

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

**CAMPAIGN FOR  
DIGNITY  
IN DYING.**

May 2020

# 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. The current law does not work:

- **Every week 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.<sup>1</sup>**
- **Every year over 300 terminally ill people end their own lives in England, often in distressing circumstances.<sup>2</sup>**
- **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.<sup>3</sup>**

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, people need to know the facts - this booklet has been written to give you the facts, to help you understand the case for change.

# DIGNITY IN DYING.

Dignity in Dying 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.<sup>4</sup>

Support for assisted dying is consistent across those who vote for Labour (82%), Conservative (86%), Liberal Democrat (89%), and the Scottish National Party (91%). 93% of people say that if their MP was supportive of assisted dying it would make them feel more positively or have no effect on their feeling towards their MP.<sup>5</sup>

## **80%** OF RELIGIOUS PEOPLE

The majority of religious people support a change in the law on assisted dying.<sup>6</sup>

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.



“I agree with the majority of religious people that life is sacred. But in my congregational work, I have seen too many die in great pain, who should have been allowed to pass away earlier, as they had wished. That, too, is part of valuing them.

Those who find suffering enriching or worth enduring to their last breath deserve every support - but in whose

interest are we forcing a person to stay alive when their final wish is to let go of life?

We see no problem in usurping God’s role by intervening when we deem fit, prolonging life through interventions such as blood transfusions or organ transplants. Similarly, we should also be able to bring life to a gentle close within limits and safeguards.

We should assert that there is nothing sacred about suffering, nothing holy about agony and those who wish to avoid it should be able to do so - as a human right but also in keeping with religious ethics.

If there is a right to die well - or at least to die as well as possible - it means having the option of assisted dying, whether or not it is taken up.”

Rabbi Dr Jonathan Romain

# 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.<sup>7</sup>

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.



"As a supporter of disability rights, I back the right of disabled people to have control over the time and manner of their death when they are terminally ill, so they can avoid unbearable suffering and achieve dignity in dying.

Being disabled in itself is no reason to die, but for many of those who have terminal illness, controlling the circumstances of their death becomes very important."

Sir Tom Shakespeare,  
disability rights  
campaigner.

# 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%).<sup>8</sup>

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, 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.<sup>9</sup> Studies have found that a request for an assisted death represents long-held philosophical beliefs among patients who highly value their independence.<sup>10</sup> 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.<sup>11</sup>

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'.<sup>12</sup>

## **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'.<sup>13</sup>

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.<sup>14</sup>

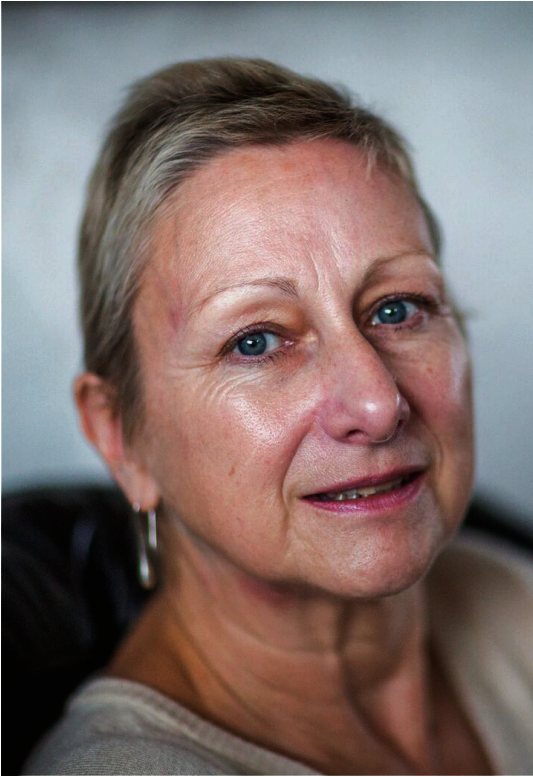
## PEOPLE WHO HAVE AN ASSISTED DEATH DO NOT WANT TO DIE

**"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.<sup>15</sup>

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.



“Knowing I had the option of an assisted death when things get too much would allow me to live now, without the constant fear of what might happen at the end. For me assisted dying isn’t about dying, it’s about living.”

Sandy Briden, who died of a rare form of cancer in the UK in 2017.<sup>16</sup>

## **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.

# DOCTORS AND ASSISTED DYING.

## 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.<sup>17</sup>

**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.<sup>18</sup>

**43%** of GPs would want the choice of assisted dying for themselves.<sup>19</sup>

## THE ROYAL COLLEGES

The Royal College of Physicians adopted a neutral position on assisted dying following a survey of its members in 2019.

**57%** thought that the college should be either supportive or neutral on the issue and less than half personally opposed law change.<sup>20</sup>

The Royal College of Nursing, the Royal College of Psychiatrists and the Royal Pharmaceutical Society are also neutral on the issue.

## DOCTORS ARE WILLING TO PARTICIPATE



"I make the choice to provide assisted death to my patients because I believe it is a compassionate response that fully respects patient autonomy."<sup>21</sup>

Dr Sandy Buchman, a palliative care physician from Canada, where medical aid in dying has been legal since 2016.

**51%** of GPs would be willing to play some role in the assisted dying process. This equates to over 18,000 GPs in the UK, which would be more than enough to respond to the relatively small number of requests from dying people.<sup>22</sup>

In 2018, 103 physicians wrote prescriptions for 249 terminally ill people under Oregon's assisted dying law.<sup>23</sup> 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.<sup>24</sup> 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 that don't may be forced to suffer against their wishes as they die.

## ASSISTED DYING COMPLEMENTS MEDICAL ETHICS

The modern version of the Hippocratic Oath, which is called the Declaration of Geneva, requires doctors to respect the autonomy of their patients. Many healthcare professionals consider that being prevented from respecting the wishes of dying people is in conflict with medical ethics. An assisted dying law would contain a clear conscientious objection clause that would mean that those doctors who did not want to consider an assisted dying request could choose not to.



“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.<sup>25</sup>

## **HEALTHCARE PROFESSIONALS ARE WELL SUITED TO BEING INVOLVED**

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 and has a diagnosis of a terminal illness and a prognosis of six months or less.

Doctors are suited to doing this. They routinely assess mental capacity and detect coercion as part of their day-to-day duties, for example when someone chooses to refuse medical treatment that will result in their death. 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 they lacked capacity or were being coerced in any way they would not be eligible for assistance.

## **ASSISTED DYING CAN IMPROVE THE DOCTOR-PATIENT RELATIONSHIP**

93% of people say an assisted dying law would either increase or have no effect on their trust in doctors.<sup>26</sup> 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.

# ASSISTED DYING COMPLEMENTS PALLIATIVE CARE.

## THE LIMITS OF PALLIATIVE CARE

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

Research shows that 17 people a day in the UK would die in pain even if there was universal access to the highest quality palliative care. 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.<sup>27</sup>

Those opposed to assisted dying acknowledge there will always be a group of people whose suffering cannot be relieved by even the best palliative care.<sup>28</sup>

## 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. It also leads to more appropriate palliative care training of physicians and greater efforts to increase access to hospice care.<sup>29,30,31,32</sup> Oregon is considered to have amongst the best palliative care in the USA.



**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 many 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.<sup>33</sup>

## WHAT YOU CAN DO:

### 1) Contact your local MP

Many politicians are out of touch with the UK public on assisted dying. We need your help to ensure your MP is aware of local support for a change in the law. Write to or email your MP using our guidance:

[www.dignityindying.org.uk/writing-to-your-mp](http://www.dignityindying.org.uk/writing-to-your-mp) or call us on **020 7479 7737**.

### 2) Sign our petition

We're building the biggest ever public record of support for assisted dying to show how many people support a change in the law. Sign your name here:

[www.dignityindying.org.uk/petition](http://www.dignityindying.org.uk/petition)

### 3) Join a local group

Local campaigning can make a huge impact. Together, you can hold events and speak to your local media to spread the word about the campaign and gather support.

[www.dignityindying.org.uk/groups](http://www.dignityindying.org.uk/groups)

### 4) Tell us your story

Telling personal stories can be extremely powerful. If you are living with a terminal illness, have witnessed a loved one suffer a bad death or have accompanied someone abroad to have an assisted death, please let us know by filling out the form on:

[www.dignityindying.org.uk/tell-us-story](http://www.dignityindying.org.uk/tell-us-story)

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# CAMPAIGN FOR DIGNITY IN DYING.

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](http://www.dignityindying.org.uk)

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May 2020