is probably unknowable unless legislation is introduced with the risk that that may entail.

## 2. Introduction

2.1 The DRC has a legitimate interest in commenting on the legalisation of voluntary euthanasia and assisted suicide. Disabled people will not only be covered by legislation to legalise euthanasia for people who are terminally ill or have a physical impairment or illness, but have in fact been targeted by such legislation; for example the Lord Joffe Bill. The Bill would have made euthanasia lawful for a person suffering unbearably as a result of an incurable and physical illness which the consulting physician has determined as being likely to result in the patient's death within 6 months of the date when he confirmed the prognosis of the attending physician; or a serious incurable and progressive physical illness.

2.2 The debate on euthanasia has raised related issues including: withholding and withdrawing of treatment that leads to death for competent adults, children, and patients who lack competence; euthanasia for people who lack competence and who therefore cannot decide either way; and the use of medication to relieve pain but which it has been argued (but also refuted) can lead to death. It is important at the outset to clarify that the issue considered in this paper is whether assisted suicide and voluntary euthanasia should be legalised for competent adults who request it.

2.3 The role of the DRC in this issue is not to enter the general debate on the morality of euthanasia and assisted suicide e.g. the religious arguments on the sanctity of life. The DRC needs to consider the issues as they impact on the rights of disabled people.

2.4 There has long been debate on the moral and ethical issues of voluntary euthanasia and assisted suicide. In 2002 the case of Dianne Pretty focused the debate on disabled people. Dianne Pretty was in the terminal phase of motor neurone disease. She and her husband fought a legal battle to permit Mr Pretty to assist her to commit suicide, without fear of prosecution. Dianne Pretty's request was turned down by the English courts and eventually by the European Court of Human Rights. The issue again hit the

headlines later in the year, when Reginald Crew, who had a terminal illness and was unable to take his own life unaided, travelled to Switzerland where he was assisted to die. Other disabled people want to maintain their autonomy through the right to legally assisted suicide or voluntary euthanasia to enable them to choose how and when to die.

2.5 The way in which the debate on these cases was reported in much of the media questioned the value of disabled people and their lives. It raised once again concerns among disabled people that decisions by medical and legal professionals on whether they lived or died, were being made against a backdrop of negative images and poorly informed assumptions of intolerable suffering and unacceptable dependence on others. This has led to some disabled people, for example Alert and no Less Human, being fearful that if voluntary euthanasia and assisted suicide are legalised then their lives will be secretly ended by others. They say that legalising euthanasia will pose a serious threat to their lives.

### **3. Why is there opposition to legalisation of euthanasia from some disabled people?**

**Indirect coercion to seek assistance to die due to, lack of social support to aid dignity and independent living, and social exclusion,**

3.1 Those against euthanasia say that disabled people and their families are subject to indirect coercion to die. They say that many disabled people are living intolerable lives, not because of their impairment, but due to lack of choice, control and autonomy brought about by the lack of basic amenities and support services including inaccessible and inadequate housing<sup>12</sup>, insufficient help with personal care<sup>3</sup>, and lack of essential equipment<sup>4</sup>. This leads to indignity and unacceptable reliance on others, and even being

<sup>1</sup> *Where Do You Think You're Going? Report of the John Grooms Inquiry into the Needs of Young Disabled People*, John Grooms, 2003

<sup>2</sup> *The housing needs of disabled children: the national evidence*, Joseph Rowntree Foundation, York, 2002

<sup>3</sup> Knight, J et al, *Inclusive Citizenship: The Leonard Cheshire Social Exclusion Report*, Leonard Cheshire, 2002

<sup>4</sup> *Fully Equipped Assisting Independence*, Audit Commission, 2002

forced into residential homes against their wishes<sup>5</sup>. Many disabled people and their families live in poverty<sup>67</sup>, reliant on benefits<sup>8</sup> or in lower paid jobs having fewer qualifications<sup>9</sup>. They face social exclusion<sup>10</sup> through inaccessible mainstream schools and bullying<sup>11</sup>, discrimination in employment<sup>12</sup> and inaccessible public transport<sup>13</sup>. Families and carers are under intolerable strain due to lack of support<sup>14</sup> and inadequate income<sup>1516</sup>, which leads to disabled people feeling they are an unacceptable burden on loved-ones.

3.2 Research shows families with disabled children tend to have lower incomes, and a less active social life, due to caring responsibilities and lack of social support, including lack of basic equipment to help with caring.<sup>1718</sup> These same problems cause the same pressures on older parents with disabled adult sons or daughters. A report in May 2003 in the East Anglian Daily Times highlighted the case of a 71 year-old mother with arthritis, who cannot lift her 50 year-old daughter who weighs 16 stone and who has learning difficulties, mobility and sight impairments. They needed a level floor shower but the housing association said they had no funds for this. The mother therefore has to wash the daughter with a sponge and a bucket in the kitchen. She said "It is most undignified for her. I am desperate for help".

<sup>5</sup> *Where Do You Think You're Going? John Grooms Inquiry into the Needs of Young Disabled People*, John Grooms, 2003

<sup>6</sup> **Disability follow-up to Family Resource Survey 1996-97**

<sup>7</sup> Saul Becker, "Carers and Indicators of Vulnerability to Social Exclusion" in *Benefits*, April/May 2000, Issue 28

<sup>8</sup> Labour Force Survey, **ONS, Summer 2002**

<sup>9</sup> Grewal, I. et al, *Disabled for Life? Attitudes towards, and experiences of, disability in Britain*, Department for Work & Pensions, 2002

<sup>10</sup> **David Gordon et al, Poverty and Social Exclusion in Britain, Chapter 5 (pp54-67), Joseph Rowntree Foundation, York, 2000**

<sup>11</sup> *Survey of young disabled people in England and Wales aged 16 to 24 years old* conducted by NOP for the Disability Rights Commission in October and November 2002

<sup>12</sup> Grewal, I. et al, *Disabled for Life? Attitudes towards, and experiences of, disability in Britain*, Department for Work & Pensions, 2002

<sup>13</sup> *Mind the Gap*, Leonard Cheshire, London, 2003

<sup>14</sup> Marilyn Howard 'Carers and Social Exclusion' in: *Paying the Price – carers, poverty and social exclusion* CPAG/Carers UK, London, 200

<sup>15</sup> Tania Burchardt, *Social exclusion and the onset of disability*, CASE report 21, Joseph Rowntree Foundation, York, November 2003

<sup>16</sup> **Opportunity for All: tackling poverty and social exclusion First Annual Report, Department Social Security, 1999**

<sup>17</sup> Supporting disabled children and their families Ref N79 Joseph Rowntree findings, York, November 1999

<sup>18</sup> *Still Missing Out*, Barnardo's, 2001

3.3 Thousands of people with severe mental health problems are turned away by their doctors when they seek help in a crisis, according to the report *Just One Per Cent* by the charity Rethink.<sup>19</sup> It found 28% of patients with a long-term history of serious mental health problems, were shunned during a relapse in the past three years, by the NHS staff who were supposed to be caring for them. The survey showed that only 1% of mental health service users were happy with their quality of life.

3.4 Opponents to legalisation of euthanasia believe that all these pressures could lead to some disabled people choosing to seek to die. They cite evidence from Oregon showing that 26% in 1999, 63% in 2000 and 24% in 2001<sup>20</sup> cited fear of being a “burden on family friends or care-givers” as a reason for seeking help with suicide. The answer, they say, is not to legalise euthanasia but to put efforts into redressing the problems and making life worth living.

3.5 Jane Campbell said in a presentation to peers in June 2003 on the dangers of the Joffe Patient (Assisted Dying) Bill “If you stripped away my care support and accessible environment, for which I have had to fight tooth and nail, I, too, would feel suicidal. Disabled peoples’ lives are seen as less worthwhile, burdensome and even desperate. Unless we are extraordinarily strong individuals it is all too easy to buy into this negativity. Every older person who fears being a burden, every disabled person with an inadequate care package will have a shadow over them from the knowledge that the law thinks it may be better if they were dead. If assisted death were a legally and socially acceptable option many would succumb and ask to be ‘put out of their misery’.”

### **Fear of direct coercion and fears for vulnerable people.**

3.6 There is a fear that disabled people will be open to direct coercion to seek assistance to die from others who have an interest in their death.

<sup>19</sup> *Just One Per Cent*, Rethink, London, 2003

<sup>20</sup> *Second, Third and Fourth Annual Reports on Oregon’s Death with Dignity Act*, Oregon Department of Human Services, Office of Disease Prevention and Epidemiology, February 2000, 2001, 2002

3.7 Professor Baroness Findlay of Llanduff quotes an example from her clinical practice. 'A lady aged 59 was very ill. Her family appeared to be very concerned about her pain and constantly asked for her diamorphine to be increased. However, we remained unconvinced that her pain was really that severe. In fact, the patient declined increasing doses of diamorphine. Her 60th birthday arrived and was passed with minimal celebration, after which the family visited very little. She became depressed and spoke to one of the night nurses, explaining that the problem was that on her 60th birthday, her fixed-term life insurance policy expired. The family would not now inherit what they thought they would if she had died, and if her drugs been duly increased.'

3.8 A case is reported of an elderly woman who died under Oregon's assisted suicide law:

Kate Cheney, 85, reportedly had been suffering from early dementia. After she was diagnosed with cancer, her own physician declined to provide a lethal prescription for her. Counselling was sought to determine if she was capable of making health care decisions. A psychiatrist found that Mrs. Cheney was not eligible for assisted suicide since she was not explicitly pushing for it, her daughter seemed to be coaching her to do so, and she couldn't remember important names and details of even a recent hospital stay. Mrs. Cheney was then taken to a psychologist who said she was competent but possibly under the influence of her daughter who was "somewhat coercive." Finally, a managed care ethicist who was overseeing her case determined that she was qualified for assisted suicide, and the lethal drugs were prescribed.<sup>21</sup>

### **Lack of palliative care: pain-killing medication.**

3.9 Palliative care specialists from around the world and disabled people and their organisations have expressed concern that lack of effective pain relief will lead people to choose to die. There is a growing body of evidence that good palliative care is currently not available to everyone in the UK who needs it<sup>22</sup> and in recognition of this, the UK Government has promised to review and improve access to palliative care.

<sup>21</sup> Erin Barnett, "A family struggle: Is Mom capable of choosing to die?" *Oregonian*, October 17, 1999.

<sup>22</sup> 'How do you deal with death', *Nursing Times*, 1 February 2001

3.10 It is stated by palliative care professionals that drugs can control most of the pain for most people - the ability to control physical pain is somewhat limited in only 5% of people. They say that palliative care can now ease the way to a painless and peaceful death even in the case of Motor Neurone Disease. Supportive care in the case of MND and of a non-life limiting illness such as multiple sclerosis can help to maintain dignity and quality of life.

3.11 In addition, experts working in palliative care say they are concerned that proper counselling is not available to people who express the wish to die. It is argued that if a disabled person expresses the wish to die the first task must be to try to enable them to make the choice to live. Professionals in the palliative care field say that their experience shows that with expert counselling people who had thought they would want to die change their minds. The literature shows that many requests for euthanasia at the end of life are not sustained. At least 50% are not sustained several months after the initial request is made. If they had been "assisted" in their attempts, it is argued, they would never have had the chance to change their minds.

### **Lack of palliative care: identification and treatment for depression and counselling.**

3.12 Among the general population, research has found that, only a small minority of people who have made a serious suicide attempt and not succeeded, go on to commit suicide. Many seek counselling or treatment and go on to lead satisfying lives. Below are the findings from two studies. This evidence is used to support the argument that the response to disabled people seeking to die should be to offer support to live.

- A study of 886 people who were rescued from attempted suicides found that five years later only 3.84 percent had gone on to kill themselves. Rosen, The Serious Suicide Attempt: Five Year Follow Up Study of 886 Patients, 235 J.A.M.A. 2105, 2105 (1976).
- A Swedish follow-up study found over 35 years only 10.9 percent later killed themselves. Dahlgren, Attempted Suicides

### 35 Years Afterward, 7 SUICIDE AND LIFE-THREATENING BEHAVIOR 75, 76, 78 (1977).

3.13 In Holland 77% of patients whose doctors assist them to die have untreatable cancer. This is evidence, it is argued, that legalised euthanasia in the Netherlands has delayed the introduction of good palliative care such as counselling. Dr Tim Maughan, an oncologist who directs the Wales Cancer Trials Network at Cardiff University is reported as saying that he has seen most cancer patients go through a period of severe depression. In a small number of cases, he has been asked by his patients to help them end their lives. "And yet, in each case, if you look with the patient at their situation, talk to them about their relationship with their families and friends, they come to regret making that request."<sup>23</sup>

3.14 It is generally accepted that some people who wish to end their life are suffering from depression. Furthermore this is difficult for the generalist doctor to diagnose, and access to specialists is crucial for anyone wishing to die. It is argued, that as many people do not have access to such expertise and help, the availability of assistance to die could be offered inappropriately leading to the deaths of people who may well have changed their minds.

3.15 Dr. Gregory Hamilton, a Portland psychiatrist and spokesman for Physicians for Compassionate Care, says the "vast majority" of patients considering suicide have depression. The feeling of being a burden, he contends, is a psychological condition that can be helped with therapy. Research among people receiving palliative care has shown that where patients experience neither depression nor 'hopelessness' then their desire for death is zero. Where they experience either depression or 'hopelessness' then their desire for death is 20% and where they experience both their desire for death is 65%.

3.16 The New York Task Force on euthanasia 1994 concluded:  
 "Moreover, terminally ill patients who do desire suicide or euthanasia often suffer from a treatable mental disorder, most commonly depression. When these patients receive

<sup>23</sup> 'Battle over euthanasia', The Tablet 17, May 2003

appropriate treatment for depression, they usually abandon the wish to commit suicide. “

3.17 It should be noted however, that it has been argued, by supporters of legalised euthanasia, that the knowledge that there is access to assistance to die if wanted, allows people who are dying to lead a better quality of life, free from depression or the worry of a painful and intolerable life and subsequent death. This is borne out by experience in Oregon they argue, where many who seek medication to help them to die, do not go on to use it.

### **The influence of the media on the attitudes of disabled people, their families, and the general public**

3.18 The media depicts disabled people as dependent objects of charity or heroes overcoming adversity<sup>24</sup>. The way in which the debate on Dianne Pretty and Reginald Crew was reported in much of the media questioned the value of disabled people and their lives.

3.19 For newly disabled people for whom the media is their only ‘experience’ of what disability means, and for other disabled people who do not have the support they need, and their families, it is very easy to buy-in to this negativity and be subtly coerced into seeking assistance to die.

3.20 Dr Ian Basnett illustrates the former attitude well in his Observer response to Miss B’s legal battle to have her life-saving ventilation withdrawn when she became paralysed. He says, “I became quadriplegic following a sporting accident 17 years ago. I was ventilator dependent for a while and at times said to people, “I wish I was dead!” I am now extraordinarily glad no one acted on that and assisted suicide was not legal. I think the first difficulty I faced was the fact that, like many people, I had a terribly negative image of disability. When you suddenly become severely disabled you still have that viewpoint. Before I was disabled, I was working as a junior doctor. That brought me into contact with disabled people and I remember clerking in a man with quadriplegia. My reaction was, how could anyone live like that? I said to my then girlfriend, “I’d rather be dead, if I couldn’t play sport”.

<sup>24</sup> Cooke et al, *STOP PRESS – How the press portrays disabled people*, Scope, London, 2000

### **Evidence of discrimination in medical encounters leading to fear of involuntary euthanasia.**

3.21 Legalised euthanasia would be carried out by doctors, and this is an area of major concern to disabled individuals and disability groups opposed to legalisation. There are reports from disabled people and their families of excellent treatment from health professionals. However, there is compelling evidence from research over a number of years up to the present day that discrimination in general health services exists. This qualitative research has recorded consistent testimony from disabled people and their families about the discriminatory attitudes they face from medical professionals, and poorer services they receive in the NHS<sup>25</sup>.

3.22 This research shows that decisions regarding whether to offer life-saving or life-enhancing treatment are made in an environment where some medical professionals openly display ignorance of, and discriminatory attitudes towards, disabled people. For instance the Down's Syndrome Association survey and report 'He'll Never Join the Army' found that: "It is clear that many medical staff are failing to adhere to existing guidelines and that their prejudice and ignorance is affecting the care that people with Down's syndrome are offered. They illustrate with quotations from parents' experience:

*"Our son was described by a senior physician as "an unacceptable burden on resources medically, socially and educationally."*

3.23 The Down's Syndrome Association questions whether the increase in availability of pre-natal testing for Down's syndrome within the NHS has negatively influenced medical opinion and attitudes towards people with Down's syndrome. They report the incident of a consultant obstetrician saying to two junior doctors, "Perhaps ante-natal testing should be insisted on so that Down's

<sup>25</sup> *The NHS – Health for all?: People with learning disabilities and health care*, Mencap, London, 1998; Lamb B and Layzell S *Disabled in Britain: Counting on Community Care*, Scope, London, 1995; *He'll Never Join the Army*, **The Down's Syndrome Association**, London; **Not Just Sticks and Stones**, Mind, London, 1996; *A bitter pill*, DIAL UK, 2002; *Turning your back on us – older people and the NHS*, **Age Concern England/Gallup**, London, 1999

babies weren't born". This sentiment is reflected in recent Government policy.

3.24 Another indication of discriminatory attitudes and decisions by some in the medical profession is highlighted in an article about euthanasia in the New Statesman (25 October 1996). Baroness Mary Warnock a leading medical ethicist is quoted as saying that years ago her father-in-law – a doctor – used to smother at birth hopelessly handicapped babies. She mourns the loss of such practices. "That was right. Doctors were bold enough to take the decisions but now it all has to be so co-operative." With Down's Syndrome children, she thinks abortion "the wiser course". In an article in the Independent 8 June 2002 commenting on the Dianne Pretty case, she is quoted as saying "if the law permits the termination of a pregnancy when the foetus is so malformed it will be a burden to the child if born, the law should allow (voluntary) euthanasia (for a disabled person)."

### **Medical guidelines not being followed.**

3.25 Opponents to legalisation say that current guidelines on life and death decision-making are not being followed. It is argued that this indicates that it would not be possible to regulate legalised euthanasia, which relies on doctors following regulations and guidance. They say that decisions are being based on discriminatory 'quality of life' judgements instead of the 'best interests' of the patient.

3.26 Evidence of how decisions are reached is difficult to come by as they are of necessity bound by rules of confidentiality. However research into DNR practice commissioned by DRC in Scotland 2003 concluded from interviews with consultants:

"... it seemed that consultants were still relying heavily on their individual views of whether a disabled person would be likely to enjoy a sufficiently high quality of life. They were aware of the problematic nature of making judgements on some one else's quality of life, but nonetheless believed it was their duty to do this. Consultants working with babies and children took into account the quality of life of the entire family when making decisions on the use of resuscitation."

3.27 In addition there is some anecdotal evidence from disabled people. These include:

- Jane Campbell, a DRC Commissioner and life-long campaigner for civil rights, is one such person. On two occasions during a recent spell in hospital, consultants made the assumption that she would not want to be put on a ventilator should the need arise. She felt so unsafe that she reports being afraid to sleep in case her life was not protected, and she made sure that either her partner or her Personal Assistant were with her at all times.
- A case reported in 1995 in the Disability Rights Task force report *'From Exclusion to Inclusion'*<sup>26</sup>. "A Company director with spinal muscular atrophy, who is also a qualified solicitor, was admitted to hospital with a chest infection. To her horror she found a doctor had placed a 'Do Not Resuscitate' notice on her medical notes because it was considered that her quality of life did not warrant such intervention."

3.28 Occasionally a case reaches the public domain. One such case (reported in Telegraph News online (*Filed: 07/10/2003*) By Celia Hall, Medical Editor) showed that doctors did not follow guidelines when there was a disagreement with the family of a patient on whether to withhold or withdraw treatment.

"A hospital was ordered to feed a 91-year-old woman last night after her family went to a High Court judge, claiming she was being left to die. The injunction forces the Norfolk and Norwich University Hospital to re-start the patient's nutrition and hydration, but any decision to give her medication was left at the discretion of the doctors. Olive Nockels, from Holt, Norfolk, a former school matron, has been in hospital for three and a half weeks. She was re-admitted after her condition deteriorated at the convalescent home she had been sent to following surgery for a broken hip. Her grandson, Chris West, 32, said yesterday that the hospital had stopped feeding and

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<sup>26</sup> *'From Exclusion to Inclusion'* Disability Rights Task force London 1995

treating her, against his and his mother's wishes. While his mother, Ivy West, waited at the bedside, Mr West sought legal help. Three years ago, the British Medical Association issued new guidelines about "end of life decisions". Any "active and intentional" termination of a patient's life is illegal. However the guidelines say: "Medical treatment can be legally and ethically withdrawn when it is futile, in that it cannot accomplish any improvement, when it would not be in the patient's best interest to continue treatment or when the patient has refused further treatment." Doctors are advised to have full discussions with family members and to seek a second opinion in the case where they do not want to continue treatment. But ultimately the doctor has the right to make the final decision, in the best interests of the patient. Where there is an argument with a family, the BMA advises doctors to seek the advice of the Official Solicitor."

3.29 It is impossible at present to quantify how widespread discrimination is, in relation to disability, in withholding or withdrawing treatment cases. The cases that have come to light have been through, for example, an individual or their family asking to see the patient's notes. There has been no national mechanism for systematically monitoring policy and practice in relation to disabled people.

3.30 However, recently introduced reviews by the Commission for Health Improvement have shown that, where policy and practice regarding Do Not Resuscitate (DNR) decisions have been reviewed, in the majority of cases they are poor. Despite progress in these areas, such as national NHS guidance on DNR<sup>27</sup>, there is growing evidence that such discrimination is still occurring, as new cases continue to be reported. For example, in relation to older people (a large portion of the disabled population) Age Concern England report that, within two days of highlighting DNR decisions being made without the involvement of older patients or their relatives, they received over 100 allegations of discriminatory practice.

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<sup>27</sup> NHS Executive – Health Service Circular HSC 2000/028 Resuscitation Policy

3.31 Although some breaches of regulations are detected and addressed, for instance through the Courts, there is a fear that many others are likely to be missed. Not every family will confront medical decision-making. Moreover, the guidelines that doctors use still emphasise 'quality of life' as a criterion for giving or withholding treatment; and the measure of QALYs (years of quality life remaining), used to determine decisions about who is highest priority for treatment, risk institutionalising the practice of deeming disabled people's quality of life lesser than that of non-disabled people.

3.32 It could be argued that institutional discrimination against disabled people in the health services needs to be eradicated before it would be safe to legalise euthanasia. Otherwise systems, procedures and clinical decision-making are likely to entrench differential treatment of disabled people at the most crucial life and death moments.

### **Attitudes of the judiciary and court decisions**

3.33 The language used in legal decisions to describe impairment and life with a disability reveal an institutional discomfort with disability. There is a very strong presumption that life with a disability is a lesser life that, even when tolerable, is tragic or regrettable. Legal decisions reinforce the notion that some people are too disabled to merit treatment, or sustain life and rely on explicit 'quality of life' assessments, largely by medical professionals, to determine what that is.

3.34 Starting in 1981, in a series of cases involving individuals deemed not legally competent to make their own decision, the courts have developed a test in which it is only acceptable to deny life-saving treatment where the individual is terminally ill or where their life is going to be 'demonstrably awful', 'full of suffering', or 'intolerable'. [*In Re B*]. The law rules that the impact of some people's disabilities are so serious that it is in their 'best interests' - and therefore lawful - to withhold life saving treatment. This will apply even where the individual is "neither on the point of death or dying." (*Re J (a minor)*(wardship: medical treatment). Put bluntly, say campaigners, the law regards some people, including some young children, as better off dead.

- In 1999 an eighteen-month-old child, ('Baby C'), with Spinal Muscular Atrophy (SMA) was denied ventilation to help her through her chest infection. It was deemed her "disability was too terrible to live a quality life". In addition she would need "total bodily care for the rest of her life" and this would be a "burden on state resources and family support"<sup>28</sup>. The family did not accept this decision and took the hospital to court. The judge ruled for the hospital having received advice from a range of doctors, who all categorically stated that no-one with this diagnosis could live beyond the age of 2 and that if they did, life would be a living hell. The baby died as a result of being denied the health care offered routinely to non-disabled babies with severe chest problems. The judgement relied on medical opinion, but medical professionals acknowledge that prognosis is not an exact science. For example Jane Campbell refutes their conclusion. She has SMA, is in her early forties, and is currently Chair of the Social Care Institute of Excellence (SCIE).

3.35 Opponents of legalisation claim that the discriminatory attitudes of some members of the judiciary is made clear when perpetrators of so-called 'mercy killing' go unpunished by the courts. Such actions they claim support and reinforce society's prejudice that the lives of disabled people are of less value than the lives of non-disabled people. Two examples reported in the press illustrate this:

1. In 2002 a man who beat his wife and severely disabled daughter to death with an axe walked free from court. Judge Sir Rhys Davies accepted that dad-of-six acted in desperation to end their suffering. Manchester Crown Court heard that Frank and his wife had devoted their lives to caring for their daughter aged 33 who was virtually wheelchair bound because of physical and mental problems. As they grew older Frank realised that Fiona might have to go into a home and be sedated. He decided the only way his wife and daughter would finally be at peace was to kill them. He waited until they slept at home,

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<sup>28</sup> Daw R, *The Impact of the Human Rights Act on Disabled People*, Report prepared for DRC & RNID 2000

whispered he loved them, and then killed them. "It was my way of solving the problem," he told police. I loved them to bits and wanted them to be at peace." He wept as he was freed after admitting manslaughter on grounds of diminished responsibility. The judge jailed him for nine months but he was released because he had been in jail since May.

2. In April 2000 James Lawson killed his daughter Sarah. She was 22 years old. Sarah had a diagnosis of manic depression and had previously tried to kill herself. According to press reports he spent two hours talking to her about her desire to end her life, after which he helped her to take an overdose of pills then lay down beside her and waited for her to die. But she did not die. So he got a plastic bag, put it over her head, then pressed a pillow down on her face and suffocated her. James Lawson walked free receiving only a suspended sentence and two years probation.

#### **4. Why are some disabled people calling for legalisation of euthanasia and assisted suicide?**

4.1 Currently Lisa Cook is campaigning for the legalisation of euthanasia. She has been diagnosed with Huntingdon's disease, an inherited genetic disorder of the central nervous system. Most commonly people develop symptoms in the 30 to 50 age group and this leads to a 10 to 15 year very slow decline. She has described how she has seen sufferers and generations of her family endure this very long and slow decline. "They have gone from being busy, lively, active, entertaining, well loved people to being twitching, bedridden, doubly incontinent, lonely, skeletal, incoherent shadows of their former selves." (The Moral Maze Radio 4 on 29 January 2003.)

4.2 Disabled people like Dianne Pretty, Reginald Crew and Lisa Cook, want to be able to choose when to die and they want to be able to receive assistance to die from somebody else without that person being liable to criminal prosecution.

4.3 Dianne Pretty was living a life she found undignified, and feared her life would end painfully choking to death, and she wanted to choose assisted suicide before that point was reached. She spent the last months of her life fighting for this choice. Reginald Crew had to undertake a difficult journey away from his home and country (to Switzerland), when he was seriously ill, to get the help to die that he wanted.

4.4 Lisa Cook firmly believes that the degradation and indignity that this condition imposes is of greater concern than death itself, and the law needs to be changed to allow her and the many others like her the chance to choose a dignified death. She said “the current law denies terminally ill people choice and dignity and fails to treat them as equals or respect their wishes. The law in this country at the moment puts me in the awful situation where I would have to take my own life if I decided not to go on with the illness, have to take my own life when I’m still physically able to do that. If I had the comfort and knowledge that I could have a medically assisted death at a time later on then I would go further on into my illness, possibly for another five or ten years, and be there for my family during that time.” (The Moral Maze Radio 4 on 29 January 2003.)

4.5 Thus it is argued legalisation of euthanasia would allow people in intolerable pain, or suffering what they would consider intolerable indignity - for example, the ramifications of incontinence or reliance on others for intimate personal care - to die at a time of their choosing. People with progressive conditions, could choose to live as long as possible rather than having to take their own life while they are still physically able to do so. They would be able to choose a dignified life and a peaceful, painless death. It would uphold the principle of autonomy which is central to the disability movement. Knowing that they could end their life when it became unbearable would relieve anxiety and enhance their enjoyment of the life they have left, even if they eventually choose not to go ahead with euthanasia.

4.6 It has been argued that, since non-disabled people are able to take their own lives, that to deny this choice to disabled people who are physically incapable of suicide is discrimination. Indeed it is argued that decriminalisation of suicide gave people who can

take their own life a right to die, and disabled people should have the same right. The DRC commissioned report from Glasgow University concludes that there is no right to die only a right to live.

4.7 Supporters of legalisation cite research that they say shows that involuntary euthanasia is worse in countries where euthanasia is not legalized. The research found that the incidence in Belgium and in Australia, where there is no legislation, was 3.2 per cent<sup>29</sup> and 3.5 per cent<sup>30</sup> of all deaths respectively, compared with 0.7 per cent in the Netherlands where there is legislation.<sup>31</sup> Supporters of legislation say this proves that legislation would offer more protection to vulnerable people than is currently the case.

4.8 They say that we do not know the real extent of secretive euthanasia in the UK. They quote a British Medical Association news review survey from 1996, of more than 750 GPs and hospital doctors, which found that 3 per cent of the doctors had ended the life of a terminally ill patient where the patient had made a request for help to die. This proves, they say, that in the UK many lives of patients are being ended with or without their consent, but there are only a handful of prosecutions each year. It demonstrates that there is a large gap between what the law says and what happens in practice. They say that while there can only be speculation about the number of such cases, it is clear that such a practice should be properly controlled.

4.9 The Voluntary Euthanasia Society (VES), argues that in the current legal framework, the fact that there is no regulation regarding assisted dying, leaves many genuinely vulnerable people unprotected - not legislating prevents proper regulation of what currently takes place anyway. It would surely be better, VES argues, to have a clear and unambiguous legal framework to enable terminally ill people to be able to ask for medical help to die, within strict safeguards.

<sup>29</sup> L. Deliens et al., "End-of-life Decisions in Medical Practice in Flanders, Belgium: a Nationwide Survey" 365 *The Lancet* 1806, 2000.

<sup>30</sup> H. Kuhse et al., "End-of-life Decisions in Australian Medical practice" (1997) 166 *Medical Journal of Australia* 191.

<sup>31</sup> G. van der Wal et al., "Euthanasia, Physician-Assisted Suicide, and other Medical Practices involving the End of Life in the Netherlands" 335 *New England Journal of Medicine* 1699, 1996

## **5. Is the threat to some disabled people sufficient to override the rights of others? Can choice be denied to people who are well informed and well supported, and who make a valid decision that they wish to end their lives?**

5.1 It has been argued by the Voluntary Euthanasia Society (VES) that the DRC's holding statement discriminates against people with cancer and Motor Neurone Disease (MND). However the DRC has a responsibility towards all disabled people, including people with cancer and MND who do not want to die, and others who want to choose the time and manner of their death but who are unable to do so.

5.2 Both the House of Lords<sup>32</sup> and the European Court of Human Rights (ECHR)<sup>33</sup>, in their deliberations of the Dianne Pretty case, ruled that legalization of assisted suicide posed a serious threat to the lives of vulnerable people, and that therefore it was legitimate to override her right to choose the manner and time of her death.

5.3 This view has been questioned by, for example, Dan Morris in a critique of the Dianne Pretty case<sup>34</sup>.

5.3.1 He reports that the ECHR ruled that the prohibition on assisted suicide does interfere with the respect for private life under Article 8(1). However under para.2 of Art.8, even if an individual is able to show that his claim engages the right to respect for private life, member States may still legitimately interfere with this right provided certain requirements are met including "for the protection of the rights and freedoms of others." Morris reports that interference by a State has to be "proportionate to the legitimate aim pursued". In *Pretty* the state aim pursued was that of protecting "the rights and freedom of others": the problem, it was thought, was that if assisted suicide were permitted by the

<sup>32</sup> R. (Pretty) v DPP and Secretary for the Home Department (2001) UKHL 61; (2001) 3 W.L.R. 1598; (2002) 1 A11 E.R. 1. As argued by Dan Morris, "Assisted Suicide under the European Convention on Human Rights: a Critique", (2003) 65 E.H.R.L.R Issue 1, 91

<sup>33</sup> *Pretty v United Kingdom* App. No.2346/02, April 29, 2002.

<sup>34</sup> Dan Morris, "Assisted Suicide under the European Convention on Human Rights: a Critique", 65 E.H.R.L.R Issue 1, 91, 2003

State, this would endanger the lives of the elderly and the vulnerable.

5.3.2 Morris argues that in this case the burden on the State to justify interference under Art.8 para.2 should be particularly heavy. He asserts that “What it should have to show is that the infringement is so necessary that it is worth not only interfering with an individual’s right to choose how he passes the closing stages of his life, but also that it is worth interfering with everything else he has done throughout his life to assert and define his own meaningful and lucid sense of self.” He agrees that the State interest in protecting elderly and vulnerable individuals is undoubtedly an extremely important one – “it is the only one which could even come close to off-setting the weight of the interest in determining the timing and manner of death.” However he quotes Harris et al.<sup>35</sup> that “the proportionality requirement is not satisfied where the government does not provide evidence to show that the claim of necessity (is) made out.”

5.3.3 Morris cites the two early reports from the Netherlands<sup>36</sup> and the studies from Australia and Belgium, together with known practices of “double-effect” and “omission” of treatment in this country, to support his assertion that this casts doubt on the finding of the ECHR that “clear risks of abuse do exist”. In addition he argues, “if the threat to the vulnerable can be dealt with by less general means than a blanket prescription, then this is what the state must do.”

5.3.4 Also, he reports, “... in any assessment of proportionality, courts should take into account the body of consensus amongst other Convention states.”<sup>37</sup> At the time of the Lords ruling on *Pretty* only the Netherlands and Switzerland had permissive practices regarding euthanasia. However Belgium has recently introduced legislation and Holland introduced new legislation in 2001.

<sup>35</sup> D. Harris et al., *Law of the European Convention on Human Rights* (London: Butterworths, (1995), p.3000, citing the case of *Kokkinakis v Greece* (1993) Eur. Court H.R., Series A No.260, para.49.

<sup>36</sup> Griffiths et al, *Euthanasia and Law in the Netherlands*, Amsterdam University Press, Amsterdam, 1998

<sup>37</sup> *R. (Pretty) v DPP and Secretary of State for the Home Department* (2001) UKHL61; (2001) 3 W.L.R. 1598; (2002) 1 A11 E.R. 1. para.28.

5.3.5 Finally he challenges the Court's analysis of the proportionality question, which he says it can be argued, is open to criticism. He concludes, "On a thorough analysis of the variables affecting proportionality, it is difficult – perhaps even impossible – to see how it can be concluded that s.2(1) of the Suicide Act is necessary in a democratic society. An outright prohibition of assisted suicide is not necessary for the aims which the state is seeking to achieve. As the Dutch experience shows, the risk to the vulnerable can be guarded against by regulation rather than outright criminalization."

5.4 Morris' arguments against the court's decision rest on his belief that the threat is not sufficiently proved or weighty. He uses the Netherlands research to support his claim, plus he believes that the lives of vulnerable people can be protected in other ways. The implication of his arguments is that the onus is on those opposing the legalisation of euthanasia is to provide evidence of a real and significant threat to others. Both courts obviously felt there was sufficient threat and stated, "Clear risks of abuse do exist."

## **6. Might it be possible to frame legislation and regulation to allow some disabled or terminally ill people assistance to die, whilst safeguarding the lives of others from involuntary euthanasia?**

6.1 There is a body of opinion internationally that legalisation of euthanasia would pose a serious threat to some disabled people. This includes the New York State Task Force on Life and the Law (1994) and the House of Lords Select Committee on euthanasia (1994), both of which undertook very thorough evidence gathering and analysis. Both concluded that to legalise euthanasia would pose a real and substantial threat to others who did not wish to die. The European Court of Human Rights (see paragraph 4) came to the same conclusion.

6.2 In May 1994, the New York State Task Force on Life and the Law, published a 217 page report titled "When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context". The members of the Task Force (comprising leading ethicists, medical practitioners, and legal experts) hold different views about the ethical acceptability of assisted suicide and euthanasia. These

views range from those opposed on religious grounds, to those who believe it would uphold the right to autonomy of the individual. Despite these differences, the Task Force members unanimously recommend that existing law should not be changed to permit these practices (assisted suicide and voluntary euthanasia). The members concluded that legalizing assisted suicide would be unwise and dangerous public policy.

### 6.3 They made the following recommendation,

"In this report, we unanimously recommend that New York laws prohibiting assisted suicide and euthanasia should not be changed.

... Assisted suicide and euthanasia would carry us into new terrain, American society has never sanctioned assisted suicide or mercy killing. We believe that the practices would be profoundly dangerous for large segments of the population, especially in light of the widespread failure of American medicine to treat pain adequately or to diagnose and treat depression in many cases. The risks would extend to all individuals who are ill. They would be most severe for those whose autonomy and well-being are already compromised by poverty, lack of access to good medical care, or membership in a stigmatized social group. The risks of legalizing assisted suicide and euthanasia for these individuals, in a health care system and society that cannot effectively protect against the impact of inadequate resources and ingrained social disadvantage, are likely to be extraordinary. ...

### 6.4 In 1994, the House of Lords Select Committee (again made up of leading ethicists, medical practitioners and legal experts) on euthanasia, reported that,

"it was virtually impossible to ensure that all acts of euthanasia are truly voluntary and that any liberalisation of the law in the United Kingdom could be abused". After extensive research, and the hearing of much evidence the committee regarded the present law as, "the cornerstone of law and of social relationships. It protects each one of us

impartially, embodying the belief that all are equal. Dying is not only a personal or individual affair. The death of a person affects the lives of others, often in ways and to an extent which cannot be foreseen. We believe the issue of euthanasia is one in which the interest of the individual cannot be separated from the interests of society as a whole".

6.5 The committee felt that it was impossible safely to legislate in this area so as to introduce proper safeguards. "We believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life". However two members of that committee, Baroness Jay, and Baroness Warnock, now say they hold different views.

### **Is legislation working in those countries which have adopted it?**

6.6 The picture regarding the law on euthanasia and assisted suicide, from around the world, is complicated. It is often not covered by specific legislation, but is bound up with criminal law. In some countries it is not unlawful to assist someone to die, e.g. Switzerland. In others, although covered by the criminal law, the fact that it often goes unpunished legitimises its practice. Holland, Belgium and Oregon have introduced specific legislation. Other countries have in the recent past, or are currently, debating the introduction of legislation including Australia, New Zealand, Guernsey and France.

6.7 The emerging picture is that there is no one agreed definition of who should be covered by such legislation, and regulation is based on a set of procedures that must be followed, and relies on doctors self-reporting.

6.8 The culture, demography, economic and political environment in each country has influenced the decision on whether or not to legislate, and could have a profound influence on the effectiveness of safeguards and regulation. For example in America, access to healthcare including pain relief is limited for those who are neither on Medicaid (the health insurance for the poorest Americans) nor able to afford to pay for themselves. In the Netherlands palliative

care, including pain relief, was rarely available but this has now improved.

6.9 The evidence from the Netherlands and Oregon on how the legislation is working, and whether it is free from abuse, is equivocal. It has been used to support arguments both for and against legislation. (see Appendix A)

6.10 Evidence from the Netherlands shows that in 2002 only 54% of cases of euthanasia were reported. Also, despite clear guidelines, and the fact that it is unlawful, doctors are still carrying out involuntary euthanasia. Even when the 0.7 per cent of involuntary euthanasia cases in the Netherlands are broken down, there were a number of patients assisted to die for whom there is no indication that euthanasia would be their wish, and with no consultation either with colleagues or family, in the decision making process. Evidence from Oregon indicates that in general doctors had not made themselves aware of the legislation, including doctors who had written scripts who had no idea of what was or was not allowed and who was to be included.

### **What safeguards are needed if legislation is to proceed?**

6.11 Whatever the situation in other countries we need to consider whether it would be possible in this country to build sufficient safeguards into legislation to prevent abuse. If not then this would be a strong argument against legislation.

6.12 There are a number of fundamental issues that would need to be resolved before legislation could be framed. For example there is currently no agreement on who should be covered by such legislation.

6.13 Some argue that it should be confined to a tight group of those in the final stages of terminal illness and suffering unbearably, not static physical impairment or ongoing mental illness. However there are difficulties in defining what this means. One approach would be to list the conditions covered, but what is a terminal illness this year may not be the next. For example AIDS was a terminal illness but a cure has been found for many. Some disabled people are diagnosed as having a terminal illness from the day they are born and could therefore find themselves covered

by the legislation. Diagnosis and prognosis of conditions and length of life are not an exact science, and doctors are the first to admit that they can get it wrong. People can go on to live for years after being diagnosed as having a few months to live.

6.14 Others have proposed that it should be those who are physically unable to take their own lives, yet others have suggested that every citizen should have the right to legalised euthanasia. They say to confine it to one group is in itself discriminatory.

6.15 Another difficulty that needs to be overcome is that regulatory controls must rely on doctors self-reporting, and on the second opinion of medical colleagues. This approach has been questioned by medical practitioners including Dr Anthony Cole in a paper given at a meeting in the House of Lords chaired by Baroness Masham of Ilton, on 5th November 2002 on behalf of the Medical Ethics Alliance: "Doctors will know full well that there are second opinions and second opinions. It is not difficult to get a concurring opinion by asking the "right" doctor. If anyone doubts this they need only look at the working of the Abortion Law where a similar requirement exists. It is almost unknown for a second doctor to disagree over an abortion. That is not because all doctors agree on abortion, but that one doctor will naturally seek out the opinion of a colleague who will agree with him or her."

6.16 The same point has been argued by Mind in relation to Second Opinion Appointed Doctors under the Mental Health Act 1983: the incidence of disagreement between first and second opinion is so small that it may be questioned whether a system of second opinions really does provide a safeguard.

6.17 It has been suggested that there may be ways to enable people to choose assistance to die other than a specific Act to legalise euthanasia. For example, it has been suggested that perhaps the way that case law had been used initially in the Netherlands as a way of defining what was acceptable, with doctors under threat of the law if they acted unlawfully, would be a way to go rather than introducing actual legislation. But alternatively it has been argued that although it may seem a good idea for people to act 'under the shadow of the law', to know they

may be charged with murder, ultimately it will be judges and juries who will interpret case law and they may do so in line with current prejudices. There could be similar problems in a system where all cases would go to the Courts for final decision.

## 7. Conclusion

The DRC is committed to the principle of autonomy for disabled people. Individual disabled people should therefore, be able to make autonomous choices, in the same way as non-disabled people, including potentially choosing the manner and time of their death. The DRC therefore does not oppose, in principle, legalisation of euthanasia for competent adults who freely choose it.

However, we believe that in the current climate of discrimination against disabled people, where a lack of access to palliative care and social support means that free choice does not really exist, the threat to the lives of disabled people posed by such legislation is real and significant. We, therefore, cannot currently support legalisation of euthanasia.

**APPENDIX A****Evidence of how legislation works in practice****The Netherlands**

1. Dutch law regarding euthanasia and physician assisted suicide has been evolving since the 1960's when public interest in the subject increased. These remained criminal acts under articles 293 and 294 of the Criminal Code until 2002 when new legislation was introduced. However since 1974 the courts have accepted the defence that, a doctor confronted by the request for euthanasia or assistance with suicide from a patient who is unbearably and hopelessly suffering, can be regarded as caught in a situation of conflict of duties. There is the duty to respect life as formulated in Articles 293 and 294 and the duty of a doctor to reduce suffering and to respect the autonomy of the patient. Where there is a conflict of duties and the doctor chooses a course of action that, considering the norms of medical ethics, is "objectively justifiable" the Courts can find the doctor not guilty under Articles 293 and 294.

2. Case law has developed over the years defining the requirements that must be met to be able to claim this defence. Case law has helped to define terms such as 'hopeless necessity' and 'unbearable suffering' which has lead to the inclusion of patients multiple sclerosis, depression and untreatable mental illness.

3. In 2002 the Dutch Termination of Life on Request and Assisted Suicide (Review Procedure) Act came into being. Under this law, euthanasia and assisted suicide are still criminal offences, but the penal code has been amended to exempt doctors from criminal liability if they report their actions and show they have satisfied the requirements for prudent practice. Most important requirements include 'unbearable and hopeless suffering', voluntary and persistent and well considered request, consultation, written reporting of the decisions, and notification. The majority of cases that have gone to court have centred on whether procedures laid down in legislation have been followed. If a doctor does not follow procedures then he could be prosecuted and subject to a period of

imprisonment. The system however relies on a process of self-reporting of euthanasia and assisted suicide by doctors.

4. In the eyes of some this slowly evolving case law and subsequent legislation has been to the good, clarifying what is acceptable and what is not, and putting regulation in place. Others however argue that the court guidelines have progressively loosened the law to allow physicians to kill a wider and wider range of people e.g. allowing euthanasia for patients with depression and non-terminal illness. However others argue that the law has never been restricted to people who are terminally ill. Therefore the argument that the Netherlands can be held up as an example of the 'slippery slope' where more and more people are being covered by legislation that should have been restricted to people who are terminally ill, does not hold up.

5. The Dutch government has commissioned three surveys on voluntary euthanasia and assisted suicide, known as the Remmelink reports.<sup>38</sup> The latest report was released in May 2003 and is currently not available in English, though some of the findings have been released in English. It is these reports that are widely quoted in the arguments for and against legalisation.

5.1 Those against legislation quote from the research:

- It relies on self-reporting by doctors and the latest report on practice in 2002 - new legislation came into force in April 2002 - shows that doctors admit they only reported 54% of cases of euthanasia. This compares to 18% in 1990 and 41% in 1995.<sup>39</sup> The 1995 research concluded that, "the low percentage of reported euthanasia deaths was because doctors wished to avoid the administrative hassle of reporting a euthanasia case and were concerned they might have breached the regulations".

<sup>38</sup> Remmelink reports, Health Policy Special Issue, Vol. 22/1+2, 1992, Elsevier, Netherlands, Euthanasia and other medical decisions concerning the end of life: An investigation performed upon the request of the Commission of enquiry into the Medical practice concerning euthanasia, PJ van der Maas et al

<sup>39</sup> Remmelink reports, Health Policy Special Issue, Vol. 22/1+2, 1992, Elsevier, Netherlands, Euthanasia and other medical decisions concerning the end of life: An investigation performed upon the request of the Commission of enquiry into the Medical practice concerning euthanasia, PJ van der Maas et al

- Problematic cases are much less likely to be reported and in their reporting doctors make cases appear legally more clear-cut than they actually are.<sup>40</sup>
- In 1990, 1000 cases (.8% of all deaths) were without explicit request of the patient, in 1995, there were 900 such cases<sup>41</sup> (.7% of all deaths), and in 2002 (following the introduction of specific legislation on euthanasia) one in four (900) cases of euthanasia were without the patient's explicit request.<sup>42</sup> Those against legislation say that this proves that legalisation leads to a 'slippery slope' from voluntary euthanasia to involuntary euthanasia and unwanted killing. Even when this is broken down, there are a significant number of patients for whom there is no indication that that would be their wish, with no consultation either with colleagues or family in the decision making process. ANY death without explicit request is totally unacceptable.
- In addition there were, in 1990, 22,500 and in 1995, 25100 cases of death related to administration of pain relief medication; and in 1990, 22,500 and in 1995, 27,100 cases of death due to abstinence from treatment<sup>43</sup>.
- A follow-up survey, to the 1995 report, found that the main reason for not consulting patients was that they had dementia or were otherwise not competent. But in 15 percent of cases the doctors avoided any discussion because they thought they were acting in the patient's best interests.
- There is no evidence from the Dutch experience compliance is improving all that dramatically. The bottom line is that anything less than 100% compliance around issues of death and dying are unacceptable.

5.2 Dr Peter Hilldering, president of the Netherlands Physician League, disagrees with the argument that legislation will lead to a regulated and transparent system. "In Holland our legislation was made originally at the request of doctors who saw suffering they

<sup>40</sup> Euthanasia and Law in the Netherlands, Griffiths et al, 1998, Amsterdam University Press, Amsterdam

<sup>41</sup> Rummelink reports, Health Policy Special Issue, Vol. 22/1+2, 1992, Elsevier, Netherlands, Euthanasia and other medical decisions concerning the end of life: An investigation performed upon the request of the Commission of enquiry into the Medical practice concerning euthanasia, PJ van der Maas et al

<sup>42</sup> *ibid*

<sup>43</sup> *ibid*

could not cope with – patients for whose suffering there was no relief”. But in Holland he says, many cases of euthanasia are not because of unbearable pain. Often, waiting lists and family pressures play a part in the decision to die. So transparency would not be achieved by making euthanasia legal, only by investigating every death – which is not feasible.<sup>44</sup>

### 5.3 Supporters of legalising euthanasia say the research shows that regulation is working:

- The figures on euthanasia without explicit request - 0.7 per cent of total deaths - were steady, with no evidence of any increase whatever.
- The number of deaths due to euthanasia is not increasing significantly and patients such as children, elderly patients and patients with dementia are rarely involved.<sup>45</sup> Thus proving that there is no ‘slippery slope’.
- They quote the same findings as anti-legislation supporters saying that it supports their case. That is, that although regulation depends on self-reporting by doctors, in 2002 54% of cases of euthanasia were reported. This compares to 18% in 1990 and 41% in 1995.<sup>46</sup> They say this shows that regulation is working and bringing practice out into the open.
- They assert that the research shows that there are many reasons for not reporting which are not sinister, including not wishing to expose the families to unnecessary investigations by police at a particularly difficult time. It is argued therefore that regulation by a means other than criminal sanctions could improve regulation.<sup>47</sup> Also in the 1991 report the researchers say that in more than half of the cases the decision had been discussed with the patient and the patient had previously expressed a wish for euthanasia should suffering become

<sup>44</sup> The Tablet 17 May 2003 ‘*Battle over euthanasia*’

<sup>45</sup> Rummelink reports, Health Policy Special Issue, Vol. 22/1+2, 1992, Elsevier, Netherlands, Euthanasia and other medical decisions concerning the end of life: An investigation performed upon the request of the Commission of enquiry into the Medical practice concerning euthanasia, PJ van der Maas et al

<sup>46</sup> Rummelink reports, Health Policy Special Issue, Vol. 22/1+2, 1992, Elsevier, Netherlands, Euthanasia and other medical decisions concerning the end of life: An investigation performed upon the request of the Commission of enquiry into the Medical practice concerning euthanasia, PJ van der Maas et al

<sup>47</sup> Euthanasia and Law in the Netherlands, Griffiths et al, 1998, Amsterdam University Press, Amsterdam

unbearable. In other cases the patients were near to death and clearly suffering but contact had become impossible. Nearly always, in these cases, the family, nurses or more than one colleague had been consulted before proceeding with euthanasia.

## Oregon

6. The Oregon Death with Dignity Act enacted in 1997 legalised physician-assisted suicide by allowing a physician to prescribe a lethal dose of medication for a mentally competent, terminally ill patient for the purpose of self-administration. 'Terminally ill' is defined as a prognosis of less than 6 months to live.

7. Concerns have been raised in Oregon where initial trends supported the view that less care is being taken in the process to assisted suicide. In February 2001, the Oregon Health Division survey<sup>48</sup> showed that people requesting to die being offered psychological help was going down.

- Doctor referred the patient for psychological evaluation down from 37% 1999 to 19% 2000 and to 14% in 2001.

The time to reconsider was shortening - but this went up to 54 days in 2001.

- Median time between a patient's initial request for assisted suicide and his or her death by overdose was down from 83 days 1999 to 30 days 2000.

The reports also show that people are choosing to die because they feel they are a burden.

- Assisted suicide patients who cited fear of being a "burden on family friends or care-givers" as a reason for their suicide was 26% 1999, 63% 2000 and 24% in 2001.<sup>49</sup>

<sup>48</sup> Oregon Death with Dignity Act Annual Reports from Oregon Department of Human Resources <http://www.ohd.hr.state.or.us/chs/pas/year1/ar-index.cfm>

<sup>49</sup> Second, Third and Fourth Annual Reports on Oregon's Death with Dignity Act, Oregon Department of Human Services, Office of Disease Prevention and Epidemiology, February 2000, 2001, 2002

8. On the other hand others maintain that the Oregon reports show that:

- Numbers of people receiving euthanasia and assisted suicide are not growing, and this is evidence against the 'slippery slope' argument.
- Many people given a prescription for drugs to commit suicide do not use the medication.<sup>50</sup> Supporters say that knowing that they have the means to end their lives if they wish gives them comfort.

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<sup>50</sup> Second, Third and Fourth Annual Reports on Oregon's Death with Dignity Act, Oregon Department of Human Services, Office of Disease Prevention and Epidemiology, February 2000, 2001, 2002

