



Written Evidence to the Commission on Assisted Dying from the British Humanist Association (BHA), April 2011

About the British Humanist Association

The British Humanist Association (BHA) is the national charity working on behalf of non-religious people who seek to live ethical and fulfilling lives on the basis of reason and humanity. We promote Humanism, support and represent the non-religious, and promote a secular state and equal treatment in law and policy of everyone, regardless of religion or belief. Founded in 1896, we have around 30,000 members and supporters, and over 70 local and special interest affiliates.

Part of our work is to promote humanist views on public ethical issues, and we focus on those issues that are either important to humanists in particular or have high social importance, especially where others are actively promoting views opposed to humanist values, such as on assisted dying.

The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns. Uniquely, the BHA's work is supported by the Humanist Philosophers¹, an advisory body of eminent philosophers and academics that provide guidance on complex ethical issues.

The Commission on Assisted Dying: Public Call for Evidence

In 2010, the BHA joined calls for an independent inquiry into assisted dying, to examine the evidence relating to a change in the law, to help towards evidence-based policy making on this sensitive issue. We welcome the creation of the Commission on Assisted Dying and the opportunity to provide both written and oral evidence to its inquiry. BHA Chief Executive Andrew Copson gave evidence to the Commission on 23rd March 2011.

In this written memorandum, we set out the moral and ethical basis and detail for the 'humanist view', and then set out the BHA's policy and campaign position, in light of those considerations. We then respond to the Commission's questions on the more practical detail of its inquiry. We hope that this submission, together with Mr Copson's oral evidence, gives a detailed and well-rounded contribution to this important inquiry from a non-religious perspective.

The humanist view

Humanists are non-religious people who live by moral principles based on reason and respect for others, not obedience to dogmatic rules. They promote happiness and fulfilment in this life because they believe it is the only one we have. Humanist concern for quality of life and respect for personal autonomy lead to the view that in many circumstances assisted dying, or voluntary euthanasia, is the morally right course.

People should have the right to choose a painless and dignified end, either at the time or beforehand, perhaps in a 'living will'. The right circumstances might include: extreme pain and suffering; helplessness and loss of personal dignity; permanent loss of those things which have made life worth living for this individual. To postpone the inevitable with no intervening benefit is not a moral act.

¹ For details of the membership and activities of the Humanist Philosophers, see: <http://www.humanism.org.uk/about/philosophers>

Individuals should be allowed to decide on such personal matters for themselves; if someone in possession of full information and sound judgement decides that her² continued life has no value, her wishes should be respected.

While humanists generally support assisted dying and voluntary euthanasia, they also uphold the need for certain safeguards. These may include counselling, the prevention of pressure on patients, clear witnessed instructions from the patient, the involvement of several doctors, no reasonable hope of recovery – measures which would prevent involuntary euthanasia.

Some religious people maintain that there is a moral distinction between acts which cause death (active euthanasia) and omissions which cause death (passive euthanasia), only the second being morally permissible. Many humanists think they've got it the wrong way round, because the first is quicker and thus kinder for everyone involved, though both are probably painless for the patient.

Many of the medical profession and politicians have also accepted this traditional distinction. It might be easier for doctors to withdraw or withhold treatment than it would be for them to administer a lethal drug – but this does not necessarily make it right. It would be wrong to force doctors and nurses to do things that they consider morally wrong, but patients wishing assistance in dying should be allowed to seek a doctor who will help them.

Some think that suicide is wrong because of the great pain it often causes to those left behind. If one believes suicide is wrong, then assisted suicide, seemingly, must be wrong too. However, the death of a terminally ill and suffering patient would probably be a merciful release for everyone involved and so is very different in its effects from other suicides. There is no rational moral distinction between allowing someone to die and actively assisting them to die in these circumstances: the intention and the outcome (the death of the patient) are the same in both cases, but the more active means is probably the more compassionate one. The BHA supports attempts to reform the current law on assisted dying and voluntary euthanasia.

The BHA's position

The BHA has been involved in the debates around assisted dying for decades. As above, humanists defend the right of each individual to live by her own personal values, and the freedom to make decisions about her own life so long as this does not result in harm to others. Humanists do not share some of the attitudes to death and dying held by some religious believers, in particular that the manner and time of death are for a deity to decide or that interference in the course of nature is unacceptable.

Currently, the needs and autonomy of patients are often disregarded. Compassionate doctors, who follow the wishes of their terminally ill and severely suffering patients by assisting them to die, risk being charged with assisting suicide or murder. The current system sometimes also results in close relatives being faced with immensely difficult choices: whether to assist a loved one who is begging for help to put an end to their suffering knowing that it is unlawful, or to deny their loved one the death they want.

We do not believe that anyone should be put in the position of having to make such choices, or a position where they believe that they have no other option but personally to end the life of someone they love. Those few terminally ill and suffering people who are able to travel abroad to die in a jurisdiction where assisted dying is legal, often die before it is necessary because they need to do so at a time when they are still able to travel.

² Read 'her or his'

In addition to the argument from autonomy, it is our position that reforming the law to legalise assisted dying would be an important step to becoming a more compassionate and caring society. The law as it stands is not compassionate. It gives no option to those who wish to end their lives without suffering and distress, and are unable to do it themselves. It makes no distinction between murder and compassionate acts of assisted dying or euthanasia, and places a great burden on those who are suffering who wish to have help and support in ending their lives.

The BHA is supportive of reforming the law to enable mentally competent adults who are either terminally ill or those who are incurably suffering, permanently incapacitated and who find their lives intolerable, to have the choice of an assisted death.

Under a reformed law, the choice of an assisted death should not be instead of palliative care, but part of a comprehensive, patient-centred approach to end of life care available to as many people who want it.

Being able to die, with dignity, in a manner of our choosing must be understood to be a fundamental human right – a position supported by the recent landmark judgment in the Purdy case, where our highest court ruled that Convention rights are invoked at end of life. Legalising assisted dying would ensure that strict legal safeguards are in place which would empower people to utilise their right to make rational choices themselves over their end of life care, free from coercion.

1. Do you think that it is right that in certain circumstances, the DPP can decide not to prosecute a person who assists another person to commit suicide?

The publication of the DPP's prosecuting policy in regards to cases of assisted suicide was welcomed by the British Humanist Association as a positive recognition that in some circumstances individuals who have assisted another to end their life should not be prosecuted. As a result, the policy also provides greater reassurance to the friends and relatives as how they are to be treated by the authorities.

However, the situation remains deeply unsatisfactory: assisted dying remains illegal. Crucially, the interests of the most vulnerable are still not addressed or protected. For as long as assisted dying remains illegal, an unknown level of clandestine assistance will continue to occur and, in those cases where it is recognised that an individual has received help in ending their life, any assessment of the condition of the patient or the motivation of the assistor will be retrospective. Effective medical and legal safeguards, in the form of consultation with palliative care specialists, psychiatrists and an investigation into the motivation of the assistor, remain entirely absent.

The DPP guidance makes clear that there is a relatively high threshold for prosecution. However, the threat of prosecution has not been eliminated. We believe this still places a significant burden of stress on the individuals concerned and, of course, the right of all individuals to die with dignity in a manner of their choosing is still not respected.

Legalising assisted dying would render the DPP's guidance redundant. Until such time, however, the BHA believes that the guidance has some use.

We believe it is appropriate that, if an individual has assisted in ending the life of a loved one, and this action is entirely motivated by compassion, the assistor should not be prosecuted. This is where the DPP's guidance is important, because it attempts to distinguish between where a person has compassionately assisted another to die, and where that was done with malicious intent or murder – a distinction that parliament has thus far failed to make in legislation.

2. Do you think it is right that it is currently illegal for a doctor or another healthcare professional to assist somebody to commit suicide and that a doctor is more likely to be prosecuted for providing assistance than a friend or family member who provides assistance?

We believe the current illegality of a doctor or another healthcare professional assisting somebody to commit suicide is wrong. It may be the case that a doctor is more likely at the moment to be prosecuted for providing assistance in that way than a friend or family member. However, should assisted dying be legalised, we would recommend that that it would be registered medical practitioners who would assist deaths and not friends and family, within a framework with strict safeguards.

The motives of those who are willing to assist individuals in committing suicide should be assessed individually; we do not believe that by virtue of being a relative alone precludes the possibility of an assistor from having a motivation other than the interests of their relative. A system which permitted assisted suicide within a strict framework would be more effective at determining motivation, rather than a retrospective consideration of the wishes of a deceased individual.

3. Does the DPP policy currently provide sufficient safeguards to protect vulnerable people?

No. Without a change in the law to legalise assisted dying, the evaluation of the need of the person or the motivation of the assistor will always be retrospective. That means there are no safeguards whatsoever protecting vulnerable people from coercion or other malicious intent at the time they are most needed – when a person is making the choice whether to ask someone to assist them to die because they are unable to commit suicide. It is hard to think of someone in a more vulnerable situation than that, and the only way we can hope to ensure real protection is through legalising assisted dying and giving the measures needed legal weight.

4. Do you think that any further clarification of the DPP policy is needed? Or has the DPP policy already gone too far?

The DPP has clarified that the prosecution policy takes (and should take) a humane and understanding approach towards compassionately motivated individuals who have assisted a friend or loved one at a time of great need. We appreciate it was not the intention or within the remit of the DPP to change the law in this regard, and though the revised prosecution guidance is welcome, it also strongly affirms the need for a thorough reform of the law in this area.

5. Do you think there should be change in the law to create a legal framework that would allow some people to be assisted to die in certain circumstances?

The BHA is strongly in favour of a reform in the law, in favour of legalising assisted dying and voluntary euthanasia for terminally ill people, and for people who are incurably suffering, permanently incapacitated and have made a clear, informed and resolute decision that they wish to end their lives. Please see 'the humanist view' and the 'BHA's position' above, in addition to the BHA's oral evidence to the Commission, for more details of our position and the ethical basis for that position'

ELIGIBILITY AND SAFEGUARDS

6. The 2005 Assisted Dying for the Terminally Ill Bill sought to provide access to an assisted death only for those who have been diagnosed with a terminal illness, who have mental capacity, who are experiencing unbearable suffering and are over the age of 18. If some form of assisted dying were to be legalised, who do you think should be eligible for assistance?

The BHA supports the categories stipulated in the 2005 Assisted Dying for the Terminally Ill Bill. In our response to the End of Life Assistance (Scotland) Committee's call for evidence on the End of Life Assistance (Scotland) Bill in May 2010, we support the eligibility criteria set out in that Bill, which are: someone a) who has been diagnosed as terminally ill and finds life intolerable; or b) is permanently physically incapacitated to such an extent as not to be able to live independently and finds life intolerable.

Much of the BHA's campaigning on the issue of assisted dying focuses on the need to reform the law in order to legalise assisted dying for terminally ill people. This is of high importance, and we understand the urgency of such a reform in the law, which would permit those who are definitely in the last stages of life to die in a manner of their choosing.

It is also the BHA's position for the law to be reformed to allow those who are incurably suffering, permanently incapacitated and who find their lives intolerable to choose an assisted death. We believe that a compassionate law is one that respects the wishes of people who have decided that their lives hold no quality for them. People should have the right to choose a painless and dignified end, either at the time or beforehand, perhaps in a 'living will'. As mentioned above under 'the humanist view', the right circumstances might include, but are not limited to: extreme pain and suffering; helplessness and loss of personal dignity; permanent loss of those things which have made life worth living for this individual.

Individuals should be allowed to decide on such personal matters for themselves; if someone in possession of full information and sound judgement decides that her continued life has no value, her wishes should be respected.

To postpone the inevitable against the wishes of an individual with no intervening benefit is not a moral act. We believe a compassionate society is one which respects and upholds in law people's right to choose to have an assisted death if that is their considered and expressed wish.

7. If some form of assisted dying were to be legalised, what safeguards would be required to protect vulnerable people?

We are not expert in the fine detail of the medical-legal safeguards and as such are not in a position to be prescriptive: we look to others more expert in this particular area, and to the experiences in other jurisdictions to make recommendations. We would expect this Commission to look in detail in this area and to make recommendations itself grounded in evidence.

However, in light of that statement, we would emphasise the importance of ensuring that individuals who request an assisted death are fully informed, are of sound mind and judgment and have made a clear and resolute wish, free from coercion, to have an assisted death. It is vitally important that there are safeguards in place to protect vulnerable people, and yet it would be impossible to safeguard against every eventuality or risk. With that in mind, we would suggest that any approach to safeguarding seeks to protect people but also to maximise people's capacity to make decisions and respect their autonomy. Reforming the law but having safeguarding measures that went so far as to prevent any practical application of that law would be no reform at all.

8. What do you think are the main risks (both to individuals and to society) that would be associated with legalising any form of assisted dying?

As mentioned above under question 7, it is impossible to rule out all risks.

However, it is our strong contention that a legalised form of assisted dying would prove safer than the current system; assistors' motives could be most clearly demonstrated if assisted dying was legally facilitated, and any degree of coercion would be more effectively detected within a legal framework rather than in a post-hoc investigation.

There is, of course, the risk that any proposed legislation would be watered down in an attempt partly to appease those who oppose it, or to get it on the statute book. We fully supported Lord Joffe's Bill in 2006, which posed no threat to patients who do not want to take advantage of assisted dying and included an 'opt-out' clause for doctors with a serious objection to ending their patients' suffering in this way. However, during its time in parliament, the Bill was amended in ways so as to weaken the provisions it contains and, looking forward from that experience, there is a risk that such tampering with a good Bill could create a bad and ineffective law.

9. If some form of assisted dying were to be legalised, who do you think should make the decision on whether somebody who requests an assisted death should be eligible for assistance? Should this decision be made by doctors, by an independent judicial body such as a tribunal, or by another type of organisation?

The BHA would encourage the participation of medical professionals in the process, as they would clearly be in a good position to assess the condition of individuals who wished to end their lives.

THE ROLE OF DOCTORS AND END OF LIFE CARE

10. If some form of assisted dying were to be legalised, should doctors be able to take a role in assisting those who request assistance to die?

- a. If yes, what actions should doctors be able to take?**
- b. If no, please explain your reasoning.**

We believe that doctors and medical professionals are often best placed to make decisions about the means of death with and for their patients.

In the End of Life Assistance (Scotland) Bill, there was a requirement that, regardless of who provides the end of life assistance, a registered medical practitioner must be present at the end of the requesting person's life. We supported that requirement, in particular because it provides for the allowance of action by a registered medical practitioner should something go wrong. This requirement is an additional safeguard to ensure that the means of death is as humane, dignified and pain-free as possible. This is to be welcomed.

Those kinds of provisions to allow action by the registered medical practitioner are important. There is no rational moral distinction between allowing someone to die and actively assisting them to die in these circumstances: the intention and the outcome (the death of the patient) are the same in both cases, but the more active means is probably the more compassionate one.

11. If some form of assisted dying were to be legalised, what provisions would be required to protect doctors and other healthcare professionals who are ethically opposed to assisted dying?

The area of 'conscientious' or moral objection is very complex, not straightforward, and is one that the BHA is working on, together with a range of philosophers, legal practitioners, medical ethicists, policy makers and more.

However, we believe there could be room to allow those with genuine ethical objections to assisting a death to 'opt out'. This would need to operate in a way so that patients' rights and choices are not compromised. It would be wrong to force doctors and nurses to do things that they consider morally wrong, but patients wishing assistance in dying should be allowed to seek a doctor who will help them.

We suggest that the Commission on Assisted Dying looks in detail at this area as it contains wider and complimentary considerations than those only focused on assisted dying. We would be happy to provide the Commission with more detail on our own work on this area as that makes progress.

12. Could assisted dying have a complementary relationship to end of life care or are these two practices in conflict?

We strongly believe that not only are they not in conflict, they are very much part of the same 'package'. The BHA is a member of the 'Dying Matters' coalition, and further, we support high quality care at end of life for all those who need it, and a choice for an assisted death, for all those who want one.

Evidence from countries where systems of assisted dying exist, such as Belgium, indicate that there is a strong correlation between providers of palliative care and those who advocate choice towards the end of life³. The practice of providing high quality, palliative care and of giving patients the choice of an assisted death are not antagonistic; both should be core part of a comprehensive, patient-centred approach to end of life care. In fact, offering real choice at end of life can enable proper care and information to be offered to patients.

Moreover, in other jurisdictions where there has been reform, such as Oregon, the numbers choosing an assisted death remains very low, with only 20.9 out of 10,000 deaths occurring as a result of individuals administering the fatal dose obtained through the scheme⁴. The experience of Oregon indicates that when patients feel able to openly discuss their desire to end their life, patient-doctor relations improve and all options can be thoroughly discussed. The availability of an option to end their terminal decline is reassuring and choice-enabling, even though the level of uptake is extremely low.

³ Bernheim, J., Deschepper, R., Distelmans, W., Mullie, A., Bilsen, J., and Deliens, L., (17th April 2008)

'Development of palliative care and legalisation of euthanasia: antagonism or synergy?' BMJ

⁴ State of Oregon's Death with Dignity Act 2010 Annual Report

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year13.pdf>

13. If the law was to be changed to permit some form of assisted dying, what forms of assistance should be permitted? Should assisted suicide be permitted? Should voluntary euthanasia be permitted? (Please see the definitions above).

The BHA would support a system that permits assisted suicide in addition to voluntary euthanasia. If a terminally ill adult, or one who is incurably suffering, has a settled wish to end their life, if all other options have been considered, and the motivation of the assistor is based entirely out of compassion, we consider there is no moral distinction to be made between who commits the final act in a properly controlled environment.

14. Should those who wish to be assisted to die, but are physically unable to end their own lives, receive assistance to die? If yes, what assistance should be provided?

As stated in our response to question 13, the BHA is in favour of permitting assisted suicide in cases where individuals are unable to fulfil their own wish to end their lives.

In terms of the means of assistance, the BHA is in favour of a physician assisted process, as medically trained professionals are best placed to ensure lethal materials are handled with the appropriate care, and provide any further assistance the patient may require.

ADDITIONAL COMMENTS

15. Please include here any further comments, evidence or personal experience that you would like the commission to consider:

Public support

Recent measures of public opinion indicate that providing assistance in cases where terminally ill individuals have a settled wish to end their lives has the support of a significant majority of the population. The British Social Attitudes survey, produced annually by the National Centre for Social Research, conducts thousands of interviews with a representative sample of the UK population. According to the 26th report, published in 2009, 82% of people believe that a doctor should be allowed to end the life of a patient with an incurable disease. This figure includes 71% of religious people questioned⁵.

This figure is by no means anomalous, with a January 2010 poll for the BBC finding 75% of those questioned supporting physician assisted suicide for the terminally ill⁶. Again, 75% expressed support for reform in a further poll commissioned by the Daily Telegraph⁷, and 74% favoured reform in a 2009 poll for the Times newspaper⁸.

Opinion polls and surveys are not a definitive gauge of public opinion, however these provide a consistent indication that the opinion of politicians, particularly that in the House of Lords, is out of step with that of the general public.

⁵ Voas, D. and Ling, R. (2009), 'Religion in Britain and the United States', in Park, A., Curtice, J., Thomson, K., Phillips., Clery E., and Butt, S. British Social Attitudes: the 26th Report, London: Sage

⁶ BBC Panorama Poll on Assisted Suicide 31 January 2010: <http://www.comres.co.uk/page1901414554.aspx>

⁷ YouGov June 2010 Poll <http://www.today.yougov.co.uk/sites/today.yougov.co.uk/files/YG-Archives-Lif-DT-euthanasia-100128.pdf> A further YouGov tracker poll conducted in June yielded the same result: <http://today.yougov.co.uk/sites/today.yougov.co.uk/files/YG-Archives-Life-YouGov-assistedsuicide-040610.pdf>

⁸ Populus poll for the Times, July 2009: <http://www.populus.co.uk/the-times-the-times-poll-19th-july-2009-190709.html>

From our experience of working for reform in the area of assisted dying for many years, we can attest to the level of misinformation and emotionally charged campaigning conducted by those who oppose reform. In response to the volume of misreporting and scaremongering surrounding the debate of Lord Joffe's Private Members Bill in 2006, the BHA issued a report titled 'In Bad Faith'⁹ cataloguing examples of egregious misreporting.

'In Bad Faith' covered the activities of many different Christian groups, and the stated purpose of the report was to show, through their own words and actions, how various Christian groups were campaigning against the Assisted Dying for the Terminally Ill Bill.

The report concludes that:

- Many of the Christian groups who oppose the Bill deliberately use scare tactics and misleading arguments in their campaign;
- Many of them deliberately avoid mentioning what we take to be their actual motives – their faith and their beliefs about the sanctity of life;
- In the case of the Catholic Church, beliefs about sanctity of life are themselves inconsistent;
- The religious press is extremely biased on the issue, and fails to represent the views of the majority of Christians;
- The resources at the disposal of Christian groups opposing the Bill are immense and are being used to distort public debate and perceptions.

There are many more examples than the ones we have included in this research.

We hope that everyone who reads this report will reflect on the integrity of the religious groups campaigning against the Assisted Dying for the Terminally Ill Bill, and that Christians, in particular, will challenge their religious leaders' approach to this very important ethical issue.¹⁰

We believe that well funded, organised, but disproportionate and unrepresentative lobbying and protestations from religious and other oppositional organisations, and the organised and influential opposition to reform by the 26 Church of England Lord Bishops in parliament, have a distorting, negative impact on the debate, severely retarding progress to take the law in a more ethical direction.

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⁹ BHA Report 'In Bad Faith: The FACTS about how religious groups are campaigning on assisted dying', 8 May 2006: <http://www.humanism.org.uk/documents/3947>

¹⁰ Ibid.