End of life care

When pain relief just isn’t enough

Even with access to the best palliative care, some patients still die in agony – assisted dying should be an option

New research from Dignity in Dying has uncovered a shocking reality: that even if there was universal access to the best possible hospice care, every day in the UK 17 people would die with absolutely no relief of their pain. This is a conservative estimate. It’s likely an even greater number would die with partial pain relief, with other horrific symptoms such as terminal haemorrhages or fungating wounds, or with the psychological torment that comes from not knowing how you will die or how long it will take.

Funding won’t fix this
Improved funding for and access to palliative care, though certainly needed and welcome, would not help in cases like these. This is the inescapable truth that can no longer be glossed over: that some people’s suffering is simply beyond the reach of palliative care. Surely they deserve another option – the choice of an assisted death.

For too long, assisted dying has been put in the ‘too difficult’ box and pushed to one side. Dignity in Dying campaigns for greater choice and control at the end of life, including access to assisted dying for mentally competent adults.

By Sarah Wootton
chief executive of Dignity in Dying, a not-for-profit organisation that campaigns for a change in the law on assisted dying in the UK
with a terminal illness. Its research reminds us that current end of life practices already involve complex ethical judgements.

Some choices already allowed
We allow people to opt for voluntary stopping of eating and drinking, to refuse life-prolonging treatment, to receive palliative sedation, and for doctors to administer pain relief that may hasten a patient's death, as long as that is not the primary reason.

Healthcare professionals are already making careful assessments about a patient’s prognosis, their level of suffering and their mental capacity, as well as identifying potential abuse or coercion that could influence a patient’s decision.

While palliative care options can provide a peaceful end for some, they can also result in protracted, traumatic deaths that are distressing for the individuals and their families.

And we shouldn’t forget the nurses and doctors caring for them. A YouGov survey of 1,008 healthcare professionals, conducted earlier this year on behalf of Dignity in Dying, found that 43% of healthcare professionals have experienced someone suffering at the end of life despite receiving high quality palliative care.

If there’s no way to ease pain
Susan Strong, who was interviewed for the Dignity in Dying report, spoke movingly about the compassionate care her 31-year-old daughter Fiona received as she died. But her nurses were left in tears as she suffered a painful, prolonged death.

Fiona was diagnosed with rhabdomyosarcoma in 2015 and underwent chemotherapy, radiotherapy and the removal of one of her eyes, among other surgeries. By April 2018, when she was moved into a hospice, she had lost all mobility and the tumour had begun growing through her nose and throat. She had trouble breathing and She had trouble breathing and through her nose and throat. The tumour had begun growing and she was moved into a hospice, surgeries. By April 2018, when she was moved into a hospice, she had lost all mobility and the tumour had begun growing through her nose and throat. She had trouble breathing and she was moved into a hospice, among other surgeries. By April 2018, when she was moved into a hospice, she had lost all mobility and the tumour had begun growing through her nose and throat. She had trouble breathing and through her nose and throat.

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Fiona said, ‘Mum, I just want them to put me to sleep, I can’t do this anymore’. She was offered palliative sedation and told that within four hours she would be asleep, wouldn’t wake up and would eventually drift off. But four days later she was still waking up in agony. Her family said goodbye seven separate times.

The nurses couldn’t believe the level of drugs Fiona was receiving. They were devastated there was nothing they could do to take Fiona’s pain away or give her the death she deserved.

Nurse support for assisted dying
Nurses are often more intimately involved in the care of a person with a terminal illness than other healthcare professionals, which may explain why they tend to be more supportive of assisted dying. In New Zealand, where an end of life choice bill recently passed its second reading, a majority of nurses (67%) said they would support legislation.

In Oregon in the US, where assisted dying has been in place for more than 20 years, a survey of hospice nurses and social workers found that it had led to care professionals becoming more interested in and knowledgeable about hospice care, leading to an increase in referrals to end-of-life specialists and better pain management.

Here, the RCN has taken a neutral stance on assisted dying for several years, whereas the Royal College of Physicians (RCP) only dropped its longstanding opposition in favour of neutrality in March 2019.

The Royal College of GPs and the British Medical Association have committed to survey their members’ views. I hope our new research provides food for thought and they can follow the RCN and RCP, adopting a neutral position that allows them to engage in the debate while putting patients’ views first.

More than 100 million people around the world live in jurisdictions with laws that provide choice and control to people with a terminal illness who are mentally competent, while ensuring robust protection for the rest of society; 84% of the British public believe we should do the same.

If the UK is serious about improving end of life care and ensuring everyone has the death that’s right for them, then assisted dying must be a part of the conversation.

Dignity in Dying dignityindying.org.uk