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*Keeping the law safe for sick and disabled people*

**Palliative Care: What is it? And what has it got to do with 'assisted dying'?**

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**Living and Dying Well is a public policy research organisation established in 2010 to examine and publish, in an evidence-based and measured manner, the facts surrounding the 'assisted dying' debate in the UK.**

## **Palliative Care – What is it? And what has it got to do with ‘assisted dying’?**

### ***Introduction***

Palliative care is one of Britain’s success stories. A report<sup>i</sup> by *The Economist* in 2010 ranked the UK first among 40 OECD and non-OECD nations for quality of care for the dying, ahead of other developed countries including the United States, Germany and The Netherlands. Yet we continue to hear stories of unrelieved suffering among people who are terminally ill. How can this apparent contradiction be explained? Just how much can modern palliative care do to relieve the suffering that terminal illness often brings? And what place does it occupy in the controversial political debate on the legalisation of physician-assisted suicide or physician-administered euthanasia?<sup>ii</sup>

### ***Cicely Saunders***

Dame Cicely Saunders has been undoubtedly the most influential figure in the development of palliative care in Britain. Having trained as a nurse during the Second World War, in the years that followed she was struck by how badly the pain of terminal cancer patients was managed. Such patients would often be shunted into side rooms and sometimes left in pain and distress. There was a reluctance to administer adequate doses of morphine for fear that this might hasten death, so pain often went unchecked.

Resolved to address this deficiency, Cicely Saunders re-trained, first as a hospital Lady Almoner (social worker), then as a physician, qualifying in 1957. Over the course of her subsequent medical career she began a revolution in the way we care for the dying. She led the way in bringing rigorous scientific principles to the management of pain, devoting herself especially to studying the effectiveness of morphine in relieving pain in advanced illness. Her observations of clinical practice convinced her that doctors were over-cautious in their utilisation of this potentially very effective analgesic, too concerned by the perceived risks of addiction, tolerance or overdose, with the result that doses were often sub-optimal and

infrequent. Through her work in the science of pain management she was able to demonstrate that, with careful titration and a regular dosing schedule, pain could be managed much more effectively and safely.

Cicely Saunders also brought a more rounded, holistic approach to the care of the dying, encompassing not just the physiological symptoms of her patients but also their emotional well-being, their psycho-social state and their ability to manage their illnesses in their own social environments. In doing so she pioneered the concept of “total pain”, which recognises that pain is more than just a physical phenomenon but the product of a much more complex and dynamic interaction between our bodies and our psychological state, our social circumstances and our sense of spiritual well-being. She argued that, to address pain effectively, it is necessary to look more widely at the patient’s experience of suffering and to address this in its totality.

To put her ideas into practice, she established a specialist medical unit where her scientific approach to pain management could be combined with the best psychological, spiritual and social care. The opening of St Christopher’s Hospice at Sydenham, near London, in 1967 is widely seen as the starting point of the modern hospice movement. The principles pioneered and established there have since spread to other hospices and palliative care units throughout Britain and the rest of the world, and they have provided a platform on which the present-day science of care of the dying has been built.

### ***Palliative Care in Britain Today***

In 1987 the Royal College of Physicians recognised palliative medicine as a specialty in its own right, like (for example) oncology or obstetrics or paediatrics. Specialist practitioners must complete a four-year training programme focused specifically on developing the knowledge and expertise needed for a dedicated career as a palliative medicine consultant. In this regard Britain differs from most other countries, such as the United States and The Netherlands, where palliative medicine is not a recognised specialty

and where palliative care is typically provided by generalist practitioners or anaesthetists who have developed a personal interest in this field. In Britain, by contrast, there are specialist teams of palliative care physicians, nurses and other health care professionals in most major hospitals and hospices, treating patients with the most intractable symptoms and able to use this experience to push forward the frontiers of the science.

There are some structural problems. From the beginning, the majority of patients receiving specialist palliative care have been those with cancer diagnoses and as a result close links have developed between oncology services and palliative care. It has taken some time to recognise that cancer sufferers are not alone in needing good palliative care. Many others afflicted by conditions such as end-stage heart failure, chronic obstructive airways disease, dementia or chronic neurological conditions are facing just as much physical, emotional or psycho-social hardship. A broadening of palliative care services is under way to embrace this wider constituency, including the development of links with other specialists, though limitations on resources inevitably constrain what can be achieved in the short term.

There is also some regional variation in the quality and breadth of services available. To some extent, this may be traced back to palliative care's roots in independent, charitably-run hospices, as a result of which it has sometimes found itself in the unusual position of standing outside the mainstream healthcare system and the NHS, with small units operating independently of one another and their local healthcare services.

It is also fair to say that, while the quality of specialist palliative care services in Britain is outstanding, many terminally or otherwise seriously ill patients do not get to access them either because their symptoms are not considered sufficiently serious or because other practitioners sometimes fail to recognise the need to 'change gear' and seek specialist help.

However, things are changing. July 2008 saw the launch by the Department of Health of a National End of Life Care Strategy for England<sup>iii</sup>. This initiative is probably the most significant development for decades in the

provision of palliative care services, seeking as it does to promote “high quality care across the country for all adults approaching the end of life”. The Strategy sets out a structure for palliative care services and a framework of quality standards.

An important requirement of the National Strategy is that specialist palliative care should integrate more effectively with primary care services, so that high quality end-of-life care is not the preserve of the few who are cared for in hospices or treated by specialist hospital teams but is available to everyone approaching the end of life. Good quality palliative care must not be something provided only by specialists. It must be available also from District Nurses, GPs and other community healthcare workers who care for patients at the end of their lives. A crucial role of specialist palliative care teams, therefore, is to train other clinicians in the principles of good palliative care, so that there is no excuse for sub-standard symptom control and all staff are able to recognise when specialist intervention is needed. Such cascading of palliative care skills into community medicine is also essential to allow more patients to die, supported by effective end-of-life care provision, in their own homes, which is where most would prefer to die, rather than to be removed in their final days or weeks to acute hospital wards.

### ***Palliative Care and ‘Assisted Dying’***

Palliative care has become enmeshed in the ‘assisted dying’ debate largely because the campaign for the legalisation of euthanasia or assisted suicide has focused on people who are terminally ill. So where does modern palliative care stand in this debate?

It is undeniable that the development of specialist palliative care in Britain has enabled much of the suffering that was once a common feature of dying to be removed or significantly alleviated. Though ‘bad deaths’ still occur, the number is now a fraction of what it was in our parents’ and grandparents’ day. The advances that have been made in the last 20 years in the science of pain management have been extraordinary. Doctors now have a considerably

broader range of painkillers available to them, with many new products offering better options for administration and longer-lasting effectiveness. There is also a much clearer understanding of how best to manage pain in incurable illness. While it is unrealistic to expect always to be able to eradicate pain completely, it is usually possible, even in the most challenging situations, to control pain significantly at a level that allows patients to experience real relief and to continue to function at an acceptable level without major side-effects. It is a widely held misconception that the use of morphine and other opioid painkillers will hasten death at the end of life: there is much evidence to show that this is not the case and that the appropriate use of opioids brings effective pain relief without shortening life.<sup>iv v</sup>

In a very small number of instances where a patient's suffering at the end of life does not respond to specialist palliative care, sedation can be employed. Continuous and deep sedation, which is not uncommon in some other countries, is rare in Britain: with specialist palliative care, it is possible to keep any necessary sedation to a minimum and for short periods. There is therefore no reason for patients to experience unrelieved suffering from terminal illness in the closing days of their lives.

This is not to say that instances of poorly-controlled pain do not occur. That does sometimes happen, but the cause is often inadequate palliative care training on the part of generalist clinicians rather than that the pain cannot be controlled. As observed above, a major challenge of the National End-of-Life-Care Strategy is to ensure that state-of-the-art knowledge of pain management is cascaded effectively from specialists into hospital wards and community medicine.

Pain relief and the alleviation of other physiological distress are just part, albeit an important part, of the palliative care picture. Depression, unsurprisingly, is a common feature of terminal illness<sup>vi</sup>, but it too can be diagnosed and treated, even when death is close. Undiagnosed depression can impact significantly on a person's quality of life at a point when time is

short. Increasing fatigue and physical weakness, which are common at the end of life and can give rise to fears among patients that they are losing control, can also be addressed. Good palliative care focuses on the patient as a whole person rather than as a collection of separate and unrelated symptoms and, if applied in a timely manner, has been shown to transform the lives of people with life-limiting illness. A recent study published in the *New England Journal of Medicine* has demonstrated that early referral to palliative care services of patients with metastatic lung cancer can result in significant improvements in both quality of life and mood<sup>vii</sup>.

However, in parallel with these advances in the science of palliative medicine and in the development of multi-disciplinary palliative care, there have been countervailing factors at work. Thanks to better medicine, surgery, hygiene and nutrition, we are living longer, but not always longer and healthier, lives. Though we have become better at surviving and coping with diseases like cancer or end-stage organ failure, we have also become more susceptible to chronic and degenerative illnesses that can sometimes bring long-lasting discomfort and distress.

We have, moreover, as a society become less familiar with death and dying and less inclined to see these events as a natural and inevitable part of life. Within the memory of many people alive today death and dying were once everyday occurrences and there was a general recognition that potentially fatal illness could arise at any time. This contrasts markedly with attitudes to death today. We take good health and a long life for granted. It is possible to reach well into one's adult years without ever experiencing a bereavement of a close relative or friend. Death and debility have increasingly been banished to hospitals, hospices or nursing homes, with doctors and nurses taking over much of the responsibility for day-to-day care as well as clinical treatment. This shift in our experience of the dying process has meant that what once was commonplace and integrated into our daily lives has become remote and unfamiliar. As a result the prospect of witnessing the typical phases of someone's death can be daunting, in a way it was not to earlier generations, and the thought of having to experience the process of dying

oneself can be a terrifying prospect to some. It is not surprising therefore that the response to diagnoses of life-limiting illness can sometimes be anger or indignation.

Stemming from this is a commonly expressed fear that, if we are terminally or otherwise seriously ill, we will be kept alive and treated against our wishes. This is an understandable fear. With society's changing attitudes to death and dying, medical teams can sometimes find it hard to recognise the inevitability of a patient's death or feel obliged to continue offering treatment beyond the point at which the benefits outweigh the burdens. However, every patient has the right to refuse treatment, including life-sustaining treatment<sup>viii</sup>. Treatment refusal should not be confused with a wish to die: in most cases it betokens a wish to be rid of burdensome treatment and, if necessary, to let nature take its course. Recent changes to the law have, moreover, clarified the process by which such refusals can be made clear and continue to be legally binding even after the person concerned is too unwell to express their wishes. One of the roles of palliative care practitioners is to help terminally ill patients to plan their care, including (where necessary) halting or declining burdensome treatments, placing a strong emphasis on preserving personal autonomy.

Palliative care is not a panacea for serious illness: no branch of medicine is that. There will always be some patients whose suffering it cannot relieve, though it is fair to say that the number of such people is small and the suffering involved is often of an existential rather than a clinical nature – ie it derives from distress either at the fact of dying or out of a desire to control the dying process rather than from the symptoms of the illness itself. What cannot be doubted is that recent advances in the science of palliative medicine and in the development of palliative care as a whole have transformed the dying process and that, if the structural and managerial changes required by the National Strategy can be achieved, there is no reason why, other than in very rare cases, anyone should have to die in pain, discomfort or fear.

But why cannot ‘assisted dying’ be seen as just another option in the end-of-life-care toolbox? Of course, if the law were to be changed to allow ‘assisted dying’, that option would legally exist. But it is difficult to see how it could be regarded as an option within palliative care. The World Health Organisation is clear that palliative care exists “neither to hasten nor to postpone death”, and surveys show that well over 90% of palliative care professionals in Britain are opposed to ‘assisted dying’ and would be unwilling to perform it if it were ever to be made legal<sup>ix</sup>.

Moreover, the impact on patient as well as physician opinion needs to be considered. Hospices are no longer regarded simply as places where seriously ill people go to die but also as centres where difficult clinical conditions can be stabilised and from which, in a large proportion of cases, patients can return to the community to live active or semi-active lives. Palliative care, whether in hospices or in specialist hospital units, needs to command the confidence of seriously ill patients as a life-affirming branch of health care. This trust could easily be undermined if it were to become associated in the public mind with physician-assisted suicide or physician-administered euthanasia. In that event some patients could be reluctant to accept the palliative care they badly need, fearful that it is simply a euphemism for hastening their deaths. It is important to be able to reassure seriously ill patients that such activities do not form part of palliative care regimes.

Whether ‘assisted dying’ could be an acceptable option *outside* palliative care is for others to say – though the opposition of doctors generally to the practice does not suggest that it could satisfactorily be embedded anywhere inside health care. Palliative care professionals can, however, make an important contribution to the debate here from their front-line experience of death and dying. Most doctors treat terminally ill patients from time to time, but those who specialise in palliative care treat dying patients all the time. They have daily, first-hand experience of the reality of death and dying and of the vulnerabilities of patients who are facing death and of what can be done to help them on their final journey. Much of this experience is

seriously at variance with stereotypical images of terminal suffering and of patients calmly and collectedly wanting help to end their lives. While unrelieved suffering at the end of life certainly exists, most deaths following terminal illness are relatively peaceful. But the public does not hear about them for the same reason it does not hear about successful surgery or safe landings of airliners. Almost all palliative care doctors have encountered the apparently highly-resolute and seemingly clear-minded patient who requests help to 'end it all' rather than complete the natural dying process but who, after experiencing good palliative care, changes his or her mind and dies peacefully – often living for much longer than predicted because palliative care has reduced the stresses of the illness. Indeed, were the legalisation of 'assisted dying' ever to be contemplated seriously, an essential requirement would be the experience of good palliative care rather than, as current campaigning seems to envisage, simply a briefing about it.

It is the vulnerability of patients who know they are going to die – their susceptibility to mood swings, to concerns about the consequences of their illness for their families and to the unconscious signals that their doctors and nurses can send them about their state of health and what the future may hold – that leads almost all palliative care specialists to take the view that offering 'assisted dying' as an option to people undergoing such stresses would be fraught with hazard. They recognise that a very small number of strong-minded and highly determined patients may not be harmed by legalising such practices, but they are conscious that, for every such patient, there are many others more afraid than resolute, more fearful of the future than wanting to die, more in need of help than of options, who could all too easily find themselves embarked on a course about which they were less than wholehearted but to which they could see no alternative. Compassion for an individual may prompt sympathy for a one-off assisted death, but compassion for our wider society should make us wary about the unintended harms of legalisation.

## *Conclusions*

Palliative care in Britain leads the world in quality. There are some structural and managerial issues to be resolved concerning distribution and access, but remedial action is in hand to correct these. Palliative care is not a panacea for solving all the problems that terminal illness brings, but there is no doubt that it has transformed the experience of dying significantly in recent years. At the same time, factors pulling in the other direction have arisen, including unfamiliarity in society with care of the dying and an unwillingness to see death and dying as natural stages of life. Given its remit neither to hasten nor to postpone death and the substantial opposition of palliative care professionals to 'assisted dying', this latter practice could not be seen as an option within palliative care. The front-line experience of palliative care specialists suggests that the case for legalisation is being built on false perceptions of death and dying and would be likely to put terminally ill patients at serious risk.

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<sup>i</sup> "The Quality of Death", Economist Intelligence Unit, Report to the Lien Foundation, February 2010

<sup>ii</sup> Often referred to by campaigners for legal change as 'assisted dying'. For the sake of brevity, this two-word term is used throughout this paper to include both physician-assisted suicide and physician-administered euthanasia

<sup>iii</sup> Similar initiatives have been developed for Scotland, Wales and Northern Ireland

<sup>iv</sup> The use of opioids and sedatives at the end of life, Sykes N, Thorns A, *Lancet Oncol.* 2003 May; 4 (5):312-8.

<sup>v</sup> Lethal opioids or dangerous prescribers? George R, Regnard C. *Palliat Med.* 2007 Mar; 21(2):77-80.

<sup>vi</sup> Depression in advanced disease: a systematic review part 1. Prevalence and case finding. Hotopf M, Chidgey J, Addington-Hall J, Ly KL. *Palliat Med.* 2002 Mar; 16 (2): 81-97

<sup>vii</sup> Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer, Temel JS et al, *N Engl J Med* 2010; 363: 733-42

<sup>viii</sup> Mental Capacity Act 2005, Advance decision to refuse treatment - <http://www.legislation.gov.uk/ukpga/2005/9/part/1/crossheading/advance-decisions-to-refuse-treatment>

<sup>ix</sup> Survey of APM members views on Euthanasia / Physician Assisted Suicide - <http://www.parliament.the-stationery-office.com/pa/ld200405/ldselect/ldasdy/86/4102113.htm>