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The case for dignity

Lessons on assisted dying, on safety, and in palliative care from around the world

Research Paper

By Pushkin Defyer, April 29th, 2024

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Contents

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About Centre

We are an independent non-profit foundation and cross-party think tank. Our mission is to rebuild the centre ground and to create a more centrist and moderate politics. We support better public services and a strong economy inspired by policies from the Nordic countries.

To achieve these goals, we work with people from across the UK and party politics. This includes engaging with politicians and our networks, which include academia, politics, and law.

Our work includes creating new conversations by hosting events and conducting interviews. We also produce new policy ideas to better inform debate, publish papers, and release articles. We aim to build consensus, shape public opinion, and work with policymakers to change policy.

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Foreword from Dr Alex Allinson

Over the past three decades, there has been a major societal shift in the way we face illness and death, and over 200 million people around the world now have legal access to some form of assisted dying.

There are broadly two types of legislation - ones that focus on terminal illness (US, Australia, New Zealand) and ones that focus on unbearable suffering (Belgium, Netherlands, Canada, Switzerland), and each jurisdiction has developed its legal processes. There are currently moves in Scotland, the Isle of Man, Jersey, and Eire to introduce assisted dying for their residents. Such moves are supported by positive changes in public opinion and within the medical profession.

Assisted dying can be seen as an emotive and contentious issue; however, it is fundamentally concerned with upholding patient autonomy and strengthening the end-of-life choices individuals have. There is a degree of misunderstanding and misinformation around the subject and a real need for research and substantive evidence to aid policy development.

The analytical work carried out by Centre Think Tank addresses key issues in the debate over assisted dying legislation, particularly the safeguards necessary and protection against abuse and coercion, but also the role of assisted dying as an extension and adjunct to quality palliative care.

I hope this research will help guide decision-makers in those countries introducing assisted dying legislation, but also assist legislators in countries that already have provided this healthcare provision to evaluate and monitor the integrity of their existing laws.

Dr Alex Allinson

General Practitioner and Member of the Isle of Man parliament, Tynwald.

Endorsements

John Wannenburgh MHK

"This paper from Centre is a useful addition to the discussion around assisted dying. For me, the key argument is about freedom of choice. Those who are terminally ill should have, if possible, the choice to die peacefully, ideally in their own bed, surrounded by their family, without prolonged indignity and suffering beforehand, and with no regrets."

John Wannenburgh

MHK for Douglas North

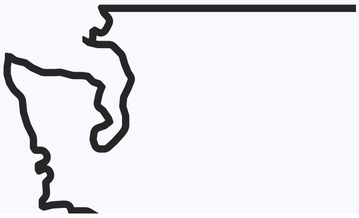
Stu Peters MHK

"I welcome this paper by Centre Think Tank on some of the common objections to assisted dying legislation. I was delighted that the Bill passed its second reading in the Isle of Man House of Keys and hope this important bill is passed. It is about giving people the choice of dignity which is an important issue which I see as a human right."

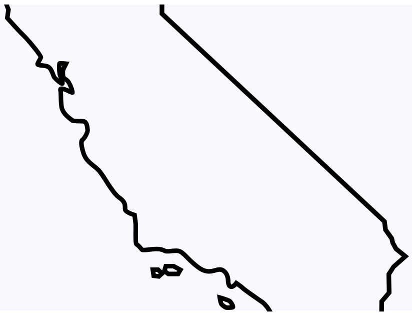
Stu Peters

MHK for Middle

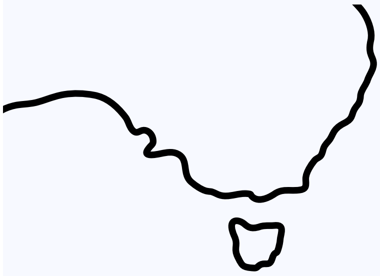
Summary



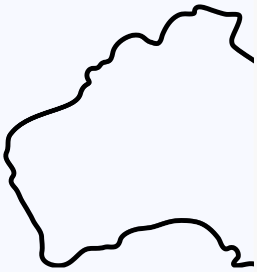
This paper covers the impacts of assisted dying legislation on the palliative care sector and what risks there are that the system could be abused using case studies around the world. Both sections conclude that new legislation carries little risk of abuse and would likely not negatively impact palliative care.



The first section looks at examples from California, Oregon, Washington, Victoria, and Western Australia for historical instances of abuse. It finds that individuals have a high degree of autonomy within the process, and many individuals decide not to use the option of assisted dying despite having direct access to it.



The second section looks at the impacts on the palliative care sector, which has often been under-invested in. It shows that there is concern amongst those in the sector, but over time some groups have voiced support for a change in the law.



The second section also shows that governments generally increased funding for palliative care following the introduction of assisted death legislation.

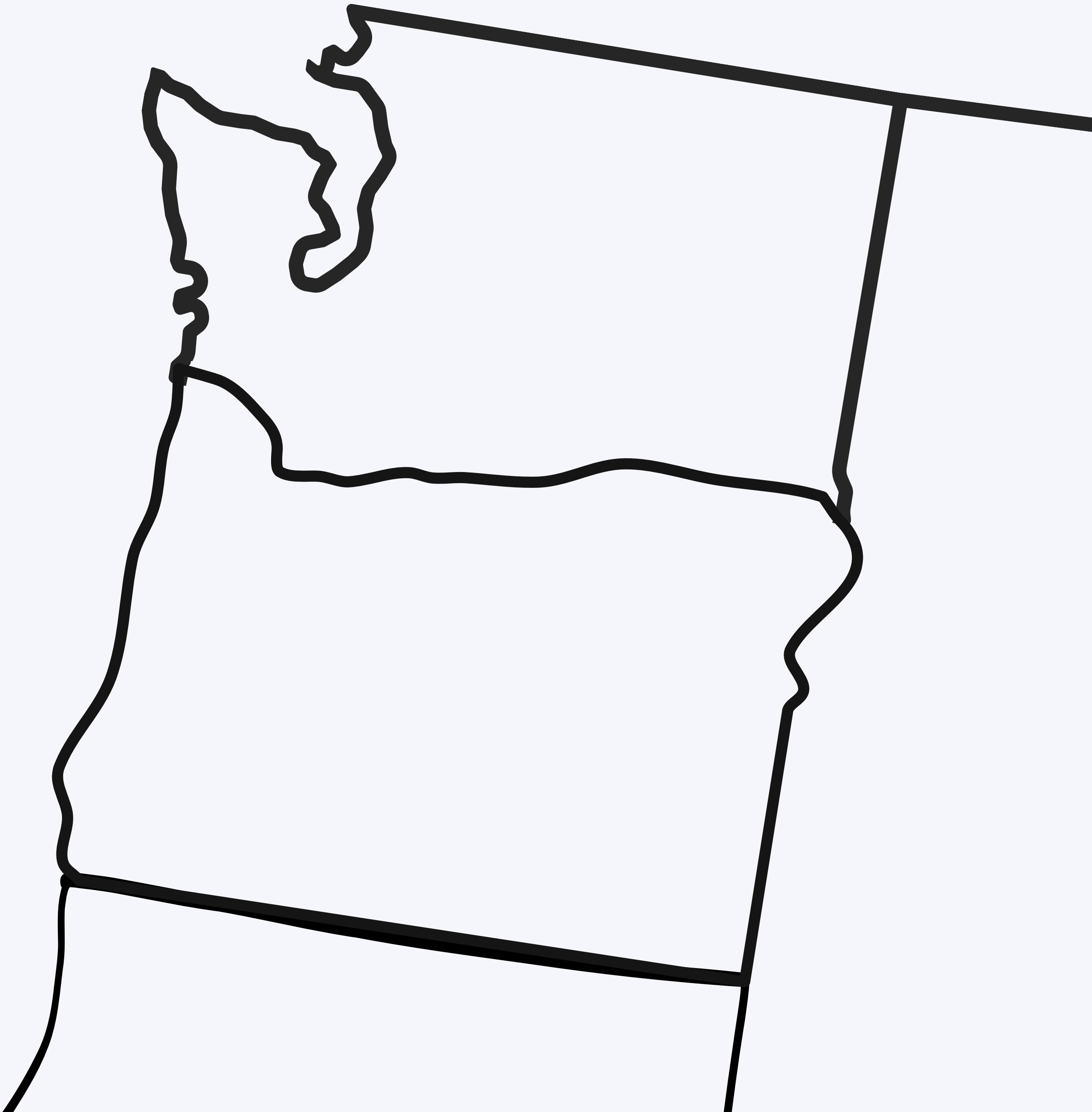
Introduction

Assisted dying is now a real possibility within the United Kingdom (UK) with support from across the political spectrum and from the public. The Isle of Man is also heading in the same direction where the House of Keys is debating a bill which would legalise assisted dying. This has already passed its second reading and looks on course to becoming law.

This paper focuses on two heavily debated and discussed aspects of the vote. Firstly, it looks at how common abuse of assisted dying is around the world and the arguments about a ‘slippery slope’ after legalisation. Secondly, the paper looks at the impact assisted dying legislation has on the palliative care sector.

Chapter one

Safety of Assisted Dying Frameworks Around the World



Assisted dying laws vary globally, with ongoing debates in the UK. Groups like ‘Dignity in Dying’ and ‘Dignity in Dying Scotland’ advocate for legislative change such as that proposed in Baroness Meacher's recent Assisted Dying bill which aimed to legalise assisted death in England and Wales[1]. This bill proposed requirements such as age verification, terminal illness diagnosis, confirmation of mental competence and volition by two independent doctors, and approval by a High Court judge. The patient could then take life-ending medication at their convenience after a 14-day minimum wait. Despite being enacted in various countries, such laws elicit concerns about potential misuse, particularly the risk of coercion and vulnerability among specific groups.

In an article published in The Economist[2], James Mildred from the Christian Action Research and Education group, which opposes assisted dying, raised concerns about a potential "slippery slope" effect associated with assisted dying legislation. He referred to cases in Oregon, where the number of instances has increased since its introduction in the 1990s. He also highlighted the Netherlands, where the concept has expanded to encompass more groups since its initial implementation in 2002. The primary concern is the initial legislation to target specific groups through euthanasia expanding to those who would prefer palliative end-of-life care.

This paper examines potential and historical instances of abuse within assisted dying frameworks in California, Oregon, Washington, Victoria, and Western Australia. It assesses the risks and real-world outcomes using official statistics.

Historical instances of abuse

In all areas reviewed, there were no reported instances of abuse, even in the face of significant and growing usage of the service (which generally occurs upon initial introduction of the service). In Victoria, where there is historical data, there has been significant growth in requests since the introduction of the legislation[3]. First requests grew by 61% between 2019 and 2022. However, of 581 first requests, 401 ended up ingesting the lethal medication in 2021-22. In Western Australia, a similar pattern is noted in the legislation’s first year of implementation (2021-22)[4]. Of the 533 first requests, only 190 deaths were recorded. The reduction indicates that there are strict eligibility criteria and thorough assessments, reducing the potential for system abuse.

Notably, in both reports, none of the rejections at the first assessment stage were due to coercion, suggesting that there is no evidence of vulnerable individuals being unduly influenced into requesting assisted dying. There were more instances of coercion or obstruction against assisted dying recorded in the Victoria report[5]. It should also be noted that the assisted dying process in every area studied also allows participants to withdraw and restart at any time, even after initial rejection, providing them with the ability to change their minds at any stage, which provides a further safeguard against potential coercion. The ability to reapply has not enabled people to get past initial rejections; when multiple requests are accounted for per person, the rejection rate increases in WA from one-third to 42%, indicating many who reapply are still considered ineligible[6].

Regarding whether the legislation's scope is being stretched to include other groups, there appears little to no evidence of this occurring. In Oregon, there have been 2,847 medically assisted deaths since its introduction in 1997[7]. The median age of these patients was 73, with over 2/3rds being 65+ and over 90% being in some form of end-of-life care. The most recent year of data (2022) continues to uphold this trend with even more of a skew towards older patients.

Under California's End of Life Option Act (EOLA)[8], 2,422 patients have received assisted dying services since 2016. Nearly 90% of those who died from ingestion were over 60, and a similar number were receiving hospice/palliative care. Again, the most recent annual data from 2022 continues to uphold this trend. This demonstrates that the system is serving its intended population - those who are terminally ill and already receiving end-of-life care.

In the 25 years of Oregon's legislation and 7 years of California's, there has been no indication of broadening the eligibility to include other, potentially more vulnerable groups. Similar patterns are observed in all other historical official data points; the vast majority of patients are above the age of 60 and are in some form of end-of-life care, with cancer being by far the most common cause of terminal illness.

There appear to be strong structures in place during the process itself in helping to prevent harm to vulnerable groups as well as offering compassionate, patient-centred care. Oversight mechanisms, such as a voluntary assisted dying board, robust data collection, and collaboration with the medical field and government, are in place to monitor the implementation of the law. These mechanisms could help in detecting and mitigating any potential abuses of the system. Between 2021-22, the Western Australia Statewide Care Navigator Service[9], which helps coordinate care and aid patients in the process, recorded more than 10,000 contacts with patients, families and carers, practitioners, or service providers. From these numbers, we can see these oversight mechanisms play a significant role throughout the process.

Potential for abuse

When reviewing the ability of the system to be abused, a key factor is the autonomy individuals hold within the process. A significant number of patients are not immediately taking their prescribed medication. In California, out of 772 prescriptions issued, 486 patients ingested the drugs and died, with 38 of those from prior year prescriptions (7.8%). Among the remaining 324, we do not know the status of 106, while 130 died from other causes. This aligns with historical data showing death rates from EOLA consistently lower than prescriptions issued, even when considering deaths from previous year prescriptions.

In Oregon, of 560 prescriptions, 367 patients died as of 2024, with 30 from previous years' prescriptions. Of the total prescriptions, 82 individuals did not take their medication and died from other causes.

Several patients did not ingest the drug. In Oregon for 2023, this percentage is 15%[10], and in California, the number of people who had not died but also had an unknown ingestion status during 2021 was 13.7%[11].

This suggests individuals have control in the process, with patients choosing whether to ingest the medication upon receipt or hold it for future ingestion. Although we are unable to say that all patients who did not take their medication were exercising autonomy, the number who ingested medication from previous years and the consistent gap between prescriptions and deaths point to a significant degree of personal choice.

A 2019 study titled ‘Trends in Medical Aid in Dying in Oregon and Washington’ analysed 3,368 prescriptions for assisted dying across Oregon and Washington, covering a combined 28 years of data. The main concerns expressed were loss of autonomy, impaired quality of life, and inadequate pain control as there are limitations. The paper also stated that there was no materialisation of assisted dying unintentionally targeting socially disadvantaged patients. It said, “Concerns that MAID would unintentionally target socially disadvantaged patients have not materialised, as evidenced by the data presented in this article“[12]. The primary concerns for pursuing assisted death, as reflected in other case studies, suggest individuals are making decisions based on their quality of life and personal values, rather than being coerced or unduly influenced by others.

Another qualitative study in Vancouver and British Columbia[13] titled ‘Experiences and perspectives of people who pursued medical assistance in dying’ reviewed 23 patients throughout their process. As in the statistics for other jurisdictions with legalised assisted dying, participants expressed the importance of control over their end-of-life decisions, with similar concerns of loss of autonomy and joy of life.

Generally speaking, those involved in the process appeared fully in control and aware of their decisions throughout. This can also be observed in the times between requesting and ingestion of medication. In Oregon[10], the median wait between the first request and death was 26 days in 2023. We see from this data that patients were not rushing or being pushed through the process but instead had considerable time to consider decisions and complete assessments to safeguard against abuse.

Conclusion

In conclusion, there were no reported instances of abuse and no evidence of undue coercion or a 'slippery slope' effect targeting specific groups since the introduction of these laws. The study also found strong structures in place during the process itself, such as rigorous eligibility assessments, the ability for participants to withdraw and reapply at any stage, and strong oversight mechanisms to prevent harm to vulnerable groups and ensure patient autonomy. The evidence strongly suggests that these frameworks are serving their original purpose: offering compassionate, patient-centred care for individuals at the end of their lives.

Despite concerns about potential system abuse, the ability of the system to be abused appears limited. A key factor in this is the considerable autonomy individuals hold within the process, with a large number of patients choosing not to immediately ingest the prescribed medication, and in doing so regaining control over their end-of-life decisions. The decision-making processes among individuals in these jurisdictions seem to be driven by personal values and a desire for autonomy, rather than external influences or coercion.

However, it is crucial to note that while these findings suggest a generally positive trend in the five jurisdictions studied, ongoing vigilance is needed to ensure these safeguards continue to function effectively. While this research presents a strong case against the arguments of potential abuse and misuse, it should not preclude the necessity for continuous evaluation and monitoring to maintain the integrity of assisted dying legislation.

The findings of this section contribute to the growing body of evidence supporting the responsible implementation and management of assisted dying laws, offering important insights to policymakers in countries where such legislation is being considered or reviewed. Yet, the debate over assisted dying is far from over. It must continue to balance the ethical, medical, and legal considerations to ensure the best possible outcomes for all involved.

Chapter two

Palliative care and Assisted Dying laws

The NHS website[14] describes palliative care as ‘care [that] should help you to live as well as possible until you die and to die with dignity,’ going on to describe how those caring for patients should ‘take into account’ their ‘wishes’ and ‘preferences’. However, even if every patient in need of care could access current services, the Office of Health Economics estimates that 6,394 people each year would still experience no relief from pain in the final three months of their lives[16].

A UK Parliamentary paper on ‘Palliative and end-of-life care’[15] also outlines how the sector is ill-prepared for both current and future demand. As we face a rapidly ageing population, growing demand will increase the overall cost of hospice provision of palliative care by £947 million a year over the next decade, potentially reaching a total cost of £4.8 billion by 2043 for hospital-based palliative care. The parliamentary report describes how over 100,000 people in the UK who could benefit from palliative care die each year without the support.

As it stands, around two-thirds of palliative care funding comes from fundraising and donations with Hospice UK voicing concern over financial sustainability[17] as a quarter of UK Hospices are under ‘severe financial stress.’ Further to this, research from the IPPR[18] brings to light disparities in funding as people in more deprived areas will spend a greater amount of time in hospital while receiving £400 less investment per person in their last year of life when compared to people in the least deprived areas.

There are concerns about establishing Assisted Dying laws and their effect on an already under-invested palliative care sector in the UK, particularly from the sector itself. 86% of Scottish palliative medicine doctors who were anonymously surveyed in 2022[19] stated the implementation of the suggested framework would have a negative impact on the service, 61% believed this would negatively impact access to palliative care for the BAME community, 76% said the same for disabled and prison populations, and 51% said for the LGBTQ+ community. Further to this, 67% felt rural communities would be adversely affected.

A further survey in 2015 conducted by the Association for Palliative Medicine[20] showed that 82% of members opposed such a change, with 72% concerned that a bill such as the one proposed by Lord Falconer at the time would harm the delivery of palliative care.

However, there is increasing support with several medical organisations shifting from long-standing opposition to neutrality, such as the RCP in 2019[21] and the BMA in 2021[22].

When surveyed in February 2020[23], 40% of members said the BMA should support a change in the law, 21% said the BMA should take a neutral position and just 33% supported maintaining opposition. When it came to personal views, 50% of doctors were in favour of a law change on assisted dying with 39% opposed and 11% undecided. The RCP saw 31.6% believe the RCP should support a change in the law when surveyed between 5th February to the 1st of March 2020[21], up from 24.6% when the same survey was conducted in 2014, while opposition fell from 44.4% to 43.3%; the remaining supported a neutral position.

Governments generally increased funding for palliative care following the introduction of assisted death legislation. In Australia, assisted dying legislation saw significant additional investment in the palliative care sector. In the New South Wales 2022/23 budget, an additional investment of $600 million over 5 years was invested, down from the initially announced $750 million as there were concerns there would not be enough additional people to work in the sector. This investment was also on top of the $300 million of funding already allocated annually.

In 2019, during the passage of legislation in Victoria, a similar announcement was made, allocating $62 million in additional funding. The funding boost in Victoria seeks to create more consistent access to after-hours palliative care advice, support services, and physician or nurse positions.

During the passage of legislation, the government of Western Australia announced an additional $17.8 million for investment in palliative care projects following recommendations of the Joint Select Committee Report on End-of-Life Choices. This followed the state budget in May which had pledged $41 million to an end-of-life choice and palliative care package. The significant increase in funding following the legalisation of medically assisted dying shows end-of-life care receiving more prioritisation in resource allocation and policy-making by governments.

The investments announced in Western Australia will go towards extending the reach of palliative care, including hiring additional healthcare professionals, increasing support for home-based palliative care, and expanding end-of-life support services. This creates a service which can be tailored more to individual needs.

When looking at other potential effects of assisted dying legislation, there appears to be no evidence of a negative impact on the palliative sector; in fact, it may be the opposite. A report from 2018 looking at several countries and US states where assisted dying is legalised, the palliative care sector sees significant advancements as a result with no adverse effects. In the countries studied, the implementation of assisted dying policies led directly or indirectly to improvements in palliative care by increasing its importance and public policy focus. Most patients accessing assisted dying services were already receiving palliative care, dispelling the argument that assisted dying would replace palliative care as an either-or choice. Increased usage of the services over time was due to greater acceptance and awareness within both the medical community and the wider population and not increased diversion of patients who could have accessed other palliative services instead.

Patient-doctor relations have also been noted to improve in jurisdictions with legalised medically assisted death. A study in Oregon concluded that physicians were making considerable efforts to improve awareness and care for patients who are terminally ill and have engaged with these patients about the choice of assisted death since the passage of legislation in 1994. As an article in The New England Journal of Medicine points out, voluntary assisted dying services have led to greater discussion in evaluating end-of-life options amongst families and between patients and doctors. In the UK, 87% said legalising medically assisted death would either positively or have no impact on trust in doctors.

In conclusion, current research shows that assisted dying legislation does not adversely affect or diminish the role palliative care plays in end-of-life support. If anything, it leads to increased awareness of the importance of offering patients a variety of choices to best suit their personal preferences and give them the most dignity in death. The parliamentary evidence from the UK further emphasises the need to learn from countries where assisted dying is legal. Studying the funding strategies and improvements made to palliative care provision in these countries can help to inform and improve palliative care provision elsewhere. This could result in more effective, sustainable, and equitable palliative care services.

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