

Should you respect a dying wish?

→ Anna Wagstaff

Some terminally ill cancer patients, seeing only suffering and indignity ahead, want to die at a time and in a manner of their own choosing. But how does legal backing for assisted dying impact on efforts to strengthen palliative care? And is helping patients to die compatible with the duty of doctors, nurses and carers to save life and protect the vulnerable?

For George and Hannah, the decision to end their lives at a time and in a manner of their choosing was not difficult. Both were dying from cancer. After 50 happy years of married life, they saw their lives spiralling downhill out of control.

Hannah (names have been changed for reasons of privacy) had pulled through a week she was not expected to survive. Blockages caused by advanced GIST (gastrointestinal stromal tumour) had triggered colonitis and peritonitis. Dosed with large amounts of diamorphine, she was troubled by nightmarish hallucinations – though fully conscious, she had been unable to move or tell anyone what she was going through.

Her husband, suffering late-stage colon cancer that had spread to the liver, had been through a similar acute crisis and

bad experiences with his pain medication.

They were unable to get about or to eat or drink properly and they knew that their pain and discomfort would only get worse. In addition, Hannah could not stray far from a bathroom and was effectively housebound.

Despite expert and dedicated care from doctors and nurses, both faced the prospect of progressively losing control over their bodies while remaining mentally active and alert. “Having seen what their end would be like, they very quickly made their decision,” said daughter Diana.

If deciding what they wanted was easy, achieving their aim was not. Their oncologist, GP and palliative care workers at the hospice were all deeply sympathetic and helpful. But this was the UK, where there was no lawful way they could intervene to help end a life. Like

others before them, disabled and unwell as they were, George and Hannah found a way to make the trip to Switzerland, together with their children, where they ended their own lives on their own terms at a Dignitas clinic.

Initially very hostile to the idea, Diana changed her mind as she saw what a tremendous relief her parents felt at taking back control. “Seeing somebody frightened of the way they are dying is a horrible thing,” she says, “Not having any control over your body or how you are looked after; knowing then that all you have to do is have a drink and go to sleep. The peace that they reached – certainly in my parents’ case – was extraordinary. I think it is absolutely inhuman that we should be left to the last weeks of harrowing deterioration, pain, not being able to eat, drink, walk...”

Why should anyone be able to tell someone in this position that they can't just slip away, she asks?

Diana is careful to be very specific about the question she poses. This is not about doctors or anyone else deciding that a person is suffering too much or their life is no longer worth living. Nor is it about a right to die that applies to everyone at any time regardless of their circumstances. It is about the right of people who are dying and who are suffering to be able to get assistance in ending their lives with dignity, without having to travel abroad and be reviewed by doctors they have never met. "You are not choosing to die – fate has determined that. You are choosing the method of your death and that is the fundamental thing," she says.

PUBLIC SYMPATHY

The stories of George and Hannah are far from unique. All over Europe public sympathy is growing for people who find themselves in this unenviable situation. Pressure is building for legal changes that would allow people who are suffering with a terminal illness to die in the manner they wish – as is already possible in a handful of countries including the Netherlands, Belgium and Switzerland.

Opposition to such legislative change comes from various quarters. There are those who, often for religious reasons, believe that taking a life – even your own life – under any circumstances is morally wrong and must always be a crime. But there are also those whose opposition takes a more pragmatic form. If laws are changed to help people in genuine need, like Hannah and George, the argument goes, a line would be crossed. We'd be on

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a slippery slope, ending a life would become socially acceptable, and vulnerable people would be at risk.

The extreme example often cited is the Nazi programme of killing 'life unworthy of life' – people deemed useless to society because they were old and infirm, disabled or had learning difficulties. This is the spectre raised by Baroness Campbell, who has muscular dystrophy and spearheaded opposition in

the House of Lords to a British bill on assisted dying, which would have granted immunity from prosecution to people helping friends or relatives make the trip to Switzerland to die. She described listening to doctors discussing whether or not she was worth resuscitating when she was hospitalised with an acute chest infection. "You wouldn't

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DIE WELT

A QUESTION OF CONTROL

Lars Johan Materstvedt is a professor of philosophy who specialises in this area. Based in Trondheim University, Norway, where he conducts research on medical ethics, he was lead author of

the position paper drawn up by an Ethics Task Force of the European Association for Palliative Care (EACP) in 2003. He says that while the Dutch euthanasia regulation was drawn up to address situations where medicine was unable to deal with 'medical' problems, today it is increasingly being used to deal with issues of 'personal control'. "In those situations of extreme physical symptoms – pain, dyspnoea and so on – they are using more and more palliative care and palliative (terminal) sedation. The main reasons people want assisted suicide or euthanasia is not pain, shortness of breath or vomiting. It is more and more a psychological and psychosocial thing."

The legislation specifies that doctors can only consider agreeing to a request by a

patient to end their life by drugs where there is 'unbearable' suffering with 'no prospect of improvement', and where doctor and patient agree that there is no 'reasonable' (palliative) alternative in light of the patient's situation. Wanting to die on one's own terms rather than slowly collapsing into incontinence and dependence, losing the will or motivation to fight on, are not strictly medical needs. Yet these sorts of issues prompt an increasing proportion of requests to die, says Materstvedt. "Research has shown that in many cases, doctors think there are good alternatives, but the patient says 'no, this is intolerable, I don't want

want to be resuscitated,' they said, causing me to even doubt myself. Why were they saying this? What did they know that I didn't? It could have been a death sentence, one that I was too ill to resist."

Given that the proposed legislation was about terminally ill people who expressed a consistent and independent wish to end their own lives, the argument may say more about the emotive and often muddled nature of public and political debate on this issue than about the real dangers inherent in legalising assisted dying. Yet evidence from the Netherlands does seem to indicate that

changing the law to relieve the suffering of people like Hannah and George may result in the law gradually being applied to a wider group of people than originally intended. In the Netherlands, since 2002 doctors have lawfully been able to end a patient's life at his or her request – they use the term 'euthanasia'.

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“In many cases, doctors think there are good alternatives, but the patient says ‘no, this is intolerable’”

further treatment, I want an injection instead.’ Doctors cannot force the patient to undergo treatment, so this puts them in a very difficult position. Sometimes they give in.”

Today, there is debate in the Netherlands over whether being ‘tired of life’ should be sufficient reason to have the right to assisted dying. This seems

unlikely to happen any time soon, and would presumably require a shift away from the current Dutch system, in which doctors are the sole arbiters, to something more akin to the Swiss model, where much of the process of assisted dying is in the hands of civic society, in the form of lay volunteers working in ‘Right to Die’ societies like Dignitas.

As a palliative care specialist who practised for 25 years in the Netherlands, Ben Zylicz (now based in the UK) is uncomfortable with the Dutch legislation. He resents the way many patients now feel they can visit a doctor and demand their ‘right’ to die. “My view is that everybody has his own autonomy, within this he may wish to die. Autonomy of the patient also means autonomy of the doctor and of society. My view is that they should look together for somewhere halfway between. The patient may ask, but not demand, that the doctor kill him. The doctor may never say, ‘Sorry, I’m not at home’ because you are asking for this. They should look for a compromise. A kind of compromise is palliative care.”

He worries that the attitude that sees assisted dying as a right is leading to doctors agreeing to perform euthanasia as a ‘first resort’, without making sufficient efforts to persuade the patient to try alternative options.

“Most patients who are requesting assisted dying are not aware of what palliative care can do. Many hundreds of patients I came across who wanted to die earlier were first of all very afraid they would have terrible pain. It was not actual pain, but fear of complications of very bad, poor dying. Many of them had experience of their parents or grandparents dying like this. They just wanted to avoid this. These are the patients who, when they seek our help, we can help in nearly 100% of cases. That’s our daily bread.”

Zylicz classifies patients asking for euthanasia into five categories – A to E – based on a study of 200 patients he did around 15 years ago.

TERMS OF DEBATE

The term ‘**euthanasia**’ comes from the Greek words *eu-* “good” + *thanatos* “death”. Its first recorded use in English was in 1869, signifying “legally sanctioned mercy killing”.

Misuse of the term to provide cover either for a state policy of killing people deemed of no value to society or for paternalistic doctors taking it upon themselves to decide which patients should be ‘put out of their misery’ and which ‘had lives worth living’, led to the adoption of the term ‘**voluntary euthanasia**’ to refer to situations where the patient has made his or her own request to die. Many now reject this term, arguing that all euthanasia is voluntary by definition – helping a patient to die without their explicit request is ‘**murder**’.

In the Netherlands, Belgium and Luxembourg, legal sanction for helping patients to die rests only with doctors and is reserved for patients who have requested help to die, who are mentally and psychologically competent to make that request (this does not necessarily exclude people suffering mental illness), who are suffering unbearably and for whom there is no prospect of improvement in their situation. These countries use the term ‘**euthanasia**’.

In Switzerland, ‘euthanasia’ – as in a doctor administering a lethal drug – is illegal. However, clause 115 in the penal code states that assisting someone to commit suicide is punishable ‘if done for selfish motives’, which effectively makes it lawful for any citizen to help someone end their life so long as they can show it was done for altruistic reasons and that they do not administer the drug themselves. The law was originally conceived as a way to enable ‘honour suicide’ in the days when bankers who reduced their clients to destitution might choose to ‘fall on their swords’. Today this is the law that allows Right to Die societies like Dignitas to help people die through ‘**assisted suicide**’. Only a doctor, however, can prescribe the drug (usually sodium pentobarbital) and there are strict rules of professional ethics – similar to those that apply in the Netherlands – that govern the circumstances under which this can be done.

Though understandable given its historical context, the term ‘assisted suicide’ is considered by many as inappropriate and demeaning when applied to people who are terminally ill. Debates about both ‘euthanasia’ and ‘assisted suicide’ now often use the term ‘**assisted dying**’.



“A huge step towards a more compassionate law”. Last July, multiple sclerosis sufferer Debbie Purdy won a landmark ruling that effectively gives the green light for her husband to accompany her to Switzerland to die. Though assisting a suicide remains a crime in England and Wales, punishable by up to 14 years in prison, the legal authorities have now been forced to spell out the circumstances under which those accompanying people like Debbie to clinics abroad will – or won’t – face prosecution

A stands for Afraid. Patients who need reassurance about what palliative care can do for them.

B stands for Burn out. Very often in the past these patients were very effectively treated for their disease, and their disease is halted or absent, says Zylicz, but they are so damaged that they cannot live. “They are exhausted by their lives. For these patients it is very difficult to help them, and the only thing is to prevent these cases from happening.” His message to oncologists is, “Be very careful of heroic operations, of overtreatment of the disease, because sometimes we can create this kind of exhausted patients who are very difficult to treat.”

C stands for Control freak. “People who are not medically ill, but they think that they can just come to a doctor and the doctor will just take out a syringe and kill them. They want to be in control. And think everybody around has a duty to support them in this,” says Zylicz. “This is a very difficult group for us, and palliative care is not a very good approach for them.”

D stands for Depression. Research has consistently found a significant link between depression and requests for euthanasia, and is a factor in about one-third of all euthanasia requests that are turned down by Dutch doctors. “With these patients, recognition and treat-

ment of depression can change enormously their wish to live.”

E stands for Extreme. These are patients who do not respond to treatment or cannot tolerate the side-effects – only 3%–4% of patients requesting euthanasia fall into this category, says Zylicz. “These patients are really not to be helped by medical means. You may sometimes look for the last resort of terminal sedation, providing they are terminally ill and dying.”

There seems to be a fair consensus on the general outlines of this classification among professionals involved in this area, though many show a bit more understanding for the wishes of the ‘control freaks’ – presumably the people Materstedt talks about, who for ‘psychosocial’ reasons don’t want to lose control of their bodies and become dependent.

THE ROLE OF PALLIATIVE CARERS

Like many palliative care specialists, Zylicz defines his job as helping people live the best lives they can, and sees euthanasia as incompatible with this aim. He talks about the need to go the extra mile to win patients’ trust, to give them the confidence that there will always be someone there for them, even at 6.00 am on New Year’s Day. He talks too about fears among many of the elderly people he cares for at the Dove House hospice in Hull, England, that the doctors will take it upon themselves to end their lives prematurely, under cover of administering pain-relieving medication. And he feels very strongly that palliative care specialists should not be expected to end lives – “If we had a duty to comply with patients’ requests for euthanasia, I think that would be the end

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of palliative care” – and nor should they take on the task voluntarily – “I cannot do euthanasia for one patient and give morphine to relieve the pain of another patient. I need a clear description of my job, for both our sakes, but particularly for the patient.”

That said, he concedes that in the case of the Netherlands, the quality of palliative care accessible to the average patients has jumped from a very low level 15 years ago to a standard comparable to what is available today in the UK, where the palliative care and hospice movement started 50 years ago. Part of that, says Zylicz, is thanks to pressure on the Dutch Minister of Health, who was criticised, at the time the euthanasia bill was being debated, for failing to invest in the country’s palliative care services. Equally important, though, was the impetus the new law gave for doctors to train up in palliative care techniques. “Many GPs and consultants realised that if they do not have the knowledge to deal with these problems they would maybe feel they had to comply with these requests when they did not want to. This process is still continuing; there is an enormous interest in Holland in palliative care among GPs.”

Eight years on, Zylicz believes that the way euthanasia requests are handled in the Netherlands is now improving. “This was a problem in the Netherlands for a long time that doctors were doing this without exploring alternatives. That’s dangerous. I think this process is now reversing in the Netherlands. Doctors have more choices and patients have more choices.”

A good result, surely. Yet questions

remain over whether greater choice will always be the outcome of introducing rights to assisted dying. As Materstvedt comments, “If we look 10, 20, 30 years ahead, there is this tsunami of old people who are going to need palliative care, and the costs are going to be enormous. Do you have the money for all that treatment as people live longer and get diseases like cancer? There is an economic issue.”

The danger that legalisation of assisted dying could be seen as a cheaper alternative to developing palliative care services is a major concern, particularly for palliative care organisations, which are still fighting to become part of mainstream medical practice in much of Europe.

But some believe these fears are misplaced – including Georg Bosshard, a GP and medical ethicist who was involved in the medico-legal investigation of early assisted suicide cases in Switzerland, and has been following the issue closely ever since. “There is no evidence that, once you have open legislation on assisted suicide, palliative care will have less support than before. I think the truth is the opposite. If you look at places like the Netherlands, Belgium, Oregon, you see that discussion on assisted suicide has always forced discussion on palliative care. I cannot see an opposition of these two worlds. The goals are different.”

This is a view strongly shared by Franco Cavalli, medical oncologist and director of the Southern Switzerland Institute of Oncology (IOSI) in Lugano, who is currently trying to make it easier to help the small minority of hospitalised cancer patients who want assistance in dying.

PATIENT CHOICE

With very few exceptions, hospitals and nursing homes in Switzerland do not permit assisted dying to be carried out on the premises, and most people, of course, want to end their lives at home. However, there are occasions when for various reasons this is not feasible. While IOSI has long provided palliative care as an integrated part of individual care plans, Cavalli believes that being able to offer assistance in dying gives patients an added option and is part and parcel of patient choice. While he sympathises with the battle palliative care specialists are still having to establish themselves in many parts of Switzerland, and agrees that lack of access to palliative care is still a significant problem, blaming this on the legal availability of assisted dying, he says, is simply incorrect. As he points out, countries with the strongest opposition to assisted dying are often also the most restrictive when it comes to giving patients in acute pain access to opioid medication – still a major issue in parts of Europe.

“To be able to help someone at the end to die increases the autonomy of the patient, and if you try to do this you also will try to give them the best palliative care you can offer. And patients in general are very much in favour of more palliative care. So you cannot say that at the end you can decide more about your death but not about which type of palliative care you are going to get. I am personally convinced that, even if we were to become more liberal in assisted suicide and euthanasia, that would not impact negatively on palliative care. It would even impact posi-

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tively in the sense that it is recognising the autonomy of the patient and that the patient can decide.”

There is, however, a caveat here. “Switzerland is Switzerland, the Netherlands is the Netherlands and the UK is the UK,” as Bosshard puts it. “Every country must find a way that fits its culture and institutions, and there is no gold standard on how to approach this issue.” The Netherlands and Switzerland are two of the most liberal states in Europe, with populations that get involved in civic issues. The right to euthanasia or assisted dying only came about after decades of debate and public pressure, and was part and parcel of a concerted move away from a traditional culture of healthcare based on paternalism to one that put patients much more in the driving seat.

It’s a moot point whether the same could be said about Belgium and Luxembourg, both of which introduced euthanasia provisions very similar to the Dutch system shortly after it was introduced in the Netherlands, prompting criticism from some quarters that there had been insufficient public debate within their own countries.

Certainly lively discussions have been underway for many years in countries like Scotland, where an assisted dying bill is currently being debated in Parliament, France, where a similar bill is being sponsored by the Socialist Party, and England, which has reached an uncomfortable compromise on the rights of friends and family accompanying someone to Switzerland to die. Even in Germany, where awareness of past crimes has made any talk of assisted dying complete taboo within the medical establishment, public debate is growing, and there are calls to open up debate on this issue within the German general medical council.

The real concerns are, perhaps,

Views from the frontline

Primary care physicians in the Netherlands have mixed feelings about their role performing euthanasia according to a study by Harm van Marwijk and colleagues published in the journal *Palliative Medicine* (2007, 21:609). No study has yet been done to investigate views on assisted dying among oncology professionals.

- “I can say ‘no’ now, with my acquired palliative knowledge, without leaving patients in the cold. I want to be skilled in palliative care and also able to perform euthanasia well. I want to feel good about this.”
- “I now say clearly to everyone: I don’t perform euthanasia any more. To my surprise a number of people say: ‘Doctor, you are so right, I understand completely.’ Then I thought to myself: how deep do these requests really go? I found that disconcerting to notice.”
- “I wish they would no longer ask me, but I’m scared to say so. Perhaps I will have the courage to say so in a few years time. I feel very close to people, but I also feel angry: ‘what do you think you can ask of me?’”
- “I found it [performing euthanasia] very hard and lonely the first time, but I felt I’d done a good thing.”
- “What has struck me most is the commitment of the family [to the patient’s circumstances], they all sympathized. I found that unique, and stood there with tears in my eyes.”
- “I need to care deeply for someone to be able to perform euthanasia. I have only performed euthanasia for people for whom I cared and whom I knew well.”
- “To have to decide about the moment of death has created enormous unrest around the deathbed”

about countries where palliative care services are rudimentary and the concept of patient autonomy is not well developed. “People tend to ask what would happen if euthanasia were allowed in Italy or Greece or Spain,” says Cavalli, “but that is a theoretical question, as there is no immediate prospect of these countries becoming very liberal as regards euthanasia because of ideological reasons.”

The same does not apply to many of the former eastern bloc states, where healthcare retains much of the paternalistic culture of former communist days, adds Cavalli. “I’m afraid that, in the current situation of financial crisis and very poor healthcare systems, if you do not really specify in the law that assisted suicide and euthanasia is pos-

sible only with the absolute consent of the patient and you have measures to enforce that, you might even have some kind of ‘social euthanasia’, because doctors in geriatric homes will say these are people of no value any longer and are just a burden to society.”

This does not mean, says Cavalli, that debate on the issue should be avoided or suppressed. “I think public debate can only improve the situation. Because you cannot talk about autonomy of the patient for the last hour of their life and not talk about the rest of their life. If you start to recognise the autonomy of the patient and the right of the patient to decide, not the doctor or the state or the Pope, in the end your whole approach to the patient will change.”