

The National Council for Palliative Care, Association for Palliative Medicine & National Palliative Care Nurse Consultants Group

JOINT STATEMENT ON THE ASSISTED DYING (No. 2) BILL, 2015-16

This is a joint statement by the National Council for Palliative Care, the Association for Palliative Medicine and the National Palliative Care Nurse Consultants Group on the Assisted Dying (No. 2) Bill that has been laid before Parliament. The Bill aims to legalise medically assisted suicide for people deemed to be terminally ill.

There is a broad range of deeply-held views about the Assisted Dying Bill. Our purpose in coming together to make this joint statement is to set out our concerns about the relationship between the proposed legislation and the provision of palliative and end of life care in this country. In particular, as national organisations leading in these areas, we wish to ensure that access to palliative and end of life care and public understanding are not compromised or harmed in any way. This includes through the ways in which public debate takes place and is informed, as well as the impact on people's access to and experience of care if legislation were to be passed.

This statement is based on five key principles. We hope that many people, whatever their views on the proposed legislation, will be able to support these:

1. The way in which we care for dying people is a test of our values as a society. Whether or not the law is changed, there is a collective responsibility on us all to ensure that round the clock access to high quality palliative care for people who are terminally ill is extended and improved and not damaged in any way.
2. People must never be placed under any pressure to choose to end their lives because palliative care is not available to them or because they fear being a burden, which is commonly felt by people nearing the end of life¹.
3. The views of organisations and people working in palliative care must be given particular weight when considering the interaction between the proposals in the Bill and the current practice and provision of palliative care.
4. The responsibility for the decision to allow someone's life to be ended prematurely should rest with the courts, with clinicians providing factual information only.
5. The assessment of requests for assisted dying and the administration or provision of lethal interventions should not become part of palliative or other clinical care services, but should be carried out by separate arrangements.

¹ Being a burden on family / friends was cited by 63% as a concern by those receiving assisted suicide in Washington, USA. Washington State's Death With Dignity Act: 2013 Annual Report

What is palliative care?

Palliative care, as defined by the National Institute of Health & Care Excellence (NICE), is:

The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:

- *Affirm life and regard dying as a normal process*
- *Provide relief from pain and other distressing symptoms*
- *Integrate the psychological and spiritual aspects of patient care*
- *Offer a support system to help patients live as actively as possible until death*

Everyone approaching the end of life has the right to the highest quality care and support, wherever they live and whatever their condition. Palliative care seeks to enable and support very vulnerable people to lead independent and symptom-free lives with comfort and dignity. It aims to provide an environment and support in which people feel safe to express their distress without judgement and have the freedom to think through their wishes and preferences for care and support until they die.

The role of palliative care is to maximise quality of life and support people until they die. It is not to shorten life prematurely.

It is important that there is clarity between medically assisted suicide, whereby doctors provide lethal drugs to assist a patient's suicide, and the current provision of appropriate palliative care. Palliative care includes the right to decline medical interventions, and requires that the patient is supported in such decisions.

Language

This issue is so controversial that even the language of "assisted dying" and "assisted suicide" is contested. The Bill refers to "Assisted Dying" although the current legal framework is governed by the Suicide Act, which the Supreme Court has called on parliament to review. We consider that "assisted dying" is a misnomer and is being used as a euphemism for "assisted suicide". Assisted suicide involves a deliberate intervention to end somebody's life earlier than would otherwise have occurred. It is currently illegal. In contrast, a core part of palliative care is to "assist" people through the dying process and to live until they die, through the provision of person-centred care and support.

The Bill and the role of palliative care

We believe that the legislative safeguards proposed in the Bill are unsafe. For example we are concerned that this proposed legislation would require doctors and nurses, particularly GPs and palliative care specialists, to make assessments outside their professional field. Whilst they are appropriately placed to diagnose and offer a broad estimate of prognosis of a terminal illness, and to advise on palliative treatment and care, they are ill-placed to make judgements on whether a request for assistance to end life prematurely stems from a clear and settled intent or whether there are any unseen pressures behind it. Those are matters better decided by the courts. Legislation should establish a framework for decision-making through a judicial process, and not solely rely on medical assessments.

The Bill also lacks clarity about what information or experience of palliative care the person seeking assisted suicide should have received. The Select Committee chaired by Lord MacKay, which considered proposed Assisted Dying legislation in 2004-5, recommended that any future Bill “should consider how patients seeking to end their lives might experience palliative care before taking a final decision”². This Bill does not achieve that. Clarity is required about whether a person seeking assisted suicide should merely be given generic written information about palliative care, which is not a strong safeguard, have an individual assessment of their own needs or a period of specialist palliative care input.

Addressing misconceptions

What palliative care is and what it can achieve are not always well-understood both by members of the public and by some health care professionals. In particular a myth persists that it is common and acceptable practice to hasten a person’s death by increasing dosages of pain relief using drugs like morphine. This is untrue and needs robust rebuttal.

Doctors are under a duty to do no harm, which includes the duty to respect life. Research³ shows that the correct use of opioids by titration (adjusting drugs and doses to control the pain for each individual patient) does not shorten life expectancy. It is unacceptable practice to increase morphine doses by such large increments that life is threatened or distressing toxicity develops. The greater risk when a person is dying is that harm might be caused by “over-treatment” and futile interventions, through providing or continuing treatments which prolong the dying person’s discomfort rather than provide benefit.

It is essential for professionals and the public to understand more clearly the legal and ethical processes behind decision-making at the end of life. Good practice advocates for a person to have the opportunity to plan their medical care and to decline life prolonging treatment, should they wish. Distress can be caused if people are given inaccurate or unclear information or advice about these issues. We call for greater efforts to support clearer, better-informed communication and decision-making. We believe the current Assisted Dying Bill puts vulnerable people at risk, without improving access to care.

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² HL Paper 86-I

³ *George R, Regnard C Lethal drugs or dangerous prescribers? Palliative Medicine 2007; 21: 1-4*