

# WHAT MATTERS DOESN'T MATTER'S

FOREWORD  
BY PROFESSOR  
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MAY 2011

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**CAMPAIGNING  
FOR YOUR  
RIGHTS AT THE  
END OF LIFE.**

**Dignity**  
in dying  
*your life, your choice*



# FOREWORD

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A few years ago, I was chairing a leading medical ethics committee and we had been asked to consider the first Bill put forward by Lord Joffe to legalise assisted dying for people with terminal illness.

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We opposed the Bill. Some members of the committee did so on religious grounds or on the basis of what they saw as ethical principles. The hostility of the many, including myself, against the assisted dying legislation was based on assumptions we had about its possible longer-term consequences on the practice of medicine and more broadly in society.

In particular, we anticipated a slippery slope whereby the situations in which assisted dying would be employed would extend - from mentally competent, terminally ill individuals, whose symptoms were not alleviated by palliative care, towards voluntary euthanasia for other groups of people or perhaps individuals with chronic non-terminal disabling illness. It might even lead, we feared, to non-voluntary euthanasia. We were also concerned about a possible adverse effect on the development of palliative care and about a breakdown in trust between doctors and patients. Some of us also imagined that the universal availability of first-rate palliative care would obviate the need for assisted dying.

What we did not appreciate was that there was sufficient evidence from countries with assisted dying legislation already in place to show

that our concerns were without foundation and that international experience showed that palliative care, though helpful for many patients, was not a panacea. Had we been better informed, we would have seen more clearly the desirability and necessity for legislation to make assisted dying possible for a small but very important group of patients, as part of improving the quality of end-of-life care and extending patient choice.

This publication, 'A matter of facts', collects in a small space the key facts relevant to the case for assisted dying legislation. It documents the present very unsatisfactory situation of clinical, legal and ethical fudge in the UK; the failures of care that lead people to seek help abroad; the wider benefits of assisted dying in countries where it is available; and the absence of those adverse effects that we worried over in our committee. It is an excellent resource for those who wish to engage in the debate or who find themselves faced by individuals who, while they are opposed to assisted dying on religious or other grounds, support their case by misrepresenting the facts.

I wish this little book had been available to me when we made that wrong decision. If it had been, I am sure we would have come to a different conclusion - the right one.

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**FACTS ARE  
STUBBORN THINGS;  
AND WHATEVER  
MAY BE OUR  
WISHES, OUR  
INCLINATIONS,  
OR THE DICTATES  
OF OUR PASSIONS,  
THEY CANNOT  
ALTER THE STATE  
OF FACTS AND  
EVIDENCE.**

**JOHN ADAMS/1770**



# INTRODUCTION

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Research consistently shows that the majority of the general public overwhelmingly support a change in the law on assisted dying for terminally ill, mentally competent adults.

However, public opinion alone will not change the law and, as with all attempts to progress social change, there are unavoidable emotions and complexities surrounding assisted dying legislation.

This publication is an attempt at setting out the evidence base for a change in the law on assisted dying for terminally ill, mentally competent adults. It does so by countering some of the more common misconceptions about assisted dying by drawing on evidence, research and statistics from the UK and from overseas jurisdictions where assistance to die is legal. Evidence tells us that even the best end-of-life care cannot alleviate the suffering of all terminally ill people and, without a change in the law, a number of dying adults will suffer against their wishes at the end of life.

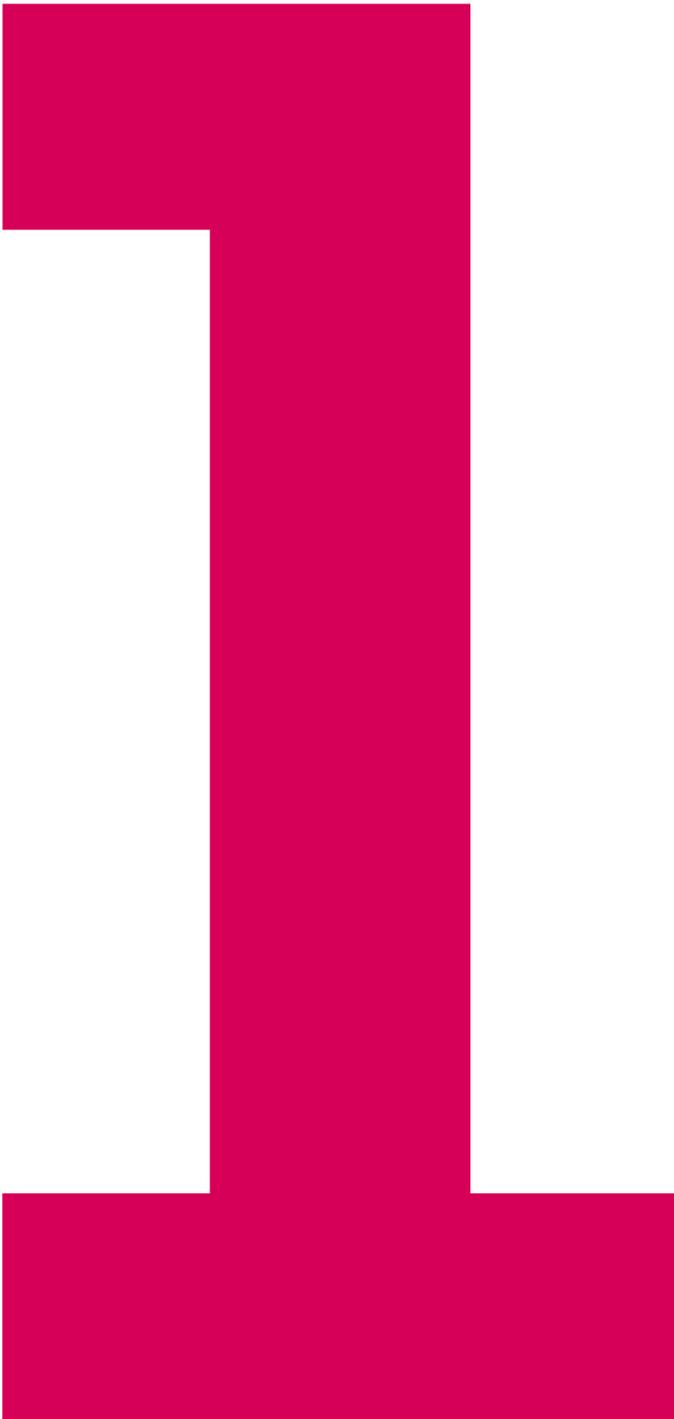
Further research shows that some patients are already being assisted to die in the UK outside of a legal framework. It is also well documented that a number of dying adults choose to travel abroad for an assisted death, others attempt suicide behind closed doors without support, or refuse food and water in order to bring about their death, and many ask family members and loved ones to help them die. All these decisions are currently

made without up-front safeguards, regulation or checks for abuse before the person dies.

In contrast, international experience has demonstrated that assisted dying legislation regulates a pre-existing practice, leads to greater patient autonomy, a better doctor-patient relationship and is accompanied by improvements more broadly in end-of-life care.

So the case for legal, regulated assisted dying is strong, as 'A Matter of Facts' makes clear by laying out the evidence, answering common questions and challenging fears, misconceptions and concerns. In so doing we hope it convinces those readers who were not yet persuaded of the case for assisted dying, strengthens the support of those who are already committed, and ultimately helps to bring about a much needed change in the law and medical practice.

**Sarah Wootton**  
Chief Executive, Dignity in Dying



# DEFINITIONS: ASSISTED DYING NOT ASSISTED SUICIDE OR EUTHANASIA

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Dignity in Dying advocates assisted dying only for terminally ill, mentally competent adults – not assisted suicide, voluntary euthanasia or euthanasia. It is important to acknowledge the distinctions between these terms in order to debate the issue accurately and fairly.

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**Assisted dying** (permitted in the US states of Oregon and Washington) sometimes referred to as physician-assisted dying, applies only to terminally ill, mentally competent adults and allows the dying patient, after meeting strict legal safeguards, to self-administer life-ending medication.

**Assisted suicide** (permitted in Switzerland) allows assistance to die for chronically ill and disabled people, along with terminally ill people.

**Euthanasia** is a term often used to refer to the administration of life-ending medication by a third party.

**Voluntary euthanasia** (permitted in the Netherlands and Belgium) allows a doctor to administer the medication directly to a requesting patient.

**Non-voluntary euthanasia** describes a situation where a third-party (usually a doctor) administers life-ending medication without the consent of the patient. Both voluntary and non-voluntary euthanasia are illegal in the UK, although evidence shows that both do occur (see pages 16/17).

The assisted dying legislation we propose is similar to that in place in Oregon and Washington and would give terminally ill adults choice and control over the timing and manner of their death. Dignity in Dying does not campaign for a change in the law to allow assistance to die for people who are not terminally ill.

# **OPINION: GENERAL PUBLIC, HEALTH PROFESSIONALS, PEOPLE WITH RELIGIOUS BELIEF AND DISABLED PEOPLE**

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Public opinion polls have consistently shown steady and unwavering support for assisted dying for terminally ill, mentally competent adults. Support drops significantly when polls ask whether this should be extended to include people who are not dying.

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## **General public**

The 2010 and 2007 BSA surveys found that the majority of the British public support assisted dying. In the 2010 survey, 82% of the general public agreed that a doctor should probably or definitely be allowed to end the life of a patient with a painful incurable disease at the patient's request<sup>1</sup> and the 2007 survey found that 80% agreed that a person with a terminal and painful illness from which they will die should be allowed an assisted death<sup>2</sup>. The 2007 survey also explored in detail whether assistance in dying should be extended to people who are not terminally ill (strictly assisted suicide rather than assisted dying), and found that support drops significantly for this. Only 45% agreed that a doctor should be allowed to end the life of somebody with an incurable and painful illness from which they will not die, and support fell further to 43% when this question was considered for someone who is 'not in much pain nor in danger of death, but becomes permanently and completely dependent on relatives for all their needs'.

## **Health professionals**

Research shows us that a majority of doctors are opposed to assisted dying but that religious belief and their medical speciality influence their views. A survey in 2009 found that 64% of doctors agreed and 34% disagreed with the notion that 'a person with an incurable and painful disease from which they will die should not be allowed by law to be assisted to end their life'<sup>3</sup>. Doctors who work in palliative medicine or hold a religious belief are more likely to be opposed to assisted dying.

A different survey from the same year found that 49% of GPs and consultants were opposed and 39% were in favour of a change in the law to permit assisted dying<sup>4</sup>. With regard to nurses, following a consultation of its members, the Royal College of Nursing moved from opposition to a position of neutrality on assisted dying in July 2009.

## **People with religious belief**

Analysis of the 2010 BSA survey revealed that the majority of the general public with religious belief support assisted dying. 71% of religious people and 92% of non-religious people agreed that a doctor should probably or definitely be allowed to end the life of a patient with a painful incurable disease at the patient's request<sup>1</sup>.

## **Disabled people**

The 2007 BSA survey found that the majority of disabled people are supportive of assisted dying: 75% of people with a disability believed that a person with a terminal and painful illness from which they will die should be allowed an assisted death<sup>5</sup>. Some opponents, including some organisations that represent disabled people, are concerned that assisted dying legislation would lead to a 'slippery slope' and the devaluation of disabled people's lives (see pages 24/25). The 2007 BSA showed that the majority of disabled people clearly disagree with this view - perhaps because choice is the principle at the heart of both the disability rights movement and the campaign for assisted dying.

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## **1961 Suicide Act**

The 1961 Suicide Act decriminalised suicide, and introduced the crime of 'assisting someone to end their life'. This carries a sentence of up to 14 years in prison. The Act explicitly gives the Director of Public Prosecutions discretion over whether to prosecute cases of encouraging or assisting suicide. In 2007, Dignity in Dying supporter Debbie Purdy, who has Primary Progressive Multiple Sclerosis, began a legal challenge to clarify under what circumstances her husband Omar would be prosecuted for assisting her to die. Debbie Purdy won her case to clarify the law around assistance to die in the House of Lords in July 2009. As a result the Director of Public Prosecutions was instructed to publish his

# **CURRENT LAW:** **1961 SUICIDE ACT,** **PROSECUTING POLICY** **AND AMATEUR ASSISTANCE,** **AND A LEGAL FRAMEWORK** **FOR ASSISTED DYING**

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Although assisting another person to die is illegal, in February 2010, following the Debbie Purdy case, the Director of Public Prosecutions was instructed to set out those circumstances under which someone would face prosecution for this act in England and Wales.

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guidelines on prosecution in cases of assisted suicide<sup>1</sup>. Following a public consultation, the final version was published in February 2010.

## **Prosecuting policy and amateur assistance**

The public interest factors for and against prosecution are set out in the Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide<sup>2</sup>. The policy does not change the law on assisted dying but does provide the first formal recognition that, in certain circumstances, someone who compassionately assists someone to die will not be prosecuted. However, whilst the policy makes a clear distinction between 'compassionate' and 'malicious' acts, without a legal framework for assisted

dying there still remains no safe means of assisted dying for terminally ill, mentally competent adults. Without such a framework, terminally ill adults can rely only on the amateur assistance of friends or relatives, or doctors willing to act outside of the law.

## **A framework for assisted dying**

Dignity in Dying is committed to achieving a change in the law for terminally ill, mentally competent adults. We propose legislation similar to that in place in the US states of Oregon and Washington and we continue to work to design and refine legislation that makes use of all that has been learned from overseas experience whilst being compatible with UK law, healthcare and culture.



# **PRESENT SITUATION:** **PALLIATIVE CARE, DIGNITAS, SUICIDE AND MERCY KILLING, REFUSING FOOD AND WATER, AND THE NEED FOR REGULATION**

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Although good palliative care is widely available in the UK, Dignity in Dying and its partner charity Compassion in Dying receive over 2,500 enquiries every year from members of the public concerned about their end-of-life care.

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Without the option of assisted dying, some terminally ill adults who are worried about their death and suffering unbearably, choose to try to take control by travelling to the Swiss assisted suicide organisation Dignitas, or by refusing food and water, or attempting suicide with or without the help of loved ones. Others may receive help from a doctor to die. But this will all be done outside of the framework of law and without a transparent process to check for abuse. It is clear that the status quo is unsatisfactory.

Legalising assisted dying would ensure the practice was regulated and so offer terminally ill people greater protection than the current system.

## **Palliative care**

The UK was ranked 1st in the world in overall quality of death according to research conducted by the Economist Intelligence Unit<sup>1</sup>. Even so, as was concluded by the House of Lords Select Committee Report on the Assisted Dying for the Terminally Ill Bill, there are a number of patients whose desire for medically assisted dying will not be addressed by more or better palliative care<sup>2</sup>. The National Council for Palliative Care, the British Medical Association and Macmillan Cancer Relief have all acknowledged this fact<sup>3</sup>.

## **Dignitas deaths**

In early 2010, it was reported that approximately 135 Britons had been assisted to die at the Swiss assisted suicide organisation, Dignitas. The first reported case of a Briton being assisted to die at Dignitas was that of Reg Crew, in 2003, and since then there has been a heavily reported,

steady stream of Britons travelling to Switzerland for assistance to die – with a further 700 Britons members of the organisation<sup>4</sup>. People who travel to Dignitas often do so unaccompanied, for fear of legally implicating loved ones, and before they are ready to die, for fear that they may be physically unable to travel if they wait any longer. In the absence of assisted dying legislation in the UK, these cases are investigated for abuse and coercion only after the death. Legislation would offer the opportunity to investigate and evaluate requests for assisted dying before someone has died.

### **Suicide and mercy killing**

It is impossible to establish precisely the number of terminally ill people who attempt or commit suicide because this information is not required to be recorded. However, personal testimonies<sup>5</sup> show that people turn to suicide in order to attempt to take control over their final moments of life. Some ask for the direct assistance of friends or family members (often referred to as ‘mercy killing’) and, although many of these cases are not discovered or do not result in prosecution, the negative effects for all concerned are clear. For example, the Home Office reported that, of 49 people suspected of acts of ‘mercy killing’, 20 went on to commit suicide<sup>6</sup>.

### **Refusing food and water**

As enshrined in the NHS constitution and confirmed in recent legislation, a patient with mental capacity can refuse life-prolonging treatment (for example, chemotherapy or antibiotics). Some terminally ill people also choose to refuse food and water in order to bring about their death. Although there are no official statistics on the numbers who do this, personal

testimonies from Dignity in Dying supporters shows this does happen, and that people who choose to bring about their death in this way without medical support, may suffer a protracted, painful death<sup>7</sup>.

### **Need for regulation**

In the UK in 2009, Professor Clive Seale surveyed doctors on their attitudes to end-of-life decisions<sup>8</sup>. He found that 0.21% of deaths were as a result of voluntary euthanasia – when a doctor takes a decision to end a patient’s life with their explicit consent. The research also found that a further 0.33% of deaths were as a result of non-voluntary euthanasia – when a doctor ends the life of a patient without their request or consent.

Both voluntary euthanasia and non-voluntary euthanasia are illegal in the UK and Dignity in Dying believes this should remain the case. However, without a legal framework for assisted dying, these practices continue unregulated, with no checks for abuse. Whilst assisted dying remains illegal terminally ill people suffering at the end of life will continue to find ways to end their lives. We believe a legal framework which distinguishes between these cases and those of non-voluntary euthanasia would offer greater protection and safety to people. Countries that have regulated assistance to die have seen the incidence of non-voluntary euthanasia significantly fall. In the Netherlands, non-voluntary euthanasia fell from 0.8% of deaths in 1990 to 0.4% in 2005,<sup>9</sup> and in Belgium, non-voluntary euthanasia fell from 3.2% of deaths in 1998 to 1.8% of deaths in 2007<sup>10</sup>.



**IN THE  
NETHERLANDS,  
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IN 2007.**



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Figures from other jurisdictions also demonstrate that legalising assistance to die brings much needed regulation and results in a decrease in illegal, non-voluntary euthanasia.

## **Demand in the UK**

It is possible to estimate the theoretical demand for assisted dying here in the UK by extrapolating figures from the US state of Oregon, where the law is similar to that which we propose and has been in place since 1997. There, the numbers of assisted deaths each year has remained at around or below 0.2% of all deaths for the last five years<sup>1</sup>. In England and Wales, where approximately 500,000 people die annually, we can expect that around 1,000 terminally ill adults would use such legislation each year.

## **Emotional insurance**

The availability of the option of assisted dying brings comfort to far more people than actually use it. The Oregon Hospice Association reported in 2007<sup>2</sup> that, of the 30,000 people who died in Oregon that year, almost 10,000 considered seeking an assisted death, around 1,000 spoke to their doctor about getting a prescription, 85 received the prescription and only 49 people actually went on to have an assisted death.

## **Figures from other countries**

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### **Oregon**

The assisted dying legislation we propose is similar to that in place in Oregon, where the law is working well and numbers of assisted deaths are low. While it is accurate to say that

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# NUMBERS: DEMAND IN THE UK, EMOTIONAL INSURANCE AND FIGURES FROM OTHER COUNTRIES

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Some opponents of assisted dying claim that, because it would only be used by a small number of terminally ill people, legislation is unnecessary. However, evidence from Oregon shows that the availability of the option brings comfort to far more people than actually go on to make use of it.

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use of the law has increased (from 16 deaths in 1997 to 65 deaths in 2010) this is to be expected, as in the early years after legislation people may not have been familiar with the option of assisted dying or the process for requesting it. However, it is important to note that, even with an initial increase, numbers remain very low at 0.2% of all deaths in Oregon<sup>1</sup>.

## Netherlands

Prior to legislation in the Netherlands, in 1995 there were 3,527 deaths as a result of voluntary euthanasia and physician-assisted dying and in 2009, after legislation, there were 2,636<sup>3</sup>. Whilst numbers fell between 2001 and 2005 and have risen in recent years (rising approximately 10% each year since 2006), they are still lower than in 1995. Research indicates that the

rise since 2006 is due to an increase in the reporting of cases by physicians from 54% in 2001 to 80% in 2005<sup>4</sup>. Non-voluntary euthanasia has also fallen since legislation from 0.8% of all deaths in 1995 to 0.4% in 2005.

## Belgium

There is a similar trend in Belgium to that in the Netherlands. While there has been an increase in the rate of voluntary euthanasia since regulation in 2002, from 235 cases (0.23% of all deaths) to 495 cases in 2007 (0.49% of all deaths)<sup>5</sup>, there has also been a decrease in non-voluntary euthanasia from 3.2% of all deaths in 1998 to 1.8% in 2007<sup>6</sup>.

These figures should be reassuring to those who are concerned about a 'slippery slope' from voluntary to non-voluntary assistance to die.

# **SAFEGUARDS:** **DEFINING TERMINAL ILLNESS, MENTAL CAPACITY, DEPRESSION AND PROGNOSIS**

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Dignity in Dying advocates assisted dying only in the context of strict legally defined safeguards. Most importantly, the person applying for assisted dying must be terminally ill and mentally competent.

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## **Defining terminal illness**

One concern raised by opponents of assisted dying is that it is difficult, if not impossible, to define terminal illness. However, within the UK, we have several definitions for terminal illness already. The rules for the Disability Living Allowance<sup>1</sup> define terminal illness as a progressive disease from which you are not expected to live for more than six months. The Department of Health's End of Life Care Strategy suggests that healthcare professionals use the question: 'Would I be surprised if this patient was to die in the next six months or one year?' when considering whether a patient is suffering from a terminal illness or a progressive condition that is reaching a terminal phase. Any future legislation could include such a definition.

## **Mental capacity**

The Mental Capacity Act 2005 and its Code of Practice define mental capacity (also known as mental competency) as the ability of a person to make decisions<sup>2</sup>. With regard to the mental capacity safeguards in

assisted dying legislation, this would mean that, should a person request assistance in dying, they would be deemed mentally competent only if they fully understood the information they requested about assisted dying, retained that information long enough to make a decision, were able to weigh up the information available in making the decision, and able to communicate and understand the consequences of such a decision.

## **Depression**

Concerns have been raised about the prevalence of depression in patients who have been assisted to die, suggesting that some individuals may choose this option when they are not entirely competent to make the decision.

A study from Oregon<sup>3</sup> examined the prevalence of depression in terminally ill patients who requested assistance to die. Symptoms of depression occurred in 1 in 4 participants who requested assisted dying and 1 in 6 who died had symptoms. However, the researchers



acknowledged that some of the indicators used to measure depression may have in fact been measuring the side effects of terminal illness (e.g. loss of appetite).

Other researchers also found that a level of 'appropriate sadness'<sup>4</sup> or depression is considered normal in terminally ill patients approaching the end of their life. Further, whilst more research is needed on how depression may affect the decision-making of terminally ill patients, the existence of depression does not necessarily mean that a person lacks mental capacity.

Dignity in Dying is considering building in a compulsory evaluation with a specialist consultant psychiatrist as part of future legislation.

### **Prognosis**

Opponents of assisted dying have argued that it can be very difficult to deliver accurate prognoses for terminal illness. While there is some truth in this, it is a reflection of the nature of medicine, which is always based on an

assessment of probabilities. Calculating prognosis and survival time to aid end-of-life decision-making is not an exact science. The complex nature of this work means that healthcare professionals often use their 'gut feeling' rather than a specific tool for measuring prognosis<sup>5</sup>. Dignity in Dying has always promoted open and honest conversations between doctors and patients and in future legislation all patients considering assisted dying should be made aware of the risk of an inaccurate prognosis.

Evidence also suggests that, where errors in prognosis occur, they are far more likely to be overestimates in life expectancy than underestimates, particularly in cases of cancer. Three studies have found that between 63% and 71% of predictions were too optimistic<sup>5/6/7</sup>.

It is also important to appreciate that a request for assisted dying generally takes place within days or weeks of a person's death, when prognosis is much more secure.

# **IMPROVEMENTS ALONGSIDE ASSISTED DYING: PALLIATIVE CARE AND THE DOCTOR- PATIENT RELATIONSHIP**

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Where assisted dying has been legalised, palliative care is delivered to a high standard. Assisted dying is complementary to palliative care rather than an alternative to it.

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Investment in end-of-life care has increased after the introduction of legislation. Legalised assistance to die also encourages better communication between patients and healthcare professionals and the level of trust between doctors and patients is highest in countries with assistance to die.

### **Palliative care**

Opponents of assisted dying sometimes argue that it would not be necessary if first-class palliative care were universally available. Even the best palliative care, however, does not obviate the need for assisted dying (see pages 14/15) as evidenced by the fact that Belgium, the Netherlands and Oregon all have excellent reputations for the quality of their palliative care services. A European-wide study in 2007 ranked the Netherlands, out of 52 countries, as the 4th most effective in terms of the development of palliative care<sup>1</sup>. Belgium ranked 5th in a study on quality of death across the world<sup>2</sup> and in Oregon in 2009 over 90% of people who had an assisted death were enrolled in hospice care<sup>3</sup>, which is considered best practice for palliative care<sup>4</sup>.

It is also incorrect to suggest that assisted dying stunts the further development of palliative care. Since the regulation or introduction of assisted dying legislation, Oregon, Belgium and the Netherlands have seen improvements in palliative care alongside the option of an assisted death. In Oregon, researchers found that physicians have improved their palliative care knowledge in order to be able to explore all options with patients<sup>5</sup>. In Belgium, at the same time as voluntary euthanasia

legislation, a Palliative Care Act was passed which mandated nationwide coverage and an increase in funding for palliative care, and in the Netherlands the number of specialist palliative care beds has increased<sup>6</sup>. Legalisation in the Netherlands has also led to an improvement in all end-of-life discussions between patients and healthcare professionals<sup>7</sup>.

### **Doctor-patient relationship**

Concerns have been raised that the availability of assistance to die might undermine the relationship between the patient and the doctor. A study from 2006, however, found that doctors in countries where assisted dying is legal are significantly more likely to say that they discussed end-of-life decisions (assisted dying as well as withdrawal/withholding of treatment) with relatives and patients, than in countries where it is not legal practice<sup>8</sup>. Other research shows that doctors' skills, knowledge and communication with dying patients has greatly improved since legislation in Oregon<sup>9</sup> and the Netherlands<sup>10</sup> and a European-wide study found that patients in the Netherlands had the highest regard and trust for their doctor, with 97% of patients feeling confident in their GP<sup>11</sup>.

# 'SLIPPERY SLOPE': OREGON, PATIENT AUTONOMY, THE NETHERLANDS AND PUBLIC ATTITUDES

Some fear that once assisted dying for terminally ill, mentally competent adults is introduced, society would stand at the beginning of a 'slippery slope' leading to a situation where people who are not dying, and those without mental capacity, will also be assisted to die, possibly against their will.

Oregon provides a good example of a jurisdiction where this has not happened, and public attitudes here in the UK show that this is highly unlikely to happen. Evidence from Oregon also shows that alongside assisted dying comes a shift from doctor-led decision-making to patient autonomy.

## **Oregon**

In Oregon, safeguarded assisted dying for terminally ill, mentally competent adults was introduced in 1997. Since then, there have been no calls to extend the legislation to include either people who are not terminally ill, or people who do not have mental competency. More recently, legislation with the same criteria has been introduced in Washington state, again with no calls to extend this to a wider group than terminally ill, mentally

competent adults who can self-administer the life-ending medication.

### **Patient autonomy**

Some people oppose assisted dying through fear that it represents a cultural shift where doctors will take life and death decisions on behalf of their patients based on their personal perception of the patient's quality of life. Studies from Oregon have examined reasons for seeking assisted dying and show this is not the case. The over-arching reasons listed for requesting assistance to die are: 'wanted to control circumstances of death' and 'future quality of life'. The least reported reasons are: 'current pain' and 'depression'<sup>1</sup>. According to Ganzini *et al*, physicians found that people requesting an assisted death in Oregon are independent, determined and strong-minded individuals who want control over the time and manner of their deaths<sup>2</sup>. Physicians also stated that their requests to die are forceful and persistent. In reality, rather than passing more power to healthcare professionals, and threatening patient choice by empowering doctors, assisted dying represents a clear shift from doctor-led decision-making to patient autonomy.

### **The Netherlands**

One commonly asserted misconception is that legislation in the Netherlands allowing assistance to die was once limited to terminally ill people and has since been extended. In fact the Termination of Life on Request and Assisted Suicide (Review Procedures) Act (2002) was drafted to cover those who make a voluntary, well-considered request for assistance to die, who face lasting and unbearable suffering, who understand

their situation and the alternatives to voluntary euthanasia, and who believe that there is not another reasonable alternative for them. The legislation also allowed advance requests for voluntary euthanasia in the event of loss of capacity to be made, and for patients aged between 12 and 18 with a good understanding of their situation to request voluntary euthanasia, with their parents'/guardians' consent<sup>3</sup>. There has been no extension of the law in the Netherlands - the law there started from a broader position than just terminal illness.

### **Public attitudes**

The most important protection from descent down a reputed 'slippery slope' comes from public attitudes. Several opinion polls show that support for legislation significantly drops when it is suggested that it might be extended beyond terminally ill, mentally competent adults to include disabled people who are not dying or people who lack mental capacity. The 2007 British Social Attitudes survey found that while 80% agreed that a person with a terminal and painful illness from which they will die should be allowed an assisted death, only 41% agreed that a person who is not in much danger of death, but 'becomes dependant on relatives for all their needs' should be allowed assistance in dying<sup>4</sup>. It therefore seems unlikely that legislation would be extended in the future with such little public support.

# CONCERN ABOUT UNDUE INFLUENCE: REASONS FOR SEEKING ASSISTED DYING, ABUSE AND COERCION, AND THE IMPACT ON VULNERABLE PEOPLE

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Perhaps one of the most commonly used arguments against assisted dying is that it would put pressure on terminally ill adults to end their life. However, research from Oregon shows that requests for assisted dying are largely prompted by concerns about loss of autonomy and dignity.

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Research which examined assisted dying practices in Oregon and practice in the Netherlands found no evidence that vulnerable people are adversely affected by assisted dying legislation.

## Reasons for seeking assisted dying

Studies from Oregon have examined the reasons why terminally ill adults seek assisted dying. Reasons for choosing an assisted death are focused on the patient's wish to gain control and their poor quality of life rather than pain, being a burden or the financial implications of treatment. Loss of autonomy (97%), being less able to engage in enjoyable activities (86%) and loss of dignity (92%) are the main reasons for patients choosing an assisted death. Inadequate pain control (10.2%), burden (25%) and financial

implications of the treatment (2%) are less frequently given as reasons<sup>1</sup>. Where burden is mentioned, this tends to be strongly related to patients' concerns about losing autonomy. Legislation in Oregon also includes the safeguards that people who apply for assisted dying must be informed of all their options (including palliative care and pain relief), must have the capacity to make this decision, and that the request for assisted dying must be voluntary and well-informed<sup>2</sup>.

## Abuse and coercion

Issues around coercion, burden and outside influences apply in existing legal end-of-life medical practices (for example the right of a mentally competent patient to refuse life-saving medical treatment has no legislative safeguards). In contrast, a safeguarded assisted



dying law would provide a regulatory framework that would require health professionals to screen for abuse and coercion. Evidence from the Netherlands demonstrates that patients who enter the process do not feel pressurised into going through with the final act. Indeed, the process is seen by some patients as an 'emotional insurance'<sup>3</sup>, with the final act being seen as an option rather than a commitment. This is similarly reflected by research from Oregon (see pages 18/19). Furthermore, evidence highlights that voluntary and non-voluntary euthanasia is taking place in the UK now (see pages 16/17) without regulation and outside of any legal framework. Dignity in Dying's view is that with a transparent, legal framework in place vulnerable people would have greater protection as cases of abuse would be picked up on more easily.

### **Impact on vulnerable people**

The most comprehensive research carried out on the impact of assistance to die on vulnerable groups was conducted in 2007 and looked at the experience of the Netherlands and Oregon. Within the study, 'vulnerable' patients included adults aged 85 or older, disabled people, people of lower socio-economic status and those with mental health problems. Researchers found no evidence that vulnerable groups had been adversely affected by legislation, and in fact those groups were underrepresented in the numbers of assisted deaths<sup>4</sup>. The typical person who seeks an assisted death in Oregon tends to be aged between 55 and 84, white, has a 'good education', has cancer as the underlying illness and has medical insurance<sup>5</sup>.

# 10

## **ETHICS:** **SANCTITY** **OF LIFE, SOCIETY** **AND DIGNITY**

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Assisted dying neither devalues human life, nor permits society to devalue the lives of disabled or dying adults. Rather, to accede to someone's request for assisted dying is to accept their own valuation of a few remaining weeks of life that they do not want to endure.

Assisted dying legislation represents a clear shift from doctor-led decision-making to patient autonomy and allows a patient to decide upon a death that they themselves deem dignified.

### **Sanctity of life**

Some people object to assisted dying because they believe that all human life is sacred and, as such, individuals should not be able to decide about the timing of their death. The belief that life is sacred cannot be endorsed or refuted with evidence. However, it is important to understand that supporters of assisted dying are not seeking to violate the principle of sanctity of life, but to uphold what lies behind it: a respect for the dignity and irreplaceable value of each human being. Accepting a dying individual's wish to die is not devaluing human life, but an acceptance of the valuation they place on a good end to their life, and their wish not to suffer unbearably at the end of life.

### **Society**

Some opponents suggest that if assisted dying were legalised, public attitudes and the general perception of the value of the lives of disabled and dying people would inevitably be affected. However, research shows that jurisdictions that have legalised assistance to die have seen a parallel fall in the rate of non-voluntary euthanasia alongside this (see pages 18/19). This is strong evidence to suggest that assisted dying, far from devaluing the lives of disabled and dying people, shifts the power to make a major decision which impacts on an individual's life and death, into the hands of that person and away from health and social care professionals. Addressing this imbalance would empower patients at the end of life and benefit a society which is willing to respect the wishes of its citizens when they make informed choices.

### **Dignity**

The concept of dignity is widely accepted as a key value in human life. Dignity in Dying strives to ensure that everyone has what they deem to be a dignified death, and we know that for a small but significant number of terminally ill adults, dignity for them will only be achieved through safeguarded assisted dying.

# AND FINALLY...

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Dignity in Dying's campaign to change the law is not a crusade based on abstract ideas. On the contrary, our evidence-based campaign aims to address a well documented social problem of people suffering against their wishes at the end of life.

The only way to address this problem is to improve access to good quality end-of-life care and to permit the choice of safeguarded assisted dying.

We use research to help build our case for change but also to design a framework for assisted dying that will be appropriate here in the UK

- socially, culturally and medically. Where concerns have been raised about practice in other jurisdictions that have legalised assistance to die, we use this to inform our thinking about any future law and to draft safeguards that will prevent abuse and malpractice but also offer choice and control to the small number of dying adults who will go on to pursue the option.

Research continues to influence and inform our thinking on future legislation but it also demonstrates that the present case for change is overwhelming.

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