

**Good afternoon, everyone,**

Thank you for inviting me and for the privilege of sharing the stage with such an esteemed panel.

I'm the Honorary Secretary of the Association for Palliative Medicine, the largest representative body for palliative care physicians in Great Britain and Ireland, with over 1,400 members. In fact, we're one of the largest such organizations in the world. This means I often represent the doctors who care for and treat dying patients the most—day in, day out. This is our work.

And because of that, it's worth noting something significant: in repeated surveys over nine years, upwards of 80% of palliative care physicians consistently oppose the legalization of assisted dying. Our official position at the APM is clear—we oppose it. But tonight, I want to set aside the official statistics. Instead, I'm here as one of many palliative care doctors outlining it from my clinical perspective.

As I prepared for this afternoon, I reflected on why people campaign so passionately for assisted dying. The proponents often say the current law boils down to a 3 way choice—either you die suffering, you go to Dignitas alone or you take matters into your own hands – with completing suicide. This is clearly not true, but terrifies many. That the only 'dignity in dying' is lethal medications, also implying there is no dignity in a natural death. Why say this?

When I listen in detail to their reasoning, it often boils down to two key desires:

1. **To avoid suffering.**
2. **To have choice and control.**

To truly address the assisted dying debate, we need to address these two things as all the arguments stem out of these two things. These are deeply human fears and hopes, but I believe they are fundamental misunderstandings as assisted dying does not actually solve or address either of them. Here's why:

### **On Suffering**

The idea that assisted dying addresses suffering is, at its core, flawed. Ending suffering by ending the sufferer is like addressing a broken radiator by removing the plumbing. It isn't fixing the problem it removes the ability to fix it. It doesn't solve the problem; it sidesteps it.

Our job in medicine has always been to alleviate suffering, not eliminate the person who suffers. As we all experience suffering a solution to suffering of permitting death will always expand its remit because suffering is everywhere. It is also subjective, what does 'suffering' really mean? I would love to know what your definition of suffering is? Indeed, I have asked, and the only reply I get is it is 'self-defined'.

### **On Choice**

Choice is often presented as the hallmark of assisted dying. 'My body, my choice'. But in practice, it insidiously becomes less about choice and more about societal suggestion.

What starts as an option can quickly morph into an expectation—or even a duty. Is it an option to wear clothes speaking to you now? In one sense it was a choice I had. But actually it was an obligation in our society that I wear clothes. A choice is rarely 50:50, there is an onus to pick one way more than another. And given all jurisdictions which legalise this ever increase, the societal expectation becomes (over time) taking lethal medications.

Here's something to think about:

- Roughly 30% of us will die of cardiac disease.
- Another 30% from cancer.
- Another 30% from frailty or dementia.

But 100% of us will experience dying. Every single one of us.

And yet, while diseases like cancer and heart disease are fully funded by the NHS, palliative care—which serves everyone—is not. Over a third of hospice care in the UK is funded by charities. Why? Why do we not fund the NHS cradle to grave? – as advertised?

I think it is because we don't like to talk about it – so lets talk about it, because underlying all this is a lot of misconceptions about dying. And I believe a lot of these misconceptions feed into the fervent fear and request for assisted dying. “I am afraid of suffering – i.e. the misconception dying is suffering”. “I want choice, i.e. the misconception I want the choice to avoid natural dying because I am scared of it.”

### **Let's Talk About It**

And as a warning shot, I am going to talk about tough stuff here, but we need to talk about it.

Here's the truth: dying itself is not painful. Please hear that. I can categorically say in and of itself dying is not physically painful. Understandably Sad (that is different) – but not painful.

I had a professor once tell me and I often repeat it to patients – it's a bit quirky but – there you go its useful – and I apologise if you are a dentist - . sorry

“Dying is like going to the dentist—you absolutely dread it, but when you're there, it's not so bad.”

We really dread the process of dying. And our misconception is that dying is like a graph – pain and suffering must increase and increase and increase like a graph going up and up, reaching a crescendo and then you die – can I say categorically that is not true. Dying is a process of the body shutting down and symptoms particularly pain do not ever increase.

So what does it look like – IT IS physically the shutting down of your body. It is a gradual process. If I was to map a dying person what happens in the vast vast majority of time is

they get progressively weaker and weaker. They spend longer and longer in a chair and then bed. They sleep more and more. Eventually they spend all their time in bed. This often happens over a number of many months, months or weeks.

They overall sleep more and more over time. But it's not a straight line, they fluctuate. There are times whereby the person is themselves, chatting albeit weaker and reminisces and laughs and cries, jokes and asks about aunt Tilly. But then they rest by closing their eyes listening. This we call the shallow sleep, the eyes closed but the ears are working and the eyebrows move when things are said, they listen and squeeze your hand, the person is listening but too weak to wholly be awake – it is more comfortable to listen and rest.

Then they go deeper, this is just like normal sleep – you are not aware of your surroundings, unconscious and unaware.

But then in a fluctuating wave it goes back up again, it fluctuates back to a shallow sleep and then awake again where we are ourselves but weaker.

But then it goes back down to a shallow sleep again, ears listening, then into a deeper unconscious sleep.

The fluctuations can be misinterpreted by the family as “mummy is getting better” or “mummy was much more alert yesterday she is getting worse” and it is important to realise the fluctuating nature of dying. However over time the peaks get less high and shorter and the dips get deeper and broader over time.

This fluctuating – up and down – nature of dying is because the ‘body knows how to die’ – this may sound like a bizarre sentence and one I need to explain. But over a long period of time watching people die I can't think of another way of saying it.

‘The body knows how to die’

Like, the body knows how to grow up when you are a child, how to go through puberty, how to be pregnant and give birth – it knows how to die. Out-with our conscious control the body knows how to shut down and die. And like all those processes our body goes through, dying is a process.

The dips get deeper with each bout, the peaks of awakesness get smaller and smaller, maybe we just rise for a small ‘shallow sleep’ before going back down deeper. Never even quite reaching awake.

The deeper sleep, the unconscious sleep gets deeper still and the family notice some changes in the breathing. Sometimes goes a bit faster, sometimes a bit slower, but pauses in the breathing inevitably start. There is a thing called a ‘death rattle’ when deep unconscious in about 30% of cases, there is a gurgling in the breathing. This is just being so weak we can't automatically move along our secretions and we breath through them rather than clear them. Families sometimes think this is the patient choking, it is

not, it is far more distressing for the family rather than the patient who is unaware. It sounds flippant, but it is more akin to snoring, annoying the wife in bed rather than the husband asleep.

The breathing starts to have pauses in it –{breath in} 1 -2 -3 seconds {breath out} and then restarts. A period of more normal breathing, before more pauses start.

Sometimes with the fluctuations the patient goes up again, and even all the way to a 'window of wakefulness' and she tells me 'I had a really good sleep Dr Matt' when I know they were pausing their breathing a few hours or even minutes earlier. Therefore I know it is not a distressing place with the breathing pausing, rather the patient is simply unaware.

The pauses get longer [breath in] 1,2,3,4,5 [breath out] – they get a bit longer still, longer still, and often without people noticing .... one of the pauses doesn't restart. That is death.

Sorry to say there isn't a burst of last words – that doesn't really exist. There is No revealing of where the lost treasure is, or where the hidden lottery ticket is. No it is almost always a peaceful death. A natural death. Don't get me wrong – always sad, always an element of reverence, but not painful.

This is mostly surrounded by loved ones. Is peaceful and full of reminiscing and if there is no family or friends, our job in palliative care is to fulfil this role.

Just to say 'sudden things' do happen, of course, but actually are incredibly rare to cause death, rather can step you along the process quicker and are even rarer whilst actually in the process of dying.

But what about the 'bad deaths' is the response from assisted dying proponents. Well, in my humble experience the bad deaths I have witnessed all have a common denominator, which means they wouldn't access assisted dying anyway. That is the person is desperate to live. That makes a hard death. And this is truly upsetting, often a young mum or dad not wanting to leave their children, or a teenager who wants to see and live life, or a mother who has caring responsibilities for her elderly Downs syndrome dependent son. They wouldn't access this anyway.

Ahh, but there must be cases whereby a bad death happened and you have thought they would have benefited from an assisted death?

The practicalities of the bill and assisted dying means it has to be pre-emptive of the dying phase. Due to consent and capacity and all the measures outlined you will only actually provide assisted dying to those who have an uncertain prognosis. We are really bad at predicting prognosis by the way. We can't predict 6 months ahead. I really wish Dame Esther Rantzen all the best, but she was diagnosed with stage 4 lung cancer 20 months ago I think. Last Christmas she said 'I got this Christmas I never thought I would get' She also said she planted bulbs she never would see bloom – she has seen them

bloom, and I truly hope she has another amazing Christmas, I truly do. But she was predicted to have a prognosis far less than 6 months 20 months ago. How many people would have accessed assisted dying 20 months ago who were in exactly Dame Esther Rantzens situation? How many early deaths are worth the cost of having this 'right' to assisted dying?

Let me tell you a true story

I was a young junior doctor, doing my haematology placement, when the gentleman who had occupied side room three for over two weeks died naturally of his leukaemia, comfortably and very peacefully. It was one of the first times I had seen death - certainly the first time I had formed a close bond with a dying patient and their family. In one of those formative moments I will always remember, his adult son handed me a tin of Chocolate Roses for the ward. And what he told me stuck:

“Dr Matt, you know, my dad taught me how to use a spoon, ride a bike, wash and dress, to be fair and generous. He taught me how to be a good husband and then father, he taught me how to graciously age... he taught me everything I know, and, you know what, he has now taught me how to die”

Assisted dying can never offer this legacy. It cuts short the natural process of dying, the opportunity to reconcile, to love, and to teach.

Assisted dying is incapable of achieving the same thing: It also creates an example and demands generational repetition of pre-emptive death. It feeds an unfounded fear of the process of dying, and a misunderstanding that the way to approach this fear is to pre-empt it. It is why it ever grows in all jurisdictions (none have even plateaued – they just keep growing) Assisted dying teaches you that you become a burden – indeed in Oregon 43% access assisted dying exactly because of this reason.

### **What do you want doctors to do—for you and for your loved ones?**

Let me ask all of you: *What do you want your doctors to do?* Truly—what do you expect for yourself, for your loved ones? What should our role be as a profession?

When patients come to me and say, “*Please end my life,*”—or sometimes even “*Kill me,*”—it’s not common, but it’s not rare either. Whether they’re in hospice, in the hospital, or at home, do you think I should take those words at face value? Should I simply refer them onward?

Or would you want me to dig deeper? To ask, *Why?* To explore the reasons, understand their suffering, and try to stand in their shoes.

This raises a critical question: Where do doctors draw the line between referral and deeper engagement? Should it depend on how convincingly the patient asks? After 30 minutes of discussion as an arbitrary time frame?

Some proponents of assisted dying might say, “Yes, *you should explore.*” But how much exploration is too much? How far can I push to uncover the root causes of suffering before I’m accused of obstructing access to a service? Not just by the patient, but often by their family. Under this Bill, it would be illegal for me to decline a referral. Ironically, it would be legal for me to suggest to the patient assisted dying as an option. Doesn’t that feel like a one-way street?

Once those words—“*Please end my life*”—are spoken, if assisted dying is legalized, palliative care is tied at the wrists. It will no longer be seen as enabling or empowering patients; it will be viewed as blocking access. Doctors who hesitate to refer may be dismissed as paternalistic, selfish, or overly influenced by their personal beliefs.

This makes it almost impossible for us to be advocates for patients, to guide them through their suffering with care and compassion.

The essence of palliative care is non-abandonment. It’s about *never* giving up on making *you more you*. That’s the true meaning of dignity.

Now, let me pause on that word: *dignity*.

Proponents of assisted dying often equate dignity with individual autonomy. But I would argue dignity is something deeper, something innate. In fact, the Universal Declaration of Human Rights declares the “*inherent dignity and the equal and inalienable rights of all people.*”

Dignity isn’t something you gain or lose as claimed by proponents. “I don’t want to lose my dignity”. Rather it’s fixed. It’s inherent. Whether you’re a king or a pauper, a drug dealer, a politician, someone with a disability, or someone facing terminal illness—you have the same human dignity as everyone else.

The real question is: Are we treating people with the dignity they deserve?

When someone meets the eligibility criteria for assisted dying—and let’s be clear, those criteria aren’t safeguards; they’re checkboxes ticked by two doctors and approved by a judge to ease society’s conscience. —how do you think that person feels within that circle of eligibility?

The law isn’t just a set of rules; it sends social messages. And the message being sent here is: “*In your circumstances, maybe it’s better if you’re dead.*”

That is not providing inherent dignity equally to all people. It is saying you are worth less now than before. That’s a statement that your life, your worth, is less now.

It tells my patients they’re a burden. That they’re taking up resources. That their lives aren’t valuable.

Well, I disagree. My patients are equally valuable as anyone else.

My patients, which as I said right at the beginning 100% of you will be one day, are valuable and have every right to true dignity, being looked after for a good death free from any pressure.

'You wouldn't let a dog go through this'

No, you are not a dog.

I don't treat you like a dog in any other circumstance

And many dogs are euthanised because of convenience, the owner can't afford the vet bills, most pets are not insured and indeed, we don't ever actually ask the dog.

No, you are valuable because to use Cicely Saunders the founder of the modern palliative care movement, you matter because you are you.

Thank you.