

ASSISTED DYING:
**THE
CASE
FOR
CHANGE.**

HPAD

Healthcare Professionals
for Assisted Dying

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ASSISTED DYING: THE CASE FOR CHANGE.

Assisted dying is prohibited in England and Wales under the Suicide Act 1961, and in Northern Ireland under the Criminal Justice Act 1966 which states that anyone who “encourages or assists a suicide” is liable to up to 14 years in prison. In Scotland there is no specific crime of assisting a suicide, but helping a person to die at their request could lead to prosecution for murder, culpable homicide or reckless endangerment.

The current law does not work:

- **Every eight days one British citizen travels to Switzerland for help to die. On average this costs £10,000. People often die earlier than they would want because they have to be well enough to travel.¹**
- **Every year over 300 terminally ill people end their own lives in England, often in distressing circumstances.²**
- **Every year thousands of people suffer at the very end of their lives despite the best efforts of care professionals. Research suggests that even if every dying person had access to the best possible specialist care, 17 people a day would still suffer as they die.³**

Terminally ill people are being denied choice and control over their deaths. They deserve an informed, evidence-based debate when lawmakers are determining what end-of-life options should be available to them. In order for this to be achieved, **healthcare professionals need to know the facts.**

HPAD.

Healthcare Professionals for Assisted Dying (HPAD) believes that assisted dying for terminally ill adults with mental capacity should be legal in the UK. We support a law which would give people who have six months or less to live the option to control the timing and manner of their death.

The law we want:

- **is for terminally ill, mentally competent adults**
- **requires the dying person to end their own life by taking life-ending medication and does not permit another person to do it for them**
- **has a waiting period to give dying people time to reflect on their decision**
- **requires assessment by two doctors and oversight by a high-court judge**
- **allows doctors to conscientiously object from being involved in the process**

This is based on the Death with Dignity Act in Oregon, which has worked safely for over 20 years and has been adopted by many other American states such as California and Washington, as well as the Australian state of Victoria.

Over 150 million people around the world live in a place where some form of assisted dying is legal. As more countries around the world change their laws to give dying people choice, terminally ill people here in the UK are being left behind.

OVERWHELMING PUBLIC SUPPORT FOR ASSISTED DYING.

For over twenty years there has been clear and overwhelming support among the UK public for law change on assisted dying. This is true regardless of who commissions the poll.

84% OF THE GENERAL PUBLIC

The general public overwhelmingly supports a change in the law on assisted dying for terminally ill people. The largest poll ever on this issue shows that 84% of the public back a safeguarded and compassionate assisted dying law.⁴

80% OF RELIGIOUS PEOPLE

The majority of religious people support a change in the law on assisted dying.⁵

A number of senior religious figures such as the former Archbishop of Canterbury Lord George Carey and Archbishop Desmond Tutu have spoken out in support of assisted dying.

86% OF DISABLED PEOPLE

Polling has shown that 86% of people living with a disability support assisted dying being a choice for terminally ill people.⁶

Disabled people would not be eligible for assistance to die under Dignity in Dying's proposed law unless they were also terminally ill and met all of the other eligibility criteria.

ASSISTED DYING LAWS ARE TRIED AND TESTED OVERSEAS.

Assisted dying is a safe and trusted medical practice which allows dying people to control their suffering and bring about a peaceful death. There is over 20 years of data from Oregon which shows the law works well.

ASSISTED DYING ALLOWS PEOPLE'S WISHES TO BE RESPECTED

Monitoring of assisted dying requests in the USA shows that terminally ill people have a number of concerns that contribute to their decision to have an assisted death. For the vast majority of people in Oregon this includes concerns about the loss of their autonomy (92%), being less able to engage in enjoyable activities (91%) and loss of dignity (67%).⁷

Other concerns, which are also common for all people approaching the end of life, include being a burden on others. This is listed as a concern for less than half of those who make use of the law.

A third of patients who formally request assisted dying in Oregon do not take the life-ending medication. This shows people want to live well for as long as possible, but with assisted dying as an 'insurance policy' if their suffering becomes unbearable.

ASSISTED DYING LAWS PROTECT VULNERABLE PEOPLE

Where assisted dying is legal the evidence shows the law is safe and effective. The people who seek an assisted death are most often aged between 65 and 85, have a 'good education', have medical insurance and have cancer.⁸ Studies have found that a request for an assisted death represents long-held philosophical beliefs among patients who highly value their independence.⁹ Potentially vulnerable groups of people such as those of a lower socio-economic status or aged over 85 do not disproportionately use the assisted dying law.¹⁰

Under an assisted dying law, two doctors would be required to independently assess the person making a request, including exploring their reasoning and motivations. This is an opportunity to make sure all options have been explored and refer the person for psychiatric assessment if necessary. The person would always be able to change their mind at any point.

Disability Rights Oregon has publicly said that they have never 'received a complaint that a person with disabilities was coerced or being coerced to make use of the Act'.¹¹

THE LAW YOU ENACT IS THE LAW YOU GET

The assisted dying law in Oregon has remained unchanged for over 20 years. There have been no proven cases of abuse of the law and no widening of its initial, limited scope.

Those opposed to assisted dying sometimes cite the wider criteria of laws in Belgium and the Netherlands as examples of indiscriminate systems. Although they are both much wider in scope than laws proposed in the UK, being based on unbearable suffering rather than terminal illness, that has always been the case. Both of these laws work as intended.

ASSISTED DYING LAWS BRING COMFORT TO MANY

Assisted deaths in Oregon and California account for less than 1% of total deaths. Around 35% of people who are given the prescription choose not to use it but instead have it as 'emotional insurance'.¹²

Therefore the number of assisted deaths in the UK would be relatively small, but the number of people who would take comfort from knowing the option was there if they needed it would be much higher.

"Many [Oregonians] simply want to know that, if it gets so bad that they can't tolerate it, the choice is there for them. There is a comfort in knowing that."

Barbara Roberts, former Governor of Oregon.¹³

PEOPLE WHO HAVE AN ASSISTED DEATH DO NOT WANT TO DIE

"I am not suicidal. I do not want to die. But I am dying. And I want to die on my own terms."

Brittany Maynard, who had an assisted death in Oregon, aged 29.¹⁴

Dying people who want to control the manner and timing of their death are not suicidal.

During Committee stage of Lord Falconer's Assisted Dying Bill, the House of Lords voted two to one against an amendment which inserted the word 'suicide' into the Bill. Peers recognised that the word suicide does not accurately reflect the assisted dying process.

Where assisted dying is legal, there is no correlation between law change and suicide rates.

UK LAW FAILS TO PROTECT PEOPLE

The current law in the UK is incapable of protecting vulnerable people. When someone travels to Switzerland for an assisted death only a minority of cases are investigated. Investigations normally happen after the person has died and they can be extremely traumatic for loved ones. Decisions taken by doctors in the UK that actively hasten someone's death have fewer safeguards than would be present under an assisted dying law.

Where some doctors are currently acting illegally to directly end a person's life at their request, there are no safeguards in place at all.

The blanket ban on assisted dying is failing: it does not stop people taking action to control the end of their lives but instead drives the practice behind closed doors. This means potentially vulnerable people cannot be, and are not being, protected.

In contrast an assisted dying law would introduce safeguards *before* a person could access an assisted death, and therefore provide both more protection and more choice than the current law allows.



"I was very much against assisted dying but I have changed my mind. Doctors have a huge amount of power and when dying people are denied choice at the end of their lives that power can be abused.

I now see that a transparent assisted dying law would be a protection against abuse. It would be safer than the current law. It would bring these conversations out into the open."

Professor Aneez Esmail, GP and academic.

"In 2017 my friend Fabi had an assisted death. I used to be utterly opposed to assisted dying. With Fabi's death I saw how safeguards worked to protect vulnerable people while giving her a meaningful end-of-life choice. Fabi helped me change my mind."

Dr David Nicholl, Consultant Neurologist.

JULIE'S STORY

When Julie's husband Paul was dying of cancer, he decided he wanted to travel to Dignitas for an assisted death.



"He spoke to his GP, who he'd been with for a very long time. Paul was decisive and he'd made up his mind about this. He didn't go to his GP for advice, he went because he needed a letter outlining his condition and prognosis. The GP said, 'What's it for?' Paul said, 'I'd rather not say,' and the GP said, 'Whatever it is, you can tell me.'

Paul told him about Dignitas and at that point his GP said, 'I need to seek advice.' He spoke to others at the surgery who said, 'Under no circumstances give this man a letter.' Paul was angry because he felt he'd been coerced into telling why he wanted the letter. He paid to have his medical records, but it took ages for him to get them, and they didn't have the level of detail Dignitas needed.

At that point he gave up. He was getting quite poorly and he didn't have the strength to keep fighting his doctors. I think he felt from the first conversation with the GP that it was pretty much game over.

He was distraught because he felt that the decision had been taken out of his hands. It was awful to see him so upset.

Paul made peace with his GP. I don't know if I would have been able to do that. He forgave him. He went back and he said, 'I don't hold you personally responsible. I understand.' That's the kind of guy he was. I later found out another patient at the same GP surgery was able to arrange their death at Dignitas. It goes to show how flawed the law is."

Paul's death was painful and, for Julie, difficult to witness.

"It was exactly what he'd feared. He was absolutely in agony. He really suffered. The palliative care team were coming in every day, but it still wasn't enough. It just didn't work for Paul. I'm sure for other people it would have done, but he was still in pain.

Paul was never really one to make a fuss but at the end he really was desperate. We gave him so much morphine but it just wasn't enough. He was in absolute agony.

At one point he shot up out of the bed and collapsed, gurgling. He was wild eyed and petrified and flailing around. They're horrible memories to have. It was horrific and about the furthest you could get from the peaceful death that he'd wanted for himself.

- **Paul's GP was following guidance from the GMC.**
- **His palliative care team did all they could but Paul still suffered unbearably at the end.**
- **The current law is broken.**

HEALTHCARE PROFESSIONALS' VIEWS.

HEALTHCARE PROFESSIONALS HOLD A RANGE OF VIEWS ON ASSISTED DYING

Most healthcare professionals recognise the current law is not working:

ONLY 13%

of healthcare professionals think that without an assisted dying law that there are sufficient options for terminally ill people to have meaningful control over their deaths.¹⁵

62%

think there are circumstances in the UK in which healthcare professionals have intentionally hastened death as a compassionate response to a patient's request to end their suffering at the end of life.¹⁶

43%

of GPs would want the choice of assisted dying for themselves.¹⁷

IN THE RCP'S 2019 SURVEY LESS THAN HALF OF RESPONDENTS PERSONALLY OPPOSED LAW CHANGE

The Royal College of Physicians adopted a neutral position on assisted dying following its survey in 2019. 57% thought that the college should be either supportive or neutral on the issue and less than half personally opposed law change.¹⁸

The Royal College of Nursing, the Royal College of Psychiatrists and the Royal Pharmaceutical Society are also neutral on the issue. Others such as the Royal College of Anaesthetists, Royal College of Radiologists and Royal Society of Medicine have also said they don't campaign for or against a change in the law.



"I support the right of terminally ill adults to control the manner and timing of their deaths. I believe the profession as a whole must seek to play a more constructive role in this debate than it has done to date. Medical bodies in the UK should seize the opportunity to play their part in determining what law change looks like."

Professor Sir John Temple, Surgeon and former President of the British Medical Association

51% OF GPs WOULD BE WILLING TO PLAY SOME ROLE IN THE ASSISTED DYING PROCESS

“I make the choice to provide assisted death to my patients because I believe it is a compassionate response that fully respects patient autonomy.”

Dr Sandy Buchman, a palliative care physician from Canada, where medical aid in dying has been legal since 2016.¹⁹

Polling suggests around 18,000 GPs in the UK would be willing to participate in assisted dying when the law changes, which would be more than enough to respond to the relatively small number of requests from dying people.²⁰

In 2018, 103 physicians wrote prescriptions for 249 terminally ill people under Oregon's assisted dying law.²¹ Where assisted dying is legal, there have been enough physicians who are willing to respect patients' wishes and participate in the process.

Doctors in the UK illegally end around 1,000 lives per year at the patient's request.²² There is no oversight of this practice and no clear, transparent choice for dying people.

Dying people face a lottery: some may have doctors willing to break the law to help end their suffering, whereas those who don't may be forced to suffer against their wishes as they die.

Allowing this to continue unregulated is no substitute for a safeguarded assisted dying law.

THE ROLE OF HEALTHCARE PROFESSIONALS.

- Only a dying person would be able to raise a request for an assisted death and they would be able to revoke it at any stage in the process.
- The dying person would be required to self-administer the life-ending medication themselves.
- Any professional might be involved in a discussion about assisted dying but only doctors would be able to carry out an assessment as to whether or not a person meets the eligibility criteria.
- This would include estimates of prognosis, assessments of capacity and also ensuring the person is aware of all their palliative care options.
- Once two doctors are in agreement, this information would then be submitted to a High Court judge, who would be the only person able to authorise a request.
- If a request was approved there would be a cooling-off period to ensure the person making the request had a clear and settled intent.
- If the person still wanted to go ahead a doctor or 'assisting health professional' would help prepare the medication and stay with the person until they died.

Nurses could be asked to contribute to doctors' assessment of patients' eligibility e.g. in assessing mental capacity or the possibility of coercion. A nurse could be authorised by the attending doctor to act as the 'assisting health professional' and deliver the life-ending medication to the patient's home when they requested it. The nurse would also check whether the patient still wanted to have an assisted death and would remain close until they had taken the medication and died, or until they had decided not to take the medicine.

Once a prescription had been written by the attending doctor it would be sent to a local pharmacist. The medication would need to be available from the point where the patient's cooling-off period finished.

HEALTHCARE PROFESSIONALS ARE WELL SUITED TO BEING INVOLVED IN THE PROCESS OF ASSISTED DYING.

Under an assisted dying law, doctors would be required to:

- **assess whether a person seeking an assisted death has the capacity to make the decision**
- **is doing so voluntarily**
- **has a diagnosis of a terminal illness**
- **could be expected to die in the next six months or less.**

Doctors are suited to doing this. For example when someone chooses to refuse medical treatment that will result in their death doctors are required to make sure the person has capacity and is not being coerced. The British Medical Association and the Association for Palliative Medicine provide guidance on how to do this.

Safeguards in assisted dying legislation would ensure that if either of the two doctors involved had doubts about a person's capacity to request an assisted death then they would be referred to an appropriately trained specialist. If the person lacked capacity or was being coerced in any way they would not be eligible for assistance.



“A doctor’s role is to heal, but when we are unable to do so we should be able to alleviate suffering.”

Dr Rohin Francis, Cardiology Registrar

THE DECLARATION OF GENEVA REQUIRES DOCTORS TO RESPECT THE AUTONOMY OF THEIR PATIENTS

Assisted dying complements medical ethics, which have evolved since the Hippocratic Oath was written. This is why many doctors feel able to participate in practices such as abortion. Many healthcare professionals consider that being prevented from respecting the wishes of dying people, at the risk of prolonging unnecessary suffering, is in conflict with medical ethics.

ASSISTED DEATHS IN OREGON AND CALIFORNIA ACCOUNT FOR LESS THAN 1% OF TOTAL DEATHS

Based on the figures in Oregon, a typical GP practice in the UK would be involved in an assisted death once every 3 to

4 years. GPs may only encounter a handful of patients who want an assisted death throughout their career. While the number of people who take the life-ending medication may be small, research from overseas has shown that assisted dying legislation can increase professionals' confidence in discussing a range of end-of-life issues, as well as leading to more appropriate and timely referrals to hospice care.

Even though assisted dying would be relatively uncommon, the government and professional and regulatory bodies would be required to have appropriate guidance and support to help doctors and other healthcare professionals understand their role in assisted dying requests, should they choose to be involved. Such guidance is available for other practices healthcare professionals may only encounter infrequently throughout their careers.

DOCTORS WOULD NOT BE REQUIRED TO DO ANYTHING UNDER THE LAW THAT THEY DID NOT WANT TO DO

Doctors and other healthcare professionals would be able to conscientiously object to supporting their patients through an assisted dying request. However, if a healthcare professional objected because of their personal beliefs, they would be required to refer the patient to someone willing to discuss their request for an assisted death. This is the same for other existing practices such as abortion and the withdrawal of life-sustaining treatment.

93% OF PEOPLE SAY AN ASSISTED DYING LAW WOULD EITHER INCREASE OR HAVE NO EFFECT ON THEIR TRUST IN DOCTORS²³

Assisted dying can improve the doctor-patient relationship. Changing the law would allow a dying person to have honest,

transparent conversations with their care team about their fears and wishes for the end of life and available palliative care options.

Where it is embedded in existing healthcare systems, assisted dying leads to improved communication and understanding of a range of end-of-life issues for healthcare professionals.

THE FINAL DECISION ON WHETHER OR NOT AN ASSISTED DEATH HAPPENS BELONGS TO DYING PEOPLE

A safeguarded assisted dying law would mean that the dying person's request for an assisted death would be recorded and checked at numerous stages. If two doctors confirmed the person met all the eligibility criteria then the request would need to be approved by a High Court judge.

The dying person would be able to revoke their request at any time.

An assisted dying law would place the dying person at the centre of decision-making, whereas the current law means doctors are often required to make final decisions over how someone's life ends.



"It is our duty to listen to our patients. I believe a physician cannot determine what constitutes suffering for our patients. In fact, our oath demands us to listen carefully to our patients and not judge."

Dr Catherine Forest is a family physician in California, where assisted dying has been in effect since 2016.²⁵

ASSISTED DYING COMPLEMENTS PALLIATIVE CARE.

17 PEOPLE A DAY IN THE UK WOULD DIE IN PAIN EVEN IF THERE WAS UNIVERSAL ACCESS TO THE HIGHEST QUALITY PALLIATIVE CARE

Some people experience severe emotional and physical suffering at the end of life despite receiving excellent palliative care.²⁴

There are other symptoms beyond pain that cause suffering and not all these symptoms can be controlled. They include nausea, constipation, fungating wounds, faecal vomiting, and rapid loss of blood caused by terminal haemorrhages. Losing autonomy can also result in severe psychological suffering.²⁵

43% of healthcare professionals have experience of caring for someone who has suffered at the end of their life despite receiving high quality palliative care.²⁶

PALLIATIVE CARE FLOURISHES ALONGSIDE ASSISTED DYING

Research demonstrates that assisted dying laws contribute to more open conversations and careful evaluation of end-of-life options, as well as more appropriate palliative care training of physicians and greater efforts to increase access to hospice care. Oregon is considered to have amongst the best palliative care in the USA.^{27,28,29,30} 90% of people who have an assisted death in Oregon are enrolled in hospice care.

This shows that palliative care access does not eliminate requests for assisted dying, nor does a request for assisted dying indicate a failure of palliative care. Rather, it shows that assisted dying is one of several options that can safely be made available to people at the end of life.

When the Australian State of Victoria passed assisted dying legislation, the government reviewed palliative care services in the area. As a result, an extra \$72 million has been provided in Victoria to increase palliative care beds and access to home-based palliative care.³¹



“As a palliative care nurse of 25 years and a recent recipient of hospice care - I know the importance of learning from patients’ perspectives, not teaching them your own.

My recent experience as a patient has only deepened my long-held views that assisted dying should be legalised.”

Harriet Copperman OBE,
Retired palliative care nurse and
a founding members of North
London Hospice.

CONCLUSION.

- The current law is failing dying people in the UK.
- The public overwhelmingly supports a change in the law on assisted dying.
- Assisted dying laws are tried and tested overseas, with over 20 years of data from Oregon.
- Over 150 million people around the world now live in places where assisted dying is legal. The UK is being left behind.
- Healthcare professionals hold a range of views on assisted dying so representative medical organisations should not campaign to block a change in the law.



“Assisted dying laws in the USA, Canada and Australia show how it is possible to give people greater end-of-life choice while protecting the rest of society. As the rest of the world makes progress, we are falling behind.”

Dr Jacky Davis, Consultant Radiologist and Chair of Healthcare Professionals for Assisted Dying.

To join Healthcare Professionals for Assisted Dying visit www.hpad.org.uk

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HPAD

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We believe that everybody has the right to a good death, including the option of assisted dying for terminally ill, mentally competent adults.

Find out more and get involved at
www.dignityindying.org.uk/hpad

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