

SUBMISSION TO
THE VOLUNTARY EUTHANASIA SELECT
COMMITTEE
HOUSE OF KEYS
ISLE OF MAN

From

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1. INTRODUCTION

This evidence is submitted on behalf of No Less Human, a group within the Society for the Protection of Unborn Children for disabled people, their families and carers. No Less Human (NLH) campaigns to secure in law the equal right to life of every disabled person, from conception to natural death.

This submission seeks to demonstrate that legalising euthanasia on the Isle of Man would compromise the right to life of disabled and sick people, and further undermine their dignity and status. NLH holds to the truth that it is fundamentally wrong to kill vulnerable people, whether or not they have requested death.

NLH asks the Committee to take account of the fact that illness and disability should not be used to justify deliberate killing, and that those who are terminally ill or incurably disabled should be treated using the same ethical code as would be applied to any other person.

2. THE QUESTION OF AUTONOMY

2.1 The case for euthanasia is often argued on the basis of the concept of autonomy, that is, the person's freedom to make decisions about his or her own treatment. However, to use autonomy as an argument for allowing "voluntary" euthanasia involves a misunderstanding of the concept, overlooking the principle that the freedom to make decisions entails a responsibility to act ethically. Personal autonomy should be regarded as a "right" only when it is exercised responsibly in the best interests of the individual concerned.

2.2 "Best interests" are generally understood, as is reflected in case law,¹ to include basic factors such as preserving life, maintaining or restoring health and minimising suffering. In recent years the interpretation of "best interests" has begun to be extended to include the "wishes and feelings" of the individual concerned,² but this is problematic for many reasons.

2.3 Not least of these reasons is the case of suicidally depressed people. They "wish" to die and "feel" that death is in their best interests, but any doctor worthy of his or her profession would nevertheless overrule these wishes and feelings and institute treatment to save and/or sustain the life of such a person. In the same way even if a patient strongly "feels" that a particular drug would benefit him and "wishes" it to be prescribed, a doctor should prescribe it only if s/he feels it will actually benefit his patient's medical condition. Relying on "wishes and feelings" suggests that life is not a basic good unless the individual recognises it as such. Similarly, relying on a subjective estimation of a person's "quality of life" is not compatible with ethical medicine.

¹ *Re F* (Mental Patient: Sterilisation) [1990] 2 AC1, 78

² *Withholding and withdrawing life-prolonging treatments: good practice in decision making*: Draft guidance from the Standards Committee of the General Medical Council May 2001; *Withholding or Withdrawing Life-prolonging Medical Treatment: Guidance for decision making*. British Medical Association. BMJ books 1999; *Draft Mental Incapacity Bill*. Presented to Parliament by the Secretary of State for Constitutional Affairs – June 2003

2.3 Doctors have a duty to act in the true best interests of their patients. This can never include deliberately killing them. This does not mean that No Less Human advocates the use of futile or disproportionately burdensome treatment, given in a vain attempt to prolong the process of dying, or that the process of dying should be artificially prolonged. Once it has been established that continued aggressive surgical or medical treatment is futile or excessively burdensome it may be stopped, and palliative care intensified.

2.4 This must never, however, be taken to mean that doctors, in the name of “beneficence” institute treatment regimens the purpose of which is to hasten death. Neither must it mean that doctors may cause the deaths of those who are *not* actually dying. Decisions about which treatments are futile or disproportionately burdensome, and who is irremediably dying are the proper realm of medical ethics. Decisions about whose “quality of life” is such that they are “better off dead” have no place in ethical medicine. Decisions to cause or hasten death masquerading as “beneficence” are unequivocally unethical, and are incompatible with the human rights and dignity of all vulnerable people.

2.5 If a doctor were to be involved in euthanasia (as would almost always be the case) s/he would have to agree that the patient was “better off dead” since one would hope that no doctor would kill a physically fit young person who was temporarily depressed. Thus the real autonomy would lie with the doctor, not the patient. Euthanasia would be seen as a duty where the doctor agreed that the patient was “better off dead”, and the doctor would be seen as negligent if s/he failed to perform euthanasia in these circumstances.

2.6 Legalising “voluntary” euthanasia” would suggest that some sorts of “volunteers” are “right to want to die” (i.e. have lives which are objectively not worth living) leading to a view that life for such people is a disbenefit whether or not they have actually requested euthanasia.

2.7 It is sometimes suggested that since attempted suicide is no longer punishable, assisted suicide should be allowed. However, the British Suicide Act 1961, whilst decriminalising attempted suicide, created no legal right to commit suicide, and made assisting suicide a serious criminal offence punishable by up to 14 years imprisonment.³ The debates on this Act show that the law was changed to show compassion to people who were so desperate they wanted to die, not to acknowledge that attempting suicide as either right or appropriate.

2.8 Relaxing the absolute prohibition on killing by euthanasia would undermine, not promote autonomy. In an attempt to exercise autonomy by requesting euthanasia, the person’s own autonomy would be forever destroyed.

³ Debate on the Suicide Act. Hansard. 19 July 1961. Cols. 1425-1426

3. THE RIGHT TO LIFE

3.1 Every human being has intrinsic, infinite value, and has an innate and inalienable right to life. The British Human Rights Act 1998 states “Everyone’s right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.”⁴ Without the right to life, all other rights become meaningless, including the right to personal autonomy.

3.2 The British Law Lords, in their ruling in the case of Dianne Pretty, ruled that this article means what it says. Lord Bingham of Cornhill commented that “The article protects the right to life and prevents the deliberate taking of life save in very narrowly defined circumstances. An article with that effect cannot be interpreted as conferring a right to die or to enlist the aid of another in bringing about one’s own death.”⁵

3.3 Pro euthanasia advocates often try to argue that if there is a “right to life” there must also be a corresponding “right to die.” This is not the case. The right to life is an inalienable right, a right of which an innocent person may not be deprived and which one cannot, in justice, intentionally deprive oneself of by intentionally bringing about one’s own death. This is true whether the killing is by commission or omission, and whether or not it is brought about for “merciful” reasons.

3.4 “Voluntary” euthanasia would intentionally deprive an innocent person of his or her life, and is thus always wrong. Allowing it would send out a strong message that some human beings have less worth and less dignity than others, and that some human lives have not only no value but a negative value – the opposite of the reality that every human being has innate and infinite value.

4. “SAFEGUARDS” TO A EUTHANASIA LAW WOULD ENSURE THAT THE MOST VULNERABLE ARE *NOT* SAFE

4.1 Euthanasia campaigners always suggest that any law to allow euthanasia should have what they term “strict safeguards” to prevent “abuse of the law.” Such supposed “safeguards” and criteria are suggested by legislators wishing to introduce euthanasia into countries where it is currently not legal, and are in place where euthanasia is legal^{6 7}

⁴ Human Rights Act 1998. Schedule 1, Part 1, Article 2 “Right to life.” 1. London. The Stationery Office.

⁵ House of Lords. Opinions of the Lords of Appeal for Judgment in the Cause: The Queen on the Application of Mrs. Dianne Pretty (Appellant) v. Director of Public Prosecutions (Respondent) and Secretary of State for the Home Department (Interested Party) on 29 November 2001 [2001] UKHL 61

⁶ House of Lords. Patient (Assisted Dying) Bill Second Reading debate. Lord Joffe Column 1590.

⁷ “Critically ill Britons seek Dutch euthanasia” by Roger Boyes. *The Times* 2 January 2002

These “safeguards” commonly require that a euthanasia request must be voluntary, “well-considered” and repeated over time, that the person must be terminally ill or incurably disabled, facing “interminable and unendurable suffering” and that doctors must agree that there is “no other reasonable solution.” Far from “safeguarding” anything, these requirements always in effect prescribe who is to be considered “right to want to die” and thus be helped to die. Those who may be equally suicidal but do not have obvious disabling conditions are considered “wrong to want to die” and are helped to live.

4.2 People considered “right to want to die” are those who the lawmakers, and usually society in general, consider “better off dead” – those with incurable disabilities or terminal illnesses. Such value judgments about the lives of vulnerable people are incompatible with their equal, innate and inalienable right to life.

4.4 It has been found that where euthanasia is legalised “with strict safeguards” such criteria are liable to be stretched or overlooked. Once it is decided that certain people are “better off dead” the fact that they might not have actually volunteered for euthanasia is not necessarily a safeguard against euthanasia being imposed upon them. For instance in Holland at least 900 people had their lives ended “without an explicit request” in 1995, the last year for which full figures are available, amounting to one in five or all reported euthanasia cases.⁸ In 22% of Dutch euthanasia cases there had been no “explicit request” by the person concerned, and 50% of those subjected to this killing without consent were competent at the time of their death.⁹ The single study yet published from Belgium, where euthanasia was legalised in May 2002 showed that 30% of euthanasia cases there were non-voluntary.¹⁰

4.3 In Holland where euthanasia was legalised in January 2002, it has been found the mentally disabled people are particularly vulnerable to euthanasia decisions. A study found that 44% of the deaths of such people living in institutions involved an “end of life decision” though only two of the 97 people concerned had “expressed a wish to die” – a “choice” which was inferred if the person pulled out a feeding tube.¹¹

4.4 Elderly Dutch people have also been vulnerable to the same sort of decision-making.¹² An 84 year old lady with heart problems and osteoporosis who said she did *not* want to die was killed by her doctor who said she was “wretched... her bed soaked in urine, her room stinking from bed ulcers and necrosis in her heel.” The court that tried this case said he had made an “error of judgment” but had “acted honourably and according to his conscience”¹³ What this lady needed was good nursing care, but she was killed because her doctor had a negative attitude towards suffering people.

⁸ H. Jochemsen & J. Keown. Voluntary euthanasia under control? Further empirical evidence from The Netherlands *Journal of Medical Ethics* 1999; 25: 16-21

⁹ Jochemsen & Keown Voluntary euthanasia under control? Ibid at p. 18.

¹⁰ L. Deliens, F. Mortier, J. Bilsen, M. Cosyns, S.R. Vander, J. Vanoverloop et al. End of life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet* 2000; 356: 1806-11

¹¹ G.M. Van Thiel et al. Retrospective study of doctors’ ‘end of life decisions’ in caring for mentally handicapped people in institutions in the Netherlands *BMJ* 12 July 1997; 315: 88-91

¹² T. Sheldon. Euthanasia endorsed in Dutch patient with dementia. *BMJ* 1999; 315: 327

¹³ T. Sheldon. Dutch GP found guilty of murder faces no penalty” *BMJ* 3 March 2001

4.5 Pro euthanasia advocates often suggest that depression would be a contra-indication for allowing euthanasia. However, this is not reflected in the criteria for euthanasia in either Holland or Belgium. Baroness Finlay of Llandaff has noted that 20% of medically ill patients have a treatable depression, but not all have their condition recognised or treated. Indeed one in four of the population has had a mental disorder at some time, and many of such people have experienced depression.¹⁴

4.7 The Bill being tabled in the British House of Lords by Lord Joffe, the latest attempt to make euthanasia legal in Britain, did not exclude depression from its terms. In fact it is notoriously difficult to assess treatable depression in those with advanced illnesses.¹⁵ In fact the will to live often fluctuates widely over the course of an illness or progressive disability, and often disappears when proper care and attention is paid to the person's fears, symptoms and emotional needs.¹⁶ Most depression can be treated in the right environment. Euthanasia merely suggests to the suffering person that s/he is right to feel there is no hope.

4.8 No "safeguards" can prevent "abuse" of a euthanasia law, because such a law is in itself an abuse of the inherent, inalienable right to life of vulnerable people.

5. THE QUESTION OF "DIGNITY."

5.1 The phrase "death with dignity" is very often used by those who want legalised euthanasia to mean the deliberately procured death of a vulnerable person. It implies that such people are only "dignified" in death. No Less Human strongly disagrees that this is the case.

5.2 In high profile cases in the media in Britain and in other countries of vulnerable people who wanted to die by euthanasia, it is consistently reported that they are requesting the right to "die with dignity" as if a natural death could not possibly be dignified.¹⁷ This highlights the terrible, and false, dilemma that is presented to vulnerable people. It is strongly suggested by the pro-euthanasia lobby that the choice is between euthanasia and an appallingly "undignified" painful death. This has particularly been the case in high profile cases involving people with Motor Neurone Disease.¹⁸ The truth is that with proper palliative care, including all necessary hospice support, the choice is between deliberate killing and a peaceful, truly dignified death made as pain free as possible by experts in pain control.^{19 20}

¹⁴ Debate on Mental Incapacity. House of Lords. Hansard. 18 December 2002. Column 765

¹⁵ D.W. Kissane & B.J. Kelly. Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian & New Zealand Journal of Psychiatry*. 34(2): 325-33

¹⁶ Yvonne Y.W. Mak et al Patients' voices are needed in debates on euthanasia. *BMJ* 2003; 327:213-215

¹⁷ "I helped my father die" by Jacqui Paterson. *Real* 25 March – 4 April 2003. The daughter of Reginald Crew, who had Motor Neurone Disease and was taken to the Dignitas Clinic in Switzerland for "assisted suicide" said after his death "He may have been stripped of dignity if life, but he got it back with his death."

¹⁸ "Farewell to wife who campaigned for right to die" by a Correspondent. *The Times* 24 May 2002. This article, reporting on the death of Dianne Pretty reported that choking and asphyxia are "often" caused by Motor Neurone Disease.

¹⁹ "The will is not to die but to flee" by Melanie Phillips. *The Observer*. 19 March 1995

5.2 Lord Justice Tuckey, in the British House of Lords judgment on the case of Dianne Pretty, who sought permission for her husband to help her die, said “In our view the right to human dignity which is enshrined in Article Three (of the Human Rights Act 1998) is not the right to die with dignity, but the right to live with as much dignity as can possibly be afforded until that life reaches its natural end.”²¹ No Less Human shares this view, and promotes the truth that vulnerable people have a right not to assisted death, but to support to enable them to *live* with dignity until they die naturally.

6. THE QUESTION OF PAIN

6.1 Fear of pain and suffering is a reason why many people feel that euthanasia should be legal. However, in Holland, even some doctors who practice euthanasia admit that pain is not the usual reason for euthanasia requests.²² In one study it was found that in Holland only in 5% of cases was pain mentioned as the most important reason for requesting euthanasia.²³ A Canadian study noted that while public support for euthanasia is highest for physical pain and lowest for “loss of purpose and meaning” “in reality patients in the latter circumstances may be more characteristic of those who would actually make requests for hastened deaths.”²⁴ In Oregon, where euthanasia is legal, the most commonly cited reasons for requesting it are “loss of autonomy, a decreasing ability to participate in enjoyable activities and loss of control over bodily functions.”²⁵

6.2 The pro euthanasia lobby say that euthanasia should be available for “unbearable and unrelievable pain” but their definition of “pain” often includes such symptoms as incontinence, vomiting, bedsores, breathlessness, oedema and insomnia.²⁶ The reality is that such symptoms can almost always be relieved with the help of good nursing and/or palliative care either given in a hospice setting or at home. It is not sufficient for a doctor simply to “inform” a patient about the alternatives to euthanasia. Unless the patient is given first proper information about such alternatives, including nursing, palliative and hospice care and then easy access to these alternative treatments the impression will persist that euthanasia is the only sensible option for those with intractable pain.²⁷

²⁰ T. O’Brien, M. Kelly and C. Saunders. Motor neurone disease: a hospice perspective. *The Lancet* 1992; 304: 471-473

²¹ In the High Court of Justice Queen’s Bench Division Administrative Court between The Queen (on the application of Mrs. Dianne Pretty) Director of Public Prosecutions (Defendant) Secretary of State for the Home Department (Interested Party), (1) Medical Ethics Alliance (2) Society for the Protection of Unborn Children (3) Alert (Intervenors) 18 October 2001

²² “Trust me, I’m a doctor ...” *Electronic Telegraph* 15 April 2001

²³ Robert Gerrit van der Wal, & J.M. Dillmann. Euthanasia in the Netherlands. *BMJ*. 21 May 1994

²⁴ K.G. Wilson et al. Attitudes of Terminally Ill Patients Towards Euthanasia and Physician Assisted Suicide. *Archives of Internal Medicine* 2000; 160: 2454-2460

²⁵ “Assisted suicide numbers surge” by Don Colburn. *The Oregonian*. 6 March 2003

²⁶ “Why, after 45 years, I can no longer support the Liberal Democrats” by Ludovic Kennedy. *The Times* 19 May 2001

²⁷ “The Patient (Assisted Dying) Bill.” A joint briefing paper by the Association for Palliative Medicine and the National Council for Hospice & Specialist Palliative Care Services. June 2003

6.3 Laws allowing euthanasia for “unbearable” suffering rely on such a condition being determinable by the doctor. In fact pain is entirely subjective, and hospice doctors note that “a clinician is only partially qualified to determine” it.²⁸ Euthanasia for reasons of pain would thus be entirely without “safeguards” (see above section 4) because no one could refute a person’s claim to be suffering “unbearably.”

6.4 It is commonly thought that the use of opiates (morphine and diamorphine) and sedatives in the terminal phase of an illness shorten life. The pro euthanasia lobby uses this “fact” to argue that “euthanasia” is already going on, and should therefore be put on a legal footing. However, there is irrefutable evidence that this is not the case.²⁹ The Association for Palliative Medicine and the National Council for Hospice & Specialist Palliative Care Services have suggested that it is “misleading and mischievous” to suggest that the law needs to change for comprehensive and effective management of distress at the end of life to be made available.³⁰

6.5 One senior Hospice doctor has estimated that at least 95% of physical pain can be completely and easily relieved, and “100% of patients can be helped.”³¹ When pain-relief drugs are not working pain can often be relieved by non-drug methods such as TENS (“Transcutaneous Nerve Stimulation”) machines, acupuncture or even simple physiotherapy. When euthanasia was legalised in Holland there was virtually no funding for palliative care, and its quality there even now is questionable.³²

6.6 Hospice doctors have observed that “The prospect of good quality end of life care and fulfilled needs helped alter (patients’) perceived reality and led to re-evaluation of their desire for death...the desire for euthanasia must not be taken at face value.”³³ Legalised euthanasia militates against the development of good palliative care and hospice services. If killing is seen as acceptable, less attention is paid to providing support services for those who suffer.

7. FEARS OF DISABLED AND ILL PEOPLE.

7.1 No Less Human has spoken out on all the recent cases brought by the pro euthanasia lobby. These matters are of direct relevance to the members of NLH, all of whom are disabled or ill people or families or carers of such people. We note that the supposed “right to die” is a subterfuge for what is often more of a “duty to die” because society refuses to provide appropriate support.

²⁸ Joint Palliative Care Briefing paper June 2003. Ibid at p. 23.

²⁹ Sykes & Thornes. Sedative use in the last week of life and the implications for end of life decision making. *Archives of Internal Medicine* 2003; 163: 341-44 & Systematic review. *Lancet Oncology*. April 2003

³⁰ Joint Palliative Care Briefing Paper June 2003. Ibid.

³¹ Commentary by Dr. Robert Twycross, Macmillan Clinical Reader, Oxford University. July 1997.

³² R. Cohen-Almagor. Dutch perspectives on palliative care in the Netherlands. *Issues in Law & Medicine*. 2002; 18: 111-26

³³ Y.W. Mak, G. Elwyn & Ilora Finlay G. Patient’s voices are needed in debates on euthanasia. *BMJ* 2003; 327: 213-5

7.2 The lack of options for many disabled people was made clear by the case of Larry McAfee, an American quadriplegic, who used a ventilator, and had been living in a succession of nursing homes and hospitals.³⁴ He requested that his ventilator be turned off, and the judge hearing the case commented “Mr. McAfee is not committing suicide... his ventilator would not prolong his life but instead would prolong his death.” In other words he was expressing the opinion that life for a disabled person is tantamount to death. Before Mr. McAfee could take his own life, he was offered a place in an independent living project for disabled people. He took that option and began working towards getting a job. Euthanasia would have robbed him of life before it could be shown that it was not his disability but his living conditions that were making him want to die.

7.3 Negative attitudes towards disabled and sick people, with the assumption that such people would be “better off dead” have been reported in the UK. Sue Maynard-Campbell, who uses a wheelchair and is Vice-Chair of an NHS Trust, went into hospital for a chest infection in 1998 and found that “Do Not Resuscitate” was written on her medical notes.³⁵ The doctor had decided she had a “poor quality of life” after, she says, speaking “no more than six words” with her. The doctor was unrepentant, and now she refuses to go into hospital. Jane Campbell, a member of the Disability Rights Commission was told when in hospital that she would not be put on life support because “you don’t want to live like that” and that she would not be ventilated because she would not live “a full and active life” afterwards. She was afraid to go to sleep for the rest of her hospital stay, and describes this approach as “ignorant, ill-informed, heartless and calculating.”³⁶ If euthanasia were legal, such negative judgments about the value of disabled lives would only become more prevalent, and would appear to be entirely justified.

7.4 Members of No Less Human fear that the authority to “assist” the deaths of sick and disabled people would become a duty to kill. Many vulnerable people feel afraid that they might be killed without their consent, because this is something that happens regularly where euthanasia is legal. We note that over 10,000 Dutch people now carry “anti euthanasia passports” because they are afraid of being killed by euthanasia.³⁷ We recognise the dangers of such a system, not least the fear of what would happen if such a document were mislaid, or simply not made available to the doctor, but cite it simply as an indication of the level of fear among people who live in a country where euthanasia is legal, even though it is allegedly “strictly controlled.”

8. ECONOMICS

8.1 There is a threat that already sparse resources for disabled and sick people would be further reduced if euthanasia were legalised, because of a subliminal view that money is better spent on those who will recover.

³⁴ “The Right to Die” Information produced by Same Difference for Channel 4. November 1991

³⁵ “How dare anyone tell me I am not worth saving” *Sunday Mirror* 30 April 2000 + Personal contact.

³⁶ “Your life in their hands” by Lord Alton of Liverpool. *The War Cry* 24 May 2003

³⁷ “Dutch carry cards that say: Don’t kill me, doctor” by Rachel Bridge. *Sunday Telegraph* 18 October 1998

8.2 It was reported in the full Government report from Holland in 1991 that "... it was gratifying to note that only one patient had non-voluntary euthanasia because there was the need for a bed."³⁸ To call it "gratifying" that such a killing happened "only" once shows how routine killing becomes once it is legalised.

8.3 It is misleading to suppose that legalised euthanasia and increased funding for palliative care could go hand in hand as was suggested in the British House of Lords by Lord Joffe in his Patient (Assisted Dying) Bill.³⁹ The former would militate against the latter. There would be costs in implementing any system of legalised euthanasia. No Less Human suggests that instead of funding deliberate killing by euthanasia, increased funding be provided for palliative care, and other support services for sick and disabled people, to enable them to make the most of their lives.

9. ADVANCE DECISIONS

9.1 The British Government has repeatedly stated that it will not make Advance Decisions legally binding. This follows the recommendation of the House of Lords Select Committee that such Decisions not be given greater legal force, because it would risk "depriving patients of the benefit of the doctor's professional expertise and of new treatments and procedures which may have become available since the Advance Directive was signed."⁴⁰

9.2 Despite the fact that subsequent British Government documents have suggested that Advance Decisions are legally binding, this has not actually been satisfactorily established⁴¹

9.3 A problem in treating Advance Decisions as if they were binding is that by the time the decision is being taken by others, the patient will almost certainly be incapable of indicating any chance of mind. What one thinks one would want in a completely hypothetical situation, never before experienced, is not necessarily what one would want if that situation actually arises. This is particularly true of disabling conditions. Able bodied people, including some doctors, frequently have a very negative attitude towards living with disability, but once they actually experience it, their attitude is likely to become much more positive.⁴²

9.4 It has been shown that people often make decision when they are ill that are not consistent with their Advance Decisions. One study found that "approximately 1/3 of patients changed their preferences in the face of actual illness, usually in favour of treatments rejected in advance."⁴³

³⁸ The Rummelink Report, 1991. Narrative accompanying the data on Nonvoluntary and involuntary euthanasia (tables 6.4 – 6.8)

³⁹ Debate in the Patient (Assisted Dying) Bill. Hansard Col 1591.6 June 2003

⁴⁰ Report of the House of Lords Select Committee on Medical Ethics 1994 (Session 1993-4, HL 21-I)

⁴¹ The claim that Advance Decisions are legally binding appears to rest upon three cases *Airedale NHS Trust v Anthony Bland, Re T and Re C*. No Less Human asserts that the claimed "proof" these cases provide for the legally binding nature of Advance Decisions is faulty.

⁴² B.P. Gardner, F. Theocleous, J.W.H. Watt & K.R. Krishnan. Ventilation or dignified death for patients with high tetraplegia. *BMJ* 1985; 291: 1620-22

⁴³ Melinda Lee. Do patients' treatment decisions match advance statements of their preferences? *Journal of Clinical Ethics* 09:03 (Fall 1998) 258-262

9.5 The same study also found that proxy decisions did not always agree with patients' stated preferences. However, they erred in the same direction as patients' changes of mind, that is, towards treatment rather than against it. Treating Advance Directives as binding means that there is no possibility of a change of mind, because the person would have been pushed into a death s/he might well no longer want.

9.6 Allowing people to set out in advance the types of treatment they would, or would not, be prepared to accept assumes a degree of medical knowledge which few lay people possess. Even if one researched the subject and found out all the possible conditions one might experience and all the possible treatments which might be available (which is in itself hardly a realistic prospect), the fact is that medicine is always advancing. What is extraordinary today may well be commonplace tomorrow, and new treatments become possible almost every day. Relying on Advance Decisions would mean that people would effectively exclude themselves from the latest advances in medical treatment.

9.7 The British Medical Association has said that it is "not proselytising" on the issue of Advance Decisions, and its Code of Practice draws attention to the disadvantages as well as the benefits of anticipatory decision making, noting that "...treatment decisions are complex, medicine is uncertain, practice is constantly evolving and there is always the possibility of a mistaken diagnosis. Views also change about what constitutes a tolerable existence. Advance Directives cannot encompass unforeseen possibilities and options. Therefore ... the BMA is not actively encouraging people to undertake the risks associated with committing themselves in advance."⁴⁴ No Less Human agrees with the BMA's cautionary approach to Advance Decisions.

9.8 Relying on the terms of Advance Decisions could mean that a conflict could be created between the law and the personal and professional principles of doctors - doctors could be punished for saving a life, a travesty of their traditional role, and of the instruction in the Hippocratic Oath "primum non nocere."

9.9 Advance Decisions do not assist in the exercise of autonomy, despite giving a semblance of so doing, since in some circumstances they could predict and demand a suicidal approach to particular conditions. A recognition needs to be made that if an Advance Decision requests or demands an action by a doctor to cause or hasten death, that Decision should not be considered binding, and should not be acted upon.

10. A PERSONAL EXPERIENCE

10.1 The problems raised above have a particular personal resonance for the author of this submission. I have spina bifida, emphysema and osteoporosis, and use a wheelchair full time. I experience severe spinal pain on a daily basis, and even morphine cannot always control my pain. When the pain is at its worst I cannot move, speak or think, and it can go on for hours. There is no prospect of relief; in fact it is very likely that the pain will get worse.

⁴⁴ "Refusal of Treatment" section *End of Life Decisions: Views of the BMA*. June 2000

10.2 Eighteen years ago, when several doctors believed that I did not have long left to live, I decided that I wanted to die due to a combination of factors including my severe physical pain. It was a settled wish that lasted about ten years, and during the first five of those years I made serious suicide attempts several times. I strenuously attempted to ensure that I succeeded, and was saved only because my friends found me in time, refused to accept my view that my life had no value, and ensured I was given emergency treatment in hospital, which was given against my will. Then I was extremely angry with them; now I am eternally grateful. Then I sincerely wished to die and felt my life had no value but, as the case with many desperate people, those wishes and feelings did not correspond with what was truly in my best interests. It should be noted that my physical pain is now at least as bad as it was then. What has changed is not my medical condition, but my outlook on life.

10.3 If Advance Decisions had been legally binding when I wanted to die, I have no doubt that I would have written one. I would not then have received the emergency treatment that saved my life, in accordance with wishes expressed in advance, and would thus have been denied the chance to re-establish a sense of the value of my life, a value which is not compromised by my frequent experience of severe pain.

11. CONCLUSION

11.1 Euthanasia is often presented as being a “merciful” or “compassionate” way to treat suffering people. However, compassion does not mean simply giving people what they want, or say they want, or what others think they “ought” to want. Similarly “mercy” does not mean killing in the name of “preventing suffering.” True compassion and mercy entail wanting the best for suffering people and having empathy with their suffering, staying with them as they suffer, offering whatever treatment may help and attempting to help them recover a sense of hope and of being loved. I was fortunate in that my friends understood the real meaning of both compassion and mercy, and demonstrated both in their care and concern for me.

11.2 Euthanasia simply colludes in the fallacy that there is such a thing as a “life not worthy to be lived.” It suggests that suffering people are “right to want to die” and represents the ultimate rejection of vulnerable people. Deliberate killing is the opposite of “mercy” and “compassion” and should never be legalised. Vulnerable people like the members of No Less Human deserve better than being told that death is in the best interests of those who suffer. What we need is help to *live* with dignity, until we die naturally.

11.3 No Less Human urges the members of the Voluntary Euthanasia Select Committee to reject calls for the legalisation of euthanasia on the Isle of Man.

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