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paulcosford@doctors.org.uk
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ESSAY

The bench: reflections on an incurable diagnosis and control at the end of life—an essay by Paul Cosford

Incurable lung cancer has prompted **Paul Cosford** to consider again his personal views on assisted dying

Paul Cosford emeritus medical director

Perhaps it is the same for us all, whatever our age—if we know that we are approaching the end of our life, it is helpful to have a place of contemplation. I walk from the back door, along an old track and across the field that is the home of two familiar chestnut coloured horses. They raise their heads as I pass, and a poorly constructed wooden bench sits in the field beyond. It is perfectly situated for the view, which appears just as the path starts to descend a sandy ridge. Two rough planks, one to sit on, one for leaning, are fixed to the two decaying tree stumps that form its legs. It wobbles slightly but is strong enough for me to rest and ponder.

I am not an old man, but like the bench I won't last long. I know that the incurable lung cancer, diagnosed three years ago, will end my life before many more years pass. But I don't rail against the world as I sit on the bench. I've seen enough people die younger and in worse circumstances for that. I do watch the world go through its familiar cycles, knowing that I won't see many more. The inquisitive lambs of spring, full of life then suddenly disappearing as their short lives end in the abattoir. The crops, subtly changing colour through hues of verdant green, then replaced by the bare soil of the ploughed fields after harvest.

I think about how the view must have looked centuries ago and how it will appear in years to come, when all of us are long forgotten. Many features will be similar to those I see now. The contours of the hills, the meandering river on the plain below. This sense of permanence helps bring perspective to my temporary existence, and I draw comfort from the contrast with the fragility of the bench.

I prefer to think about today

I try not to think about the disease itself. I will probably live another year or two. Who knows, maybe more? But the remaining treatments and their impact, the gradual demise that will accompany the cancer's inevitable spread, the fact that life will end much sooner than I had hoped—I know these will come, but there's little point in focusing on them. I prefer to think about today, this week, this month. To focus on what I can still do; the writing I've started to enjoy; the contribution I can still make, even working limited hours, to my specialty and to challenges such as the current pandemic response. Most importantly, making time to spend with the people close to me. I try to value life for what it is now, to keep calm and carry on.

But sometimes, as I sit on the bench, I cannot avoid thinking about less pleasant things. I did not relish switching to carboplatin, in combination with other drugs, after three years of targeted biologic treatments with few side effects. Of course, they are effective chemotherapies, and I am hugely grateful for them. But they are also noxious drugs that make me feel unwell. And my exercise tolerance, already much lower than before my cancer, is likely to reduce still further. I already get out of breath walking uphill, and I can manage only a few miles on the bike instead of the several hundred I used to enjoy as an ultra long distance cyclist.

I try hard not to, but inevitably I sometimes ponder how I will die. I know there is tumour close to vital structures in my chest, I have a permanently collapsed lobe in one lung, and there is the liver metastasis, there at diagnosis, which might grow again. There are many unpleasant scenarios I can contemplate. In some ways I hope it will be an infection that takes me, as that may be a quicker and kinder option. Perhaps, paradoxically, covid-19 or flu, which I have worked so hard to control over the years as a public health professional, will come to my aid.

The fear of lack of control

My biggest fear around dying is the lack of control. The lack of ability, if all becomes too much, to advance the end a little, to take some control in my final days. I might have a diamorphine pump at that time, and the idea of having an extra vial in the fridge for me to use if I need it is appealing. But I know it cannot be prescribed legally for this purpose so is not really an option. Despite helpful conversations with excellent palliative care specialists, this final element of choice and self-determination seems to evade me.

I never wanted to be a supporter of changing the law in favour of assisted dying. I have always thought that the law is too blunt an instrument to deal well with the complexities of such difficult moral and ethical matters. I hope that my doctors, working with me and my family, will be able to navigate, carefully and sensitively, to the end of my life with the Hippocratic saying of "cure sometimes, relieve often, comfort always" at the forefront.

Yet the legal frameworks around the end of life do seem to get in the way. The option of a prescription to allow me, in my last days, to bring forward the end of my life is simply not there. If it were, I and others

in a similar position could have more open conversations with our carers about how our lives will end. Conversations that include clear and practical options that I would probably not take up. But knowing those options were there would help me live better now and with less concern about the end of life.

Of course, there are dangers. That assisted dying becomes an expectation, not just an option in certain clearly defined circumstances. That the lives of people who are seriously ill, live with disability, or are just different from the norm might be devalued. That some doctors might feel compelled to provide treatments that, on a deeply personal level, they think are wrong. These are genuine concerns. Yet I am sure that a careful look at other countries' experiences can help us get this right so we can learn from where it works well, identify the risks, and agree how to mitigate them.

Set aside entrenched positions

I am convinced that it is time to look at this again. A review that takes account of changing views across wider society seems timely. Of course, professional bodies will have a view, but this is a wider societal issue around the fact that we die and the need to think properly about how we die. We need to set aside entrenched positions on each side of the debate and look openly at the problems faced by people at the end of their lives. We need to understand why rational, law abiding people sometimes feel compelled to travel to Switzerland for such care, often not telling their families why they are going. And we need to understand why their loved ones are sometimes prosecuted afterwards for helping them. Surely this tells us that our current arrangements are inhumane. I, among others, would be happy to help with such a review.

My cancer, stable for the past two years, is growing again. When I recently switched to the carboplatin combination, an antibiotic resistant empyema infection soon followed as my white cell count fell. Life seems even more precarious, and I need that longer term perspective again. I think I will head to the bench now.

The views expressed in this article are entirely my own and do not reflect the position of Public Health England or any other organisation that I am associated with.

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