

**Written evidence to the Scottish Parliament's Health and Sports Committee
call for evidence on the Palliative Care (Scotland) Bill by the British Humanist
Association. August 2010**

About the British Humanist Association

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 support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society and for a rational approach to public ethical issues.

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. The BHA is also a member of the Dying Matters Coalition, which was established by the National Council for Palliative Care to promote public awareness of dying, death and bereavement.

Introduction

We are pleased to provide written evidence to the Scottish Parliament's Health and Sports Committee call for evidence on the Palliative Care (Scotland) Bill.

In this memorandum we take the opportunity to set out our position towards aspects of palliative care that relate to the work of the BHA generally, and on the Palliative (Scotland) Bill specifically.

Our position on palliative care

Humanists defend the right of each individual to live by their own personal values, and the freedom to make decisions about their 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 reasonable and justifiable interference in the course of nature is always unacceptable.

The BHA believes that being able to die with dignity in a manner of our own choosing must be considered a right which should be recognised in a civilised society. We believe it essential that all patients are fully informed of all the options available to them, and provided with as much assistance and information as possible.

Modern methods of palliative care can do much to relieve pain for those with terminal illnesses and we believe that all patients should have access to high quality palliative care.

However, there remain cases where the only means of relieving suffering is by hastening the end. The BHA has long argued for the legalisation of a system of assisted dying with strict legal safeguards that would empower people to utilise their right to make rational choices over their end of life care. Although we recognise that this matter is not the focus of this Bill, we do not believe that the two issues can be clearly separated.

The present Bill advocates a patient-centred approach, building on the 2008 NHS Scotland paper *Living and Dying Well*. For some terminally ill individuals, their wish to end their life at a time of their own choosing will be a priority that is not reflected in the choices available for end of life care at present.

Although we are strongly supportive of the aims of the Bill in creating a culture where individual care needs are met, we believe that a truly comprehensive approach to end of life care cannot exclude the issue of assisted dying.

Considerations of the Palliative Care (Scotland) Bill

- **Do you agree or disagree with the general principles of the Bill?**

The BHA agrees with the intended aims of creating greater awareness of the options and services available to patients requiring palliative and end of life care, and their friends or relatives.

- **Do you believe there should be a specific duty on the provision of palliative care in the NHS (Scotland) Act 1978, over and above the general duty of “providing a comprehensive and integrated health service”?**

The BHA supports the inclusion of a specific duty into the NHS (Scotland) Act 1978, as the pre-existing requirements for NHS Scotland do not sufficiently clarify the importance and distinctiveness of end of life care. Presently, aspects of palliative care are covered under section 36 concerning the provision of accommodation and medical or nursing services in the home of an individual, and section 37, the duty to provide arrangements to prevent illness and aftercare. We believe the creation of a specific duty would affirm that palliative and end of life care are a core function of the health service, and also capture the wider needs of serving the family and friends of patients.

The BHA supports the creation of a specific statutory duty to provide palliative care in order to improve the consistency of the services and information provided. In addition to the regional variation in the quality of support available, as raised in the paper *Living and Dying Well*, recent research indicates that non-religious doctors are more likely to discuss end of life care with their patients than doctors with strongly

felt religious beliefs¹. The BHA believes that patient care must be of paramount importance and, in implementing this explicit legal obligation to provide palliative care, it must be made clear to clinicians that their patients have a right to information and options, including those options do not accord with the clinicians' own religious views.

- **Are you content with the definitions contained in the Bill, particularly that of “palliative care”?**

A term used within the Bill that is a source of particular concern is the use of the term spiritual/spirituality, as recorded in Section 48C part a, *ii* under the definition of the term ‘palliative’, describing exactly which areas the Scottish Government has a duty to provide assistance

(ii) psychological, social or spiritual help and support with the intention of improving their quality of life;

(b) in relation to family members of persons with a life-limiting condition, psychological, social or spiritual help and support to enable them to cope with the fact of their relative's life-limiting condition and its consequences;

Furthermore, the term spiritual is used in the performance indicators that must be reported to the Scottish Parliament:

9. Information on the nature of the psychological, social and spiritual help and support given to persons with a life-limiting condition and to their family members.

The term *spiritual* has a variety of definitions, and in many contexts may refer to religious concerns, to an individual's ‘inner life’; to an intellectual characteristic or to an ability to reflect on deeper meanings that has no grounds in the supernatural.

However, *spirituality* and *spirit* are often used synonymously for religion. In this instance, as the term *spiritual* is contrasted against ‘social’ and ‘psychological’, there is a strong sense that this may refer exclusively to the religious belief of the person with a life-limiting condition or their family or friends.

While the BHA is strongly supportive of the aims of the Bill in promoting end of life care that is responsive to the circumstances of each individual, and respecting characteristics including religion or belief, we consider it important that this term is clarified, and the breadth of the pastoral care and counselling services available is sufficient to meet the needs of the entire community.

It is important to recognise that individuals who do not hold a religious belief may wish to have access to support or advice from persons’ with a similar outlook, and

¹ “Being very or extremely religious is associated with fewer discussions of decisions with patients judged competent to do so, when decisions were taken that involved an expectation, or some degree of intent, to hasten the end of life”. <http://press.psprings.co.uk/jme/august/jme36194.pdf> *The role of doctors’ religious faith and ethnicity in taking ethically controversial decisions during end-of-life care*

who may be able to assist them with practical considerations, such as providing advice on non-religious funeral services.

- **Do you have any comments on the provisions concerning reporting and indicators contained in the Bill?**

The BHA have specific concerns regarding the collection of data on the provision of *“Information on the nature of the psychological, social and spiritual help and support given to persons with a life-limiting condition and to their family members”* that is stipulated in point 9, of *Schedule 9A (introduced by section 48B) Reporting and Indicators*.

Although we recognise the importance of monitoring the services provided, we believe it important to recognise that an apparent discrepancy between the numbers of individuals receiving end-of-life care and not utilising the ‘spiritual’ services available should not be recognised as a failure on behalf of the organisation reporting the figures.

Please note our previous response indicating the difficulties in defining spiritual services, and how this is not a purely a religious concern.

Due to the immense range of what may constitute a spiritual service, and the even greater variation in individuals’ beliefs, many people may not wish to use the services available to them, such as chaplaincy or counsellors, as they may not feel they are appropriate or relate their religion or belief.

It is extremely important that individuals with any belief (religious or not) do not feel pressured to use a service that is inappropriate for them at a time when they may feel particularly vulnerable. Equally, it is imperative that organisations do not feel obliged to compel patients into using religious services in order that they can report a high percentage uptake of their ‘spiritual’ services.

- **Do you have any comment on the costs identified in the Financial Memorandum?**

The BHA does not maintain a view on the costs relating to the collection of the performance indicators.

However, in relation to the provision of care, the BHA is firmly of the view that public policy decisions must be made on a rational basis, and the provision of treatments made on solid scientific grounding. We note that organisations including hospices and NHS Scotland in some cases offer complementary and alternative therapies to individuals with life-limiting conditions. While we recognise this is a matter of considerable sensitivity, the BHA would urge extreme caution in the allocation of resources for therapies in instances where there is little or no evidence of their clinical effectiveness, particularly if there is a risk of diverting funds away from services with proven value.

Additionally, in considering the spiritual care of individuals with life-limiting conditions and their friends and family, we believe it is important that any expenditure remains proportionate; i.e. we do not believe it is appropriate to subsidise the work of religion or belief groups using funds from a healthcare budget.

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1 September 2010