

BHA response to GMC consultation 'End of life treatment and care: Good practice in decision-making. A draft for consultation.'

About us

The British Humanist Association (BHA) is the national charity representing the interests of the large and growing population of ethically concerned non-religious people living in the UK. It exists to promote Humanism and support and represent people who seek to live good lives without religious or superstitious beliefs. The BHA is deeply committed to human rights, equality, democracy, and an end to irrelevant discrimination, and has a long history of active engagement in work for an open and inclusive society. In such a society people of all beliefs would have equal treatment before the law, and the rights of those with all beliefs to hold and live by them would be reasonably accommodated within a legal framework setting minimum common legal standards.

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. These include a Humanist Philosophers' Group, a body composed of academic philosophers whose purpose is to promote a critical, rational and humanist approach to public and ethical issues.

Introduction

We are delighted to respond to this consultation on the GMC's draft guidance for End of Life Care. We have chosen to respond in this format, rather than using the online form, as we wish to comment in detail only on certain aspects.

We were invited to, and attended, the GMC's consultative conference on end of life care on 3rd June, as key stakeholders in the debates on end of life care.

We will respond on 3 key points, namely: terminology; organ donation and assisted dying.

Our response

Terminology – religion or belief

We are pleased to see in this guidance that there is not a specific focus on 'faith' but a more inclusive use of terminology to include 'beliefs'. However, it would be helpful for the guidance to make explicit that 'beliefs' include non-religious beliefs, such as Humanism. For example, where beliefs are referred to in the document, it could be useful to have an endnote reference to explain what the terminology means. We have attached our recent guidance on equality and the religion or belief strand, which we believe may be helpful.

Organ Donation

It is excellent that organ donation has been included in this guidance. This is certainly an advance and indicates the importance of this subject for individuals and families, as well as for the wider public benefit. However, it may be more useful to have a more detailed and longer section on organ donation, given its importance and that it is a highly sensitive issue.

The BHA has been involved with the Organ Donation Taskforce, providing it with information regarding humanist perspectives on organ donation. It would be useful to have links to the work of the Taskforce in the document, as a resource.

There is also no mention of the organ donation register. While we still have an 'opt in' system in the UK as opposed to one of 'presumed consent', the organ donation register is especially crucial. Paragraph 71 states: 'You should be prepared to explore with those close to the patient whether the patient had expressed any views about organ donation, and to discuss sensitively with them the possibility of donation.' However, organ donation is not a topic that many people do discuss with their loved ones and so many do not know what the deceased's wishes would have been. That is why we advocate an 'opt out' system of organ donation, where people actively have to take their names off the register.

In the present system however, given the proportionately low numbers of people on the organ donation register, those who have actively put their name on the register can be understood to have had a strong position in favour of having their organs donated after their death. It would be important for loved ones to be made aware if the deceased had registered themselves; it is quite possible they would not have known before the death and may help them to make their decision to allow organs to be donated.

Assisted dying

We welcome the broad statement of support for the Human Rights Act 1998 in the guidance. Respect for the rights and dignity of patients must underpin every aspect of this guidance.

While we appreciate that assisted dying for terminally ill people is not legal in the UK, for the BHA, the issues around end of life care are inseparable from our view that there is a right to die with dignity and that this includes the availability of physician assisted suicide for the terminally ill.

Of more immediate importance to this draft guidance is the legislation currently making its way through Parliament which seeks to reform the law on assisted dying in such a way as would take away the threat of prosecution of those accompanying terminally ill loved ones abroad for an assisted death. If such legislation is passed this Autumn (or similar legislation is passed in the future), then the effects of that would have to be included in any guidance on end of life care. Doctors, for example, would have a key role to play in assessing patients' mental and physical conditions if they were seeking to travel abroad for an assisted death.

In such circumstances, patients must be made aware of their options and legal position.

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