



THE UNIVERSITY
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Edinburgh Law School

To what extent, if at all, are the eligibility criteria in the Assisted Dying Bill likely to adequately safeguard terminally ill persons?

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INTRODUCTION

Debilitating and chronic diseases are the largest cause of death in the world.¹ Although health care systems have taken steps to improve public health, a debate on whether the legalisation of hastened death in the context of terminal illness is emerging.² Similarly, assisted dying is seen as an extension of the health care decision making for terminally ill persons ('TIP').³ Since 2013 and at the time of writing this dissertation, the Assisted Dying Bill ('ADB') was introduced 7 times in the UK Parliament.⁴ Except for the bills introduced by Lord Falconer on 6 June 2014 in the House of Lords⁵ and by Labour MP Rob Marris on 4 September 2015 in the House of Commons,⁶ none of the ADBs was able to progress beyond the committee stage. On 26 May 2021, Baroness Meacher introduced the most recent ADB in the House of Lords, which is currently approaching the second reading stage.⁷ Similar to the previous bills that were recently introduced in the UK Parliament, it is uncertain whether the latest ADB will progress any further.

Safeguards of the ADB were one of the main topics of debate in the UK Parliament.⁸ Before the 2015 bill introduced by Rob Marris, the main safeguards of the ADB were capacity, consent, age and residence requirements, terminal illness with a 6-month life expectancy, declaration of medical practitioners and a cooling-off period of 14 days.⁹ Judicial involvement was the additional safeguard added to the 2015 ADB. This requires the applicant to satisfy a High Court (Family Division) judge and two medical practitioners of their "voluntary, clear, settled and informed wish" to die as prescribed by the ADB.¹⁰ Additional safeguards were also suggested by Lord Pannick in the 2014

¹ Derek Yach, Corinna Hawkes, C. Linn Gould et al, 'The Global Burden of Chronic Diseases: Overcoming Impediments to Prevention and Control' [2004] 291 JAMA 2616.

² Peter L. Hudson, Linda J. Kristjanson, Michael Ashby et al, 'Desire for Hastened Death in Patients with Advanced Disease and the Evidence Base of Clinical Guidelines: A Systematic Review' [2006] 20 Palliat Med 693.

³ Thomas DG Frost, Devan Sinha and Barnabas J Gilbert, 'Should Assisted Dying be Legalised?' [2014] 9 PEHM 3.

⁴ Assisted Dying Bill HL Bill (2013-14) [24]; Assisted Dying Bill HL Bill (2014-15) [6]; Assisted Dying Bill HL Bill (2015-16) [25]; Assisted Dying Bill HC Bill (2015-16) [7]; Assisted Dying Bill HL Bill (2016-17) [42]; Assisted Dying Bill HL Bill (2019-21) [69] and Assisted Dying Bill HL Bill (2021-22) [13].

⁵ Assisted Dying Bill HL Bill (2014-15) [6].

⁶ Assisted Dying Bill HC Bill (2015-16) [7].

⁷ Assisted Dying Bill HL Bill (2021-22) [13].

⁸ HC Deb 11 September 2015, vol 599, cols 656-727.

⁹ Assisted Dying Bill HL Bill (2013-14) [24] col 1-3.

¹⁰ Above n 6 cl 3(1).

House of Lords debate¹¹ citing the judgment of Lord Neuberger in the *Nicklinson*¹² case. No significant changes in the ADB and its safeguards since the judicial involvement was added in 2015 despite several ADB issues being mentioned in the debate, including the determination of life expectancy,¹³ enhancing palliative care,¹⁴ and protecting vulnerable people.¹⁵ While all the issues raised in the debate would not be resolved precisely, the ADB could be improved by considering the terms of assisted dying legislation from overseas jurisdictions.

The purpose of this dissertation is to examine the level of safeguards the ADB provides to the TIP and explore alternative options in enhancing the ADB's safeguards. Throughout the dissertation, I will examine the assisted dying legislation of various overseas jurisdictions such as the Australian states of Western Australia and Victoria, Oregon, Canada, Netherlands and Belgium. Then, I will contrast the ADB with these jurisdictions and argue about the appropriate provisions to enhance the ADB's safeguards. From time to time, ethical concerns will be discussed throughout the dissertation. As safeguards are vital to protect the TIP and health care practitioners ('HCP'), I argue that additional safeguards are imperative to improve the current ADB and its chance of being enacted by the UK Parliament.

In chapter one, I will explore the meaning, determination and application of safeguard. I argue that safeguard applies to all the parties involved in assisted dying and not only to the TIP. In chapter two, I will analyse the capacity and consent requirements to access assisted dying in various mental states. I argue that assisted dying should be limited only to persons with independent decision-making capacity. In addition, I will mention the possible inclusion of mature minors based on the current laws on capacity. However, the possible application of ADB to minors is beyond the scope of this dissertation and no stand will be taken on this issue. In chapter three, I will investigate the intricacies of determining terminal illness, suggest other HCP involvement in assessing terminal illness and decision-making capacity, and promote palliative care prior to discussing the assisted dying to TIP. I argue that the involvement of specialist

¹¹ HL Deb 17 November 2014, vol 756, col 1853.

¹² *R (on the application of Nicklinson and another) v Ministry of Justice* [2014] UKSC 38 [108].

¹³ Above n 8 col 658.

¹⁴ Above n 8 col 660.

¹⁵ Above n 8 col 664.

medical practitioners focusing on the TIP's physical and mental health is necessary for determining terminal illness. I also argue the inclusion of palliative care promotion through extensive individual discussion with the TIP who wants to access assisted dying and education in the community to enhance public awareness. Chapter four will briefly discuss the importance of residency requirements in accessing assisted dying and suggest further measures to prove this requirement. Chapter five will explore the code of practice and other safeguards in assisted dying and argue the importance of protecting other parties in the process, specifically the HCP. Finally, I conclude by making recommendations in reinforcing the ADB's safeguards after considering the ethical and legal aspects of assisted dying laws from various overseas jurisdictions. Compared to the safeguards of other jurisdictions with assisted dying legislation, the ADB should consider the legislation of other jurisdictions to enhance its safeguards to the TIP and HCP.

CHAPTER 1: SAFEGUARDS

1.1 What is Safeguard?

The ordinary meaning of safeguard is “to protect against something undesirable with an appropriate measure”.¹⁶ Another safeguard definition is “a legal proviso or a stipulation serving to prevent some encroachment”.¹⁷ In assisted dying perspective, specifically for the TIP, safeguard includes procedures to properly assess the person’s mental capacity, diagnosis and prognosis of current illness.¹⁸ The current ADB has stipulations protecting the TIP in accessing assisted dying and the HCP in performing their part in assisted dying. Based on TIP’s perspective, safeguards in the ADB are the requirements a TIP must satisfy to access assisted dying, such as the following:

- a. Has a valid declaration made to the High Court (Family Division) proclaiming the TIP’s voluntary, clear, settled and informed wish to end the life;¹⁹
- b. 18 years or over;²⁰
- c. Has the capacity to make decision on ending own life;²¹
- d. An ordinary resident of England and Wales for at least 1 year;²²
- e. Has an irreversible and progressive terminal illness diagnosed by a medical practitioner with a life expectancy of 6 months or less;²³ and
- f. Assessment of 2 suitably qualified medical practitioners who act as the TIP’s attending and independent doctors.²⁴

These ADB’s safeguards aim to protect the TIP are almost identical to other jurisdictions with assisted dying legislation. In some jurisdictions, additional safeguards are incorporated in their assisted dying legislation, such as making three

¹⁶ Oxford English Dictionary (Oxford University Press, 2000)

<<https://www.oed.com/view/Entry/169677?rskey=5Lh3hm&result=2#eid>> accessed 7 July 2021.

¹⁷ Ibid <<https://www.oed.com/view/Entry/169678?rskey=5Lh3hm&result=1#eid>> accessed 7 July 2021.

¹⁸ J Guy Edwards, ‘Assisted Dying Bill calls for stricter safeguards’ [2015] 385 *The Lancet* 686.

¹⁹ Above n 7 cl 3(1)(a).

²⁰ Above n 7 cl 1(2)(c)(i).

²¹ Above n 7 cl 1(2)(c)(ii).

²² Above n 7 cl 1(2)(c)(iii).

²³ Above n 7 cl 2.

²⁴ Above n 7 cl 3(1)(b)-(5).

separate assisted dying requests and passing all the necessary requirements of each request.²⁵

For the HCP, especially the medical practitioners, safeguards in the ADB are practices that the HCP must perform to ensure the safety of TIP in accessing assisted dying. At the same time, the HCP's safeguards exonerate or decriminalise them in the legitimate exercise of their duty regarding assisted dying. Other safeguards consider the personal values of the HCP towards assisted dying and allowing them not to participate in the said procedure. These safeguards to the HCP are the following:

- a. Providing the final act of administering the medicine to the TIP is prohibited;²⁶
- b. Absolution from criminal liability if assisted dying is done according with the ADB;²⁷ and
- c. Conscientious objection.²⁸

The above HCP-oriented safeguards are common in other jurisdictions with assisted dying laws.²⁹ Other jurisdictions like Western Australia have additional safeguards such as restricting HCP to initiate discussion regarding assisted dying.³⁰ However, discussion regarding assisted dying is not prohibited should the HCP have discussed the TIP's diagnosis, prognosis, treatment options and outcomes, and palliative care options.³¹

The ADB's safeguards oriented toward the TIP and the HCP ensure that all parties in the assisted dying process are protected from adverse consequences. On the other hand, safeguards must not be too onerous to defeat its purpose. There must be a system in place to ensure the balance of accountability and purpose for implementing ADB. The safeguards can be determined if adequate once this balance is achieved.

²⁵ Voluntary Assisted Dying Act 2017 (Victoria, Australia) s 6.

²⁶ Above n 7 cl 4(4)(c).

²⁷ Above n 7 cl 6.

²⁸ Above n 7 cl 5.

²⁹ Owen Dyer, Caroline White and Aser Garcia Rada, 'Assisted dying: law and practice around the world' [2015] 351 BMJ 1.

³⁰ Voluntary Assisted Dying Act 2019 (Western Australia) s 10(2).

³¹ *Ibid* s 10(3).

1.2 Adequate Safeguard Determination

In achieving the right balance of exercising the purpose of the legislation while safeguarding the people affected by the legislation, it is argued that learning from the experience of other jurisdictions is essential, “both in terms of what safeguard have been demonstrated to ensure quality and accountability in decision making, while also identifying those which appear to serve no purpose”.³² Learning from other jurisdictions does not necessarily mean transplanting the laws of one jurisdiction to another, just like what is believed that the UK did to Oregon’s Death with Dignity Act.³³ Therefore, examining the ADB in light of other jurisdictions with assisted dying legislation is inevitable to determine if the current ADB safeguards are adequate.

Although there are minor differences, such as documentary requirements to prove residency,³⁴ the safeguards of the ADB protect the TIP and the HCP which is similar to other overseas jurisdictions. The Oregon’s Death with Dignity Act is the closest equivalent of ADB, where the law only applies to people who have reached the age of majority and have been diagnosed with a terminal illness.³⁵ Other requirements such as the voluntary request to die, written request for life-ending drugs, and the determination of terminal illness from the attending and consulting physicians are the other similarities of ADB and Oregon’s Death with Dignity Act.³⁶ The heading of section 3 of the Oregon’s Death with Dignity Act is named ‘safeguard’, which makes easier for the parties in assisted dying to determine their responsibilities and entitlement to the said law. Looking at the section 3 safeguards of the Oregon’s Death with Dignity Act, this is almost identical to the terms of the ADB, which aims to protect the parties to the ADB, specifically the TIP and the HCP. The section 3 safeguards of Canada’s Medical Assistance in Dying law are almost similar to Oregon’s Assisted Dying Act and the ADB. Some of these safeguards include foreseeable natural death of the TIP, consent to assisted dying, capacity to make decisions and compliance of HCP.³⁷ Therefore,

³² Samantha Halliday, ‘Comparative reflections upon the Assisted Dying Bill 2013: A plea for a more European approach’ [2013] 13 *Medical Law International* 135, 137-38.

³³ *Ibid* 138.

³⁴ The Oregon Death with Dignity Act Oregon Revised Statutes s 3.10.

³⁵ Select Committee on the Assisted Dying for the Terminally Ill Bill, *Assisted Dying for the Terminally Ill Bill [HL]* (HL 2005) para 144.

³⁶ Above n 34 s 2.

³⁷ Criminal Code 1985 (Canada) s 241.

the welfare of the TIP and HCP are the main considerations to determine if the safeguards are adequate. These safeguards from different jurisdictions could be considered the standard, and the terms of the ADB agrees to it.

Despite the similarities in assisted dying safeguards of various overseas jurisdictions, there should be changes in the safeguards of one jurisdiction to meet the needs of its people. For example, mental illness is not enough to access assisted dying in Australia;³⁸ however, Canada considers this option. The Canadian government will initiate an expert review to consider protocols, guidance, and safeguards for individuals with mental illness seeking assisted dying, which is due on 17 March 2023.³⁹ Like Australia, there is no expressed stipulation in the ADB that allows assisted dying for persons with only a mental illness to qualify for the terminal illness requirement.⁴⁰ The use of evidence-based law-making could assist in resolving the issues of who will benefit most from the ADB and the manner the law should be made, including its safeguards.⁴¹ As evidence-based practise in medicine is proven effective, the challenge in using the evidence-based law-making method is its effectiveness in legal matters.⁴² However, it could be corrected by incorporating a pyramid structure where the most important consideration, such as the expert panel review, should be on top, and the lesser important concerns like opinions are at the bottom of the structure.⁴³ This way of determining the safeguards of the ADB would also consider the voice of the public who will get affected in the implementation of the law. Therefore, all the stakeholders of ADB will not be disadvantaged, and all their concerns will be properly addressed.

The eligibility requirements of the ADB should be changed if necessary to meet the genuine needs of the public without adversely affecting the TIP and HCP. Adapting the law of other jurisdictions should only serve as a guide. Other law-making methods should be adopted to suit the legitimate needs of the public, leading to enhanced

³⁸ Above n 25 s 29(2).

³⁹ Government of Canada, 'Medical Assistance in Dying' (2021) <<https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>> Accessed 20 July 2021.

⁴⁰ Above n 7 cl 2.

⁴¹ Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' [2020] 44 Australian Health Review 544.

⁴² *Ibid*, 545.

⁴³ *Ibid*.

safeguard determination. Therefore, the concerns of the TIP, HCP and other stakeholders affected by the ADB should be considered in determining adequate safeguards.

1.3 Application of Safeguards

Once the safeguards have been determined, its application must be the next priority. There is one British travelling to Dignitas every eight days who seek assisted death in Switzerland.⁴⁴ The number of these individuals seeking assisted dying is massive, considering it is still illegal in the UK. Therefore, the safeguards must be properly applied should ADB becomes a law. The most important aspects to consider for the TIP are their ability to fully converse the concept of mental capacity and the conditions that could affect their capacity, such as coercion or duress and their knowledge about the diagnosis and prognosis.⁴⁵ Similarly, the HCP have to consider their ability to participate in the process of assisted dying where the assessment of their qualifications, experience, training and ability to monitor all the HCP involved in the process should be examined.⁴⁶

It is vital properly diagnose the TIP to determine if they are legitimate candidates for assisted dying. Furthermore, the correct diagnosis of TIP's illness is a prerequisite to an appropriate prognosis. For example, in suspected cancer patients, most misdiagnosis happens due to misrepresented or incomplete medical evidence and incorrect reporting of the patient's test results.⁴⁷ A person might consider assisted dying after this misdiagnosis even though there are no plans of doing so. Therefore, the degree of confidence of medical practitioners must be stated in the diagnosis⁴⁸ as their prediction of a patient's survival is not always accurate.⁴⁹

⁴⁴ Dignity in Dying UK website <<https://www.dignityindying.org.uk/why-we-need-change/dignitas/>> accessed 21 July 2021.

⁴⁵ J Guy Edwards, 'If an assisted dying bill becomes law, medical and psychiatric safeguards must be extremely strict' [2019] 87(3) *Medico-Legal Journal* 135, 137.

⁴⁶ *Ibid.*

⁴⁷ WD Rees, SB Dover and TS Low-Beer, 'Patients with terminal cancer who have neither terminal illness nor cancer' [1987] 295 *BMJ* 318, 319.

⁴⁸ *Ibid.*

⁴⁹ Paul Glare, Kiran Virik, Mark Jones et al, 'A systematic review of physicians' survival predictions in terminally ill cancer patients', [2003] 327 *BMJ* 195.

TIP's mental capacity is the other major concern in safeguard application. The TIP should be able to comprehend and retain the treatment information, believe in the information, and weigh the information among other factors before reaching a decision to satisfy the common law test for capacity.⁵⁰ There are various clinical tools to satisfy the common law test for capacity. The focus is to determine the TIP's "ability to communicate a choice, factual understanding of the issue, appreciation of one's situation and the consequences, and the ability to rationally manipulate information".⁵¹ Adhering with the common law test for capacity and applying the clinical tools used by HCP in practice should ensure that the TIP's capacity to access assisted dying is warranted.

Assisted dying is not common practise everywhere, and its existence might not be long enough to justify a universal procedure on its application. In Victoria, there is required training for medical practitioners who wants to involve in assisted dying. In the said training, the medical practitioners must know how to assess the eligibility criteria in assisted dying, identify and assess the risk factors for abuse and coercion of the TIP and the procedural matters applicable to all medical practitioners involved in assisted dying.⁵² One of the medical practitioners must have relevant experience and expertise in the TIP's medical condition; however, this experience and expertise need not be an expertise in the assessment of TIP's capacity.⁵³ The ADB has no equivalent provisions regarding mandatory training of HCP. It would be prudent to consider HCP training in the ADB as the importance of professional training is evident.

In applying the safeguards of the ADB, there must be a combined effort of the medical practitioners to improve themselves in tackling this issue, whether in determining the capacity of the TIP or their clinical skills. On the other hand, the law must be specific for these requirements in enhancing the safeguard application that will affect the TIP and HCP. The procedures in improving the safeguard application should be of vital

⁵⁰ *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 290, 292.

⁵¹ Cameron Stewart, Carmelle Peisah and Brian Draper, 'A test for mental capacity to request assisted suicide' [2011] 37 J Med Ethics 34.

⁵² Above n 25 s 114.

⁵³ Carmelle Peisah, Linda Sheahan and Ben White, 'Biggest decision of them all – death and assisted dying: capacity assessments and undue influence screening' [2019] 49 Internal Medicine Journal 792, 795.

importance as plenty of individuals will be affected should ADB become a law, which is evident by the current situation in the UK.

1.4 Consequences of decreased safeguards

Like most aspects of the implementation of the law, reduced safeguards in ADB could lead to unwanted consequences. In addition to the Netherlands and Belgium, the overseas jurisdictions mentioned earlier have safeguards in place. However, there are still some mishaps in conducting assisted dying despite the implemented safeguards. In the Netherlands, approximately one in every five persons undergo assisted dying without explicit consent.⁵⁴ Similarly in Belgium, approximately 32% of assisted dying recipients underwent the procedure in the absence of consent or request.⁵⁵ Some of the reasons for failing to meet the threshold consent requirements are due to the person's condition, such as being in a comatose state or having dementia which accounts for 70% and 21%, respectively.⁵⁶ On the other hand, the medical practitioner's autonomy is the other reason for failing to obtain consent. The HCP felt that discussing assisted dying with the patient would be harmful, although ending their life was clearly in the patient's best interest.⁵⁷

The other major consequence of poor safeguard in assisted dying could lead to unwanted death due to misdiagnosis. It is inferred that a diagnosis of terminal illness with a life expectancy of six months and below would affect a person's outlook regarding assisted dying. For instance cancer patients, 80% of assisted dying requests are from these patients and approximately 25% of them are suffering from depression.⁵⁸ The request for assisted dying is four to seven times higher among cancer patients suffering from depression compared to patients suffering from cancer without clinical depression.⁵⁹ Up to half of these TIP seriously considering assisted

⁵⁴ J Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls' [2011] 18(2) *Current Oncology* 38, 39.

⁵⁵ Kenneth Chambaere, Jordan Bilsen, Joachim Cohen et al, 'Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey' [2010] 182(9) *CMAJ* 895, 896.

⁵⁶ *Ibid.*

⁵⁷ *Ibid.*

⁵⁸ Charles L. Sprung, Margaret A. Somerville, Lukas Radbruch et al, 'Physician-assisted suicide and euthanasia: emerging issues from global perspective' [2018] 33(4) *Journal of Palliative Care* 197, 199.

⁵⁹ *Ibid.*

dying changed their minds over time once they feel improvement in their health and received psychological support.⁶⁰ The majority of those who changed their minds are suffering from depressive illnesses.⁶¹

Looking at these examples on whether a person would be interested in assisted dying is more likely due to the HCP's involvement in the process, such as proper diagnosis and counselling, and this warrants safeguard to the HCP. Therefore, the HCP should deviate from any actions that might result in medical negligence. Otherwise, a civil or criminal liability might be charged against the HCP. The ADB has expressly stipulated that an HCP is free from criminal liability should assisted dying was conducted according to the bill.⁶² Furthermore, an HCP has no duty and is not legally bound to participate in the process.⁶³ These safeguards from the ADB are somehow sufficient to protect the HCP in participating in the assisted dying process while upholding high standards in their clinical skills that will safeguard the TIP.

1.5 Conclusion

The TIP and HCP's interests are the main concerns for establishing safeguards. These safeguards must be specific yet flexible enough to adapt to the changing needs of the public, and this could be learned from other jurisdictions with assisted dying legislation. Although the flexibility of the law is of vital importance, the TIP and HCP's rights should not be compromised as upholding these would make the safeguards of assisted dying adequate. Creativity in making laws in assisted dying and collaboration from various sectors such as lawmakers, HCP, and the public is needed to determine the appropriate safeguards properly. These steps could protect all the concerned parties from adverse consequences of inadequate safeguards. All these improvements have been tried and tested by other jurisdictions with assisted dying law. The UK should be prepared to apply a similar approach.

⁶⁰ Ezekiel J. Emmanuel, Diane L. Fairclough and Linda L. Emmanuel, 'Attitudes and desires to euthanasia and physician-assisted dying among terminally ill patients and their caregivers' [2000] 284 JAMA 2460, 2464.

⁶¹ Ibid.

⁶² Above n 7 s 6.

⁶³ Above n 7 s 5.

CHAPTER 2: CAPACITY, AGE AND CONSENT

2.1 Declaration and request

In the ADB, the applicant should make an assisted dying request to the High Court (Family Division).⁶⁴ The request must be voluntary, clear, settled, and informed wish to end life which is countersigned by two qualified medical practitioners.⁶⁵ These two medical practitioners must be the attending doctor whom the TIP requested assisted dying and the independent doctor who is not a relative or colleague of the attending doctor in the same practice.⁶⁶ The requirements for requesting assisted dying in the ADB are similar to other jurisdictions such as Oregon and Canada, especially the need for two medical practitioners who will determine if the TIP has satisfied the terminal illness requirement. However, other jurisdictions such as Victoria⁶⁷ and Western Australia⁶⁸ require three requests in applying for assisted dying. Increasing the number of requests adds an extra layer of safeguard for those who seek assisted dying.

Applying the ADB, it can be argued that the TIP can withdraw anytime from accessing assisted dying.⁶⁹ Compared to requesting access to assisted dying, the withdrawal has no formality requirements, and the TIP could revoke its earlier request whether in writing or any other means.⁷⁰ Therefore, it can be ruled that the ADB provides protection should the TIP change their mind. However, it is implied that satisfying more procedural requirements take time to complete, and this gives the TIP additional opportunity to consider an alternative decision aside from assisted dying. During the extended period of completing the request requirement, the TIP could contemplate about its current circumstance and decide accordingly. There is a tendency for a person to have a fixed decision at one point in time and change it eventually. At the time of processing the assisted dying request using the ADB, the TIP might have decided to proceed with the process. However, the likelihood of the TIP changing its mind is higher if there are more requirements to satisfy due to time and procedural

⁶⁴ Above n 7 cl 3(1).

⁶⁵ Above n 7 cl 3(1)(b)(i).

⁶⁶ Above n 7 cl 3(1)(b)(ii).

⁶⁷ Above n 25 s 6.

⁶⁸ Above n 30 s 5.

⁶⁹ Above n 7 cl 3(7).

⁷⁰ *Ibid.*

demands. Hence, the TIP could reject the idea of assisted dying in the first place and keep its stance in the status quo.

On the other hand, it can be argued that requesting access to assisted dying is cumbersome, and this would not serve its purpose. However, for the purpose of safeguarding the TIP, access to ADB should be stringent enough to protect the vulnerable individuals who might change their minds due to unbearable suffering from their illnesses. The 14-day cooling-off period⁷¹ is one of the safeguards in ADB that protect the TIP in case they change their minds. Other jurisdictions like Oregon has 15 days cooling-off period.⁷² However, there is no specific cooling-off period mentioned in the Western Australian legislation aside from making the third or final request after at least 9 days since the first request was made.⁷³ The one day difference between the Oregon's law and the ADB could make a difference when it comes to TIP's decision making and safeguarding the public, although the difference is minimal. However, adopting the flexibility of the Western Australian approach is a double-edged sword due to its partial lack of specificity compared to the ADB and Oregon. It can be argued that there is more than 15 days gap between the first and third requests due to the lack of specificity in the legislation. At the same time, it could be shorter than the ADB's 14-day requirement as the Western Australian legislation only requires 9 days gap between the first and third requests; hence, a 10-day cooling-off period is a possibility.

Based on the above request requirements in assisted dying, it would be desirable for the ADB to become specific and flexible. At the same time, this approach will avoid possible difficulties in interpreting the law. Sufficient specificity and flexibility of the law will also maintain its safeguards and serve its purpose without the unnecessary inhibition to access assisted dying.

⁷¹ Above n 7 cl 4(2)(d).

⁷² Above n 34 s 3.06.

⁷³ Above n 30 s 48(2).

2.2 Adults with capacity

Similar to most other jurisdictions with assisted dying legislation, the ADB made it clear that only individuals with the “capacity to make decisions to end his or her own life”⁷⁴ could apply for assisted dying. The ADB has no specific definition of capacity; however, this bill referred to the Mental Capacity Act 2005 (‘MCA’) for definition.⁷⁵ Capacity is not defined too in the MCA; however, people who lack capacity is described as “a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain”.⁷⁶ The assumption is that the individual has capacity unless it is established the lack thereof.⁷⁷ Furthermore, making an unwise decision is not considered incapacity.⁷⁸ Despite the law’s direct definition of capacity, there are some issues in assessing and determining capacity.

Despite possessing capacity, a TIP has different reasons why assisted dying is justified in their case and not due to their possible mental illness.⁷⁹ It is safe to assume that the unbearable pain experiencing by the TIP are pushing them to end their life. This suffering motivates the TIP to be suicidal and unable to assess their situation objectively.⁸⁰ In addition to pain and suffering, helplessness, demoralisation, losing dignity and fear to see their body falling apart are the other reasons for TIP wanting assisted death.⁸¹ Due to the devastating physical and mental suffering of the TIP, assisted dying could warrant their objective. The illegality of assisted dying could result in the TIP refusing treatment, which is more physically and mentally painful for these individuals.

⁷⁴ Above n 7 cl 1(2)(a).

⁷⁵ Above n 7 cl 12.

⁷⁶ Mental Capacity Act 2005 s 2.

⁷⁷ Ibid s 1(2).

⁷⁸ Above n 76 s 1(4).

⁷⁹ Rhea K. Faberman, ‘Terminal illness and hastened death requests: the important role of mental health professional’ [1997] 28(6) *Professional Psychology: Health and Practice* 544.

⁸⁰ Phoebe Friesen, ‘Medically assisted dying and suicide: how are they different, and how are they similar?’ [2020] 50(1) *Hastings Centre Report* 32, 35.

⁸¹ Marianne Dees, Myrra Vernooij-Dasse, Wim Dekkers, et al, ‘Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide: an integrative review’ [2010] 19(4) *Psycho-Oncology* 339, 344.

In the refusal of treatment, the TIP may decline any medical intervention to extend their life, considering they are mentally competent.⁸² Nevertheless, the TIP will bear more suffering from this option. According to Lord Donaldson in the case of *Re T*:⁸³ “this appeal is not in truth about the “right to die.” There is no suggestion that Miss T. wants to die. I do not doubt that she wants to live and we all hope that she will. This appeal is about the “right to choose how to live.” This is quite different, even if the choice, when made, may make an early death more likely. It is also about whether Miss T. really did choose and, if so, what choice she made”.⁸⁴ Lord Goff also supported this principle in *Bland*⁸⁵ when His Lordship mentioned that it is acceptable to administer painkilling drugs even the incidental effect of that is to shorten the patient’s life.⁸⁶ Following the rules in *Re T*⁸⁷ and *Bland*⁸⁸, assisted dying is somehow happening and the ADB could be considered a codification of a different variety of assisted dying. It can be assumed that assisted dying is disguising under the refusal and administration of treatment unless the consequences of these actions would not permit death. Though mental capacity is a hurdle in both assisted dying and refusal of treatment, overcoming this requirement is only applicable to the latter. Currently, this is the only option for TIP in the UK unless they travel to the neighbouring European countries to access assisted dying.

Another issue in the assessment of mental capacity in assisted dying is the recognition of advance decision. The definition of advance decision is “a decision you can make now to refuse a specific type of treatment at some time in the future”.⁸⁹ Assisted dying needs a positive action to eventuate the result while it is not required in refusal of treatment, and this is the subtle difference in these 2 actions that makes the former prohibited. However, the effect of these 2 actions will both result in death of a person. In ADB, a person must have a “voluntary, clear, settled and informed wish” to die.⁹⁰

⁸² General Medical Council, ‘Treatment and care towards the end of life: good practice in decision making’ (2010), para 14.

⁸³ *Re T (Adult: Refusal of Treatment) (C.A.)* [1993] Fam 95.

⁸⁴ *Ibid* [102].

⁸⁵ *Airedale NHS Trust v Bland* [1993] AC 789.

⁸⁶ *Ibid* 867.

⁸⁷ Above n 83.

⁸⁸ Above n 85.

⁸⁹ NHS website, Advance decision (living will) <<https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/>> accessed 3 August 2021; Above n 76 s 24(1).

⁹⁰ Above n 7 cl 1.

Similar to the request for assisted dying, mental capacity is also required in making an advance decision.⁹¹ The person who has an advance decision or requested assisted dying could withdraw from their earlier requests if they wish to do so. Furthermore, the final act that resulted in a person's death could be done by the person itself through self-administration of a lethal drug. The HCP has no participation in the final act of death but is an accessory in providing the lethal drug. Likewise, the HCP did not directly cause the person's death but the result of its inaction to provide life-saving treatment or procedure. In both cases, the HCP has no involvement in the direct death of the person or committed the final act that resulted in the person's death. Similarly, the HCP acted as an accessory to eventuate the person's wish. Hence, it would be reasonable to consider the inclusion of advance decision in the legalisation of assisted dying. The person in both circumstances is mentally competent to make such decisions, and the principle involved during the process is closely related. However, this is not to suggest the relaxation of the ADB's safeguards. Instead, it is an opportunity to examine the current principles of advance decision which share the same capacity requirement, procedures and outcome as assisted dying.

The attending or independent doctor is primarily responsible for determining the capacity of the TIP and if applicable, the need for specialist assistance to assess capacity.⁹² Despite their specialties in medical practice, it will be challenging to set a standard to determine capacity and its elements to consider in the decision-making process. For example, the effect of depression and other psychological issues experiencing by the TIP would make this capacity determination more difficult.⁹³ Also, the wording of the MCA and the ADB in assessing capacity is vague as these instruments cannot determine whether the TIP or the medical practitioner has the burden of proof in establishing capacity.⁹⁴ Therefore, relying on the legislation alone would be problematic in assessing capacity. Though a TIP could be referred to a specialist physician for assessing capacity, it is not mandatory under the ADB. In Oregon, the complexity of psychiatry especially when death is related is evident, and

⁹¹ Above n 76 s 24(1).

⁹² Above n 7 cl 3(5).

⁹³ Anabel Price, Ruaidhri McCormack, Theresa Wiseman, et al, 'Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying' [2014] 15 BMC Medical Ethics.

⁹⁴ Annabel Price, 'Mental capacity as a safeguard in assisted dying: clarity is needed' [2015] 351 BMJ h4461.

they believed that primary care physicians have limited ability to detect psychiatric disorders.⁹⁵ In addition, only 6% of psychiatrists in Oregon are confident to determine on a single consultation if the TIP's mental condition was influencing the request for assisted dying.⁹⁶ Therefore, the complex process in determining capacity should warrant the mandatory involvement of mental health specialist physicians, and this should not only occur at the discretion of the other non-mental health medical practitioners involved in the TIP's capacity assessment.

It is a difficult task to assess the capacity of the TIP, let alone those who are suffering from other mental health issues. The mandatory involvement of mental health specialists in the assessment of capacity should not be undermined. Although the mental health specialists themselves are having difficulties assessing the capacity of the TIP,⁹⁷ involving them early in the process would appropriately assist in the proper capacity assessment. Other issues such as the possible inclusion of assisted dying in advance decision and treatment refusal should be revisited. The imminent death of a person is the result of these currently operating principles, and these closely resemble assisted dying. Despite these challenges, the safeguards in assisted dying should be maintained while appropriately and consistently applying the legal principles shared by assisted dying and other medical-related decision-making procedures.

2.3 Adults without capacity

The ADB and other jurisdictions such as Australia specifically require the capacity of the TIP in requesting for assisted dying. This safeguard ensures that every candidate for assisted dying is aware of the consequences of such a decision. However, the carers of the TIP might argue that it is burdensome to look after a person who has no chance of surviving. These carers are in the best position to determine the best interests of the TIP. Though this reasoning has sensibility, the orbiter of Lord Keith in *Bland*⁹⁸ supported the current stand on medical futility where His Lordship has stated, "in general it would not be lawful for a medical practitioner who assumed responsibility

⁹⁵ Sandy Macleod, 'Assisted dying in liberalised jurisdictions and the role of psychiatry: a clinician's view' [2012] 46(10) *The Royal Australian and New Zealand College of Psychiatrists* 936.

⁹⁶ *Ibid.*

⁹⁷ Above n 95.

⁹⁸ Above n 85.

for the care of an unconscious patient simply to give up treatment in circumstances where continuance of it would confer some benefit on the patient". On the other hand a medical practitioner is under no duty to continue to treat such a patient where a large body of informed and responsible medical opinion is to the effect that no benefit at all would be conferred by continuance".⁹⁹ Furthermore, Lord Hoffmann mentioned that the court's decision is not solely based on legal precedent but also upon ethical values.¹⁰⁰ Respecting someone's life and dignity are important ethical values for an individual. Whether the cause of incapacity is due to cognition or frailty, the decision to end one's life should be left to the person itself.

The ADB's purpose is to allow terminally ill adults to assisted dying at their request.¹⁰¹ While it is reasonable to consider the other parties responsible for the care of the TIP, this will undermine the latter's dignity and right to life. This principle is dissimilar to advance decision where the TIP has a capacity when the decision has been made, and this capacity has been subsequently lost due to various physiological causes. Hence, the possible review of the legal principles behind advance decision should be considered in assisted dying to protect the dignity of the TIP in the event they lose their mental faculties. The respect for individual autonomy must be considered in assisted dying as individuals have the right to shape their own life by choosing how to live and the manner of their death.¹⁰² Confining the assisted dying in adults with capacity enhances the ADB's safeguards as this limits access to those who are competent to make such decisions and simultaneously upholds a person's dignity.

On the other hand, Gillick competence is recognised in medical decision making. Although *Gillick*¹⁰³ is a case involving the prescription of contraception, this case has tested the capacity of a minor and respected a minor's decision subject to the understanding of the matter involved. Lord Fraser's requirements of capacity and best interests in *Gillick*¹⁰⁴ have similar requirements in assisted dying. Similarly, other

⁹⁹ Above n 85, 858-859.

¹⁰⁰ Above n 85, 825.

¹⁰¹ Above n 7.

¹⁰² M. Cholbi and J. Varelius, 'New directions in the ethics of assisted suicide and euthanasia' [2015] International Library of Ethics, Law and the New Medicine 64.

¹⁰³ *Gillick v West Norfolk and Wisbech Area Health Authority and Department of Health and Social Security* [1986] AC 112.

¹⁰⁴ *Ibid* 174.

jurisdictions like the Netherlands allow euthanasia on children aged 12 to 15 years as long as they reasonably understand their interests, subject to the parent's decision.¹⁰⁵ Parent's involvement in decision making is not applicable for children who are 16-17 years of age.¹⁰⁶ The concept of Gillick competence is also applicable in the Netherlands; however, it is also applied in assisted dying. For the purpose of enhancing the safeguards of ADB, there is no recommendation in this dissertation supporting assisted dying in minors, and this is a separate matter to consider, which is outside the scope of the discussion.

The ADB's provisions regarding patients without capacity should not be changed. Restricting assisted dying to distinct groups while maintaining the other requirements would enhance its safeguards. Nevertheless, the law should bravely adapt to the possible changes in future if there is a genuine demand and benefit from it.

2.4 Conclusion

The ADB's rule for request should be specific yet flexible to serve its purpose and maintain its safeguards. It is accepted that capacity assessment is a complex task even for medical practitioners; hence, it is recommended to leave this job to the specialist mental health physicians due to their advanced knowledge and experience in this discipline. Despite all these possible improvements, challenging the status quo in advance decision, refusal of treatment, and Gillick competence is challenging, and this would require time, patience, and energy like pursuing the ADB. On the other hand, some aspects of the ADB should remain in its current state, especially if there is no obvious benefit in changing them. Otherwise, the law must adapt to the current situation without compromising its safeguards. Although the ADB's safeguards in capacity and consent seem adequate, it could be improved if the law could adapt to controversial situations and challenge the status quo if needed.

¹⁰⁵ The Netherlands Ministry of Foreign Affairs, 'The Termination of Life on Request and Assisted (Review Procedures) Act in practice: FAQ euthanasia 2010' (2010).

¹⁰⁶ Ibid.

CHAPTER 3: TERMINAL ILLNESS AND DIAGNOSIS

3.1 Criteria for determining terminal illness

In considering terminal illness, the TIP must be diagnosed by a medical practitioner with a progressive and irreversible condition, and a life expectancy of six months or less due to terminal illness.¹⁰⁷ Relieving the symptoms of terminal illness cannot be considered as treatment as the condition is still irreversible.¹⁰⁸ Compared to other jurisdictions, the ADB's definition of terminal illness is almost similar except its wider interpretation. In Victoria, Western Australia, and Canada, a person must have intolerable and unrelievable suffering from a terminal illness.¹⁰⁹ Victoria further stretched its criteria to excluding sole mental health conditions¹¹⁰ and disability due to sensory, physical, or neurological impairment.¹¹¹ Similar to Victoria, Western Australia has a more specific definition, like excluding sole mental health conditions and a life span of 12 months for neurodegenerative disorders.¹¹²

In reference to these three overseas jurisdictions, there is no need for intolerable suffering that cannot be relieved by treatment to qualify for terminal illness in ADB. There is a possibility that a person is suffering from a terminal illness without experiencing excruciating pain. Therefore, allowing assisted dying in this case could weaken the safeguard as more people can end their lives even if there is no evident pain. The pain from terminal illness is the result of a person's suffering¹¹³ and not the actual terminal illness itself. To maintain the ADB's safeguards, it would be sensible to include a phrase in bill that will require suffering from unbearable pain that cannot be relieved by treatment. The extended life expectancy of 12 months for neurodegenerative disorders would be an additional safeguard if adopted by the ADB. As neurodegenerative disorders are the only conditions in the Western Australian statute with a longer life expectancy, this should mean that there are progressive, irreversible, and untreatable conditions with longer life expectancy. Specific mention

¹⁰⁷ Above n 7 cl 2(1).

¹⁰⁸ Above n 7 cl 2(2).

¹⁰⁹ Above n 25 s 9(1)(d)(iv); Above n 30 s 16(1)(c)(iii); Above n 37 s 241.2(2)(c).

¹¹⁰ Above n 25 s 9(2).

¹¹¹ Above n 25 s 9(3); Disability Act 2006 (Vic) s 3.

¹¹² Above n 30 s 16(1)(c)(ii)-(2).

¹¹³ Above n 80.

of mental health disorders and physical or cognitive disability will also reinforce the ADB's safeguards. These disorders might have horrific disease expression. However, these are not progressive or irreversible conditions. Severe mental health problems and catastrophic disabilities could be managed on some occasions through appropriate medications and supportive treatment.

Therefore, it is advisable for the ADB to be more specific on its terms to maintain adequate safeguards. The current determination of terminal illness in the ADB is open to many interpretations. This issue is avoidable by adopting a more specific approach like Canada, Victoria and Western Australia.

3.2 Diagnosis of terminal illness

In all jurisdictions with assisted dying, such as the Netherlands, Belgium, Western Australia, Victoria, Oregon, and Canada, there is no specific legislation on how to diagnose a TIP. It seems that the diagnosis of terminal illness was totally left to the medical practitioners. Although it is logical to leave this aspect to the medical practitioners, there should be some legal guidance on the procedures of diagnosing terminal illness in the ADB that would not affect the role of medical practitioners. It is common for medical practitioners to misdiagnose non-progressive illnesses such as malaria, which resulted in patient's harm.¹¹⁴ Although a medical practitioner could be liable for negligence in misdiagnosis, the patients are still in a vulnerable position as the court is entitled to prefer one diagnostic procedure over another without providing a detailed reason.¹¹⁵

It can be argued that in the ADB, the attending or independent doctor could refer the TIP to a specialist if there is doubt in capacity assessment.¹¹⁶ However, it is not the same for the diagnosis of a terminal illness. The diagnosis of a registered medical practitioner is sufficient for the purpose of ADB.¹¹⁷ A graduate of an acceptable medical program is entitled to provisional registration, and they are considered as

¹¹⁴ *Langley v Campbell* [1975] 1 WLUK 312.

¹¹⁵ *Burnett v Lynch* [2012] EWCA 347.

¹¹⁶ Above n 7 cl 3(5).

¹¹⁷ Above n 7 cl 2(1)(a).

registered medical practitioners regardless of their experience and further medical training.¹¹⁸ This does not suggest undermining the professional competency of junior doctors. However, it is prudent to mandatorily involve the expertise of specialist doctors in determining conscientious issues. It is a common medical practice to refer patients with advanced illnesses to a specialist. Nevertheless, some non-specialist doctors fail to refer their cancer patients to a medical specialist despite showing obvious signs of the disease, and the consequence of this is death.¹¹⁹ It does not suggest that specialist doctors are not committing mistakes in diagnosis. However, this potential problem could be alleviated by giving medical specialists an exclusive right to determine terminal illness as they are more qualified and experienced in this matter. If giving this exclusive right to medical practitioners is restrictive, it is desirable to include a clause in the ADB regarding referral to specialist doctors for the purpose of diagnosing terminal illness, which is similar to capacity assessment.¹²⁰

The practice of medicine and law have different yet complementary effects in the ADB. Matters that are considered common practice are sometimes neglected; hence specific mentioning of them in the law could be helpful. Giving other members of the same profession an exclusive right to do something due to their knowledge and experience is beneficial as this is a common practice too in other professions. Therefore, the ADB should embrace these changes to ensure the safeguards in diagnosing terminal illness.

3.3 Focus on palliative care

It is a requirement in the ADB that the attending and independent doctor must be satisfied that palliative care was discussed to the TIP before signing its declaration. This is also similar to Victoria¹²¹ and Western Australia;¹²² however, other jurisdictions like Canada and Oregon have no similar specific requirement in their respective legislation. On the other hand, the availability of appropriate palliative care to the TIP's circumstance will not be a reason for rejecting assisted dying request. One of the roles

¹¹⁸ Medical Act 1983 s 3(1); Interpretation Act 1978 sch 1.

¹¹⁹ *Official Solicitor v Allinson* [2004] EWHC 923 (QB).

¹²⁰ Above n 6 cl 2(1)(a).

¹²¹ Above n 25 s 28(1)(c).

¹²² Above n 30 s 4(1)(c).

of palliative care is to discourage assisted dying; however, it is accepted that sometimes palliative care is not a universal solution to alleviate the TIP's condition.¹²³ Before the request to end their life, it is arguable if the TIP are aware of the palliative care's role in supporting them to overcome the agony of their terminal illness while having the quality of life.¹²⁴ It is suggested that educating the public regarding palliative care is vital in being confident to discuss the TIP's priorities and wishes during the end of life care.¹²⁵

Despite the role of palliative care in opposing assisted dying, this should not prevent the TIP from wanting to end their life. Palliative care should serve as a guide for the TIP in making an informed decision. In Australia, it is recommended that referral to palliative care is strongly recommended for all TIP wanting assisted dying.¹²⁶ The Royal Australasian College of Physicians suggested that the following should be considered to improve palliative care in the context of assisted dying:

- “supporting system changes including enabling health professionals to take the time they need to discuss end-of-life care with patients, and to conduct and document family conferences including goals-of-care discussions, appropriate social work support and bereavement care;
- providing adequate resources in the community to support patients wishing to die at home, in a hospice or in a residential aged care facility;
- ensuring patients can access specialist palliative care support as needed, at any time of day or night;
- streamlining patient information to ensure health professionals have access to key patient information and documents; and
- funding systems to measure and benchmark outcomes of end-of-life care”.¹²⁷

¹²³ Hamilton Inbadas, Jose Miguel Carrasco and David Clark, 'Representations of palliative care, euthanasia and assisted dying within advocacy declarations' [2020] 25(2) *Mortality* (Abingdon) 138, 139.

¹²⁴ *Ibid* 146.

¹²⁵ *Ibid*.

¹²⁶ Eswaran Waran and Leeroy William, 'Navigating the complexities of voluntary assisted dying in palliative care' [2020] 231(5) *Medical Journal of Australia* 204, 205.

¹²⁷ The Royal Australasian College of Physicians, 'Statement on Voluntary Assisted Dying' (2018), 25.

The above recommendations do not discriminate the TIP's position on assisted dying, and these support any decision the TIP made regardless of their views on end-of-life care. In addition, end-of-life care should include all the aspects of a person's life, such as physical, psychological, social, and spiritual.¹²⁸ Making recommendations covering these aspects will provide holistic end-of-life care and serve the genuine needs of the critics of assisted dying due to their faith and religious affiliations.¹²⁹ On the other hand, stellar recommendations would not prosper if the funds are insufficient to implement such recommendations. The allocated annual budget for each palliative care patient is between £51.83 to £2,329.19, which is insufficient to sustain a decent service.¹³⁰ In 2015, about two-thirds of statutory funds of 117 hospices in the UK were either suspended or reduced.¹³¹ The palliative care sector should receive a boost in their budget first to have the capacity to implement their aspirations in involving palliative care in assisted dying.

The improvement of palliative care is an ideal safeguard of assisted dying. Suppose the overall welfare of the person is considered in palliative care. In that case, it does not persuade nor inhibit a person from participating in assisted dying. Aside from assisting the TIP in making an informed decision about their end-of-life choices, palliative care is also receptive to everyone's views and beliefs about life and death. The UK should keep this provision in the ADB and improve the allocation of funds in this aspect in order to strengthen the assisted dying safeguard.

3.4 Involvement of other HCP

The delivery of the lethal drug to the TIP can be done by either the registered practitioner or registered nurse with authorisation from the attending doctor.¹³² However, the determination of terminal illness and mental capacity is the sole

¹²⁸ World Health Organisation website, Fact sheets: palliative care < <https://www.who.int/news-room/fact-sheets/detail/palliative-care>> accessed 5 August 2021.

¹²⁹ Society of Catholic Social Scientist, 'Statement of the Society of Catholic Scientists to the United States Catholic Bishops regarding cases on assisted dying before the United States Supreme Court' [1997] 2 The Catholic Social Science Review 315.

¹³⁰ Clare Gardiner, Tony Ryan and Merryn Gott, 'What is the cost of palliative care in the UK? A systematic review' [2018] 8 BMJ 250.

¹³¹ Ibid.

¹³² Above n 6 cl 4(2)(a)-(b).

responsibility of medical practitioners.¹³³ However, this is more relaxed compared to other jurisdictions like Oregon, Victoria and Western Australia, where only medical practitioners could administer the lethal drug. Although the outcome of delivery of a lethal drug will lead to death, it is preferred that the drug will be delivered by someone with extensive medical training in case of unexpected events like withdrawal of the patient in the middle of drug administration. TIP could revoke their wish to end their life at any time,¹³⁴ and this could happen while the TIP is receiving the drug but still capable of expressing his wish. Medical practitioners are trained to deal with this type of situation. They have the required knowledge in pharmacology and toxicology that can be applied to patients' circumstances.

On the other hand, other HCP should not be barred from assisting the medical practitioners in the assisted dying process. Subject to certain limitations, registered nurses could perform their usual clinical tasks like providing support to medical practitioners and other HCP. In medical practice, only anaesthesiologists are allowed to administer toxic drugs and not every other medical practitioner. Therefore, it is prudent that the ADB should be revised and limit the allowed HCP to medical practitioners only for the purpose of administering the lethal drug.

Similar to the recommendation in determining terminal illness, specialist physicians should determine the capacity of the patient due to its complexity. As discussed in chapter 2.2 of this dissertation, even psychiatrists are having difficulties determining patient's capacity, let alone non-specialist medical practitioners. There is a suggestion that independent doctors should be "consultant palliative care physicians and psychiatrists with at least 10 years' experience in their respective consultant roles".¹³⁵ However, the advice of other HCP such as nurses and social workers should be sought when relevant.¹³⁶ This step acknowledges the expertise of every HCP, and at the same, time ensuring all the relevant parties will act competently.

¹³³ Above n 6 cl 2(1) and 3(3).

¹³⁴ Above n 6 cl 3(7).

¹³⁵ J Guy Edwards, 'Assisted Dying Bill calls for stricter safeguards' [2015] 385 *The Lancet* 686.

¹³⁶ *Ibid.*

Collaboration between HCP is important as everyone's perspective will contribute to performing the objectives of assisted dying. Nevertheless, some duties in a clinical setting are assigned only to medical practitioners, like assessing capacity and administering a lethal drug. Thus, the changes in the ADB should be made to reflect the established clinical practice. The clinical aspects of the ADB should be designated to medical practitioners and specialist physicians only, especially assisted dying has not been tried in the country.

3.5 Conclusion

The safeguards of the clinical aspects of the ADB have various weaknesses that should be addressed. Adopting the Canadian, Victorian, and Western Australian legislation regarding the determination of terminal illness is a good start as these jurisdictions have more defined criteria which are insusceptible to multiple interpretations. Diagnosing an illness is prone to mistakes due to varying disease expression to the individual and competence of medical practitioners. However, the law could assist in matters they could control, such as the mandatory involvement of specialist physicians in diagnosing terminal illness. All HCP should have a defined role and must not deviate from their usual tasks to uphold the integrity of their profession during their involvement in assisted dying. The government should prioritise comprehensive palliative care through adequate funding and carefully drafted policies. Through this way, the dignity and quality of life of the TIP will be looked after, which might persuade these individuals to avoid the end-of-life option. In achieving these changes, the involvement of all stakeholders such as the HCP and the government is needed.

CHAPTER 4: RESIDENCY REQUIREMENTS

4.1 Avoiding medical tourism and maintaining state responsibility

Similar to other jurisdictions such as Victoria¹³⁷ and Western Australia,¹³⁸ there is a one-year residency requirement in the ADB.¹³⁹ However, these Australian jurisdictions require Australian citizenship or permanent residency status.¹⁴⁰ The ADB seems to allow foreign nationals who resided in England and Wales for one year to meet the residency criteria sufficiently. From 2008-2012, 611 overseas residents travelled to Switzerland to access assisted dying.¹⁴¹ Dignitas assisted the residents of 31 countries during this 4-year period where Germany and the UK accounted for almost two-thirds of cases with 268 and 126 cases, respectively.¹⁴² This suggests that many foreign nationals, especially from the UK, are willing to travel overseas to access assisted dying. Hence, the safeguards should consider the prospective access from interested overseas residents. The threshold of a country's responsibility to its own citizens or permanent residents is higher compared to foreign nationals. Therefore, limiting the access to assisted dying in the UK should be restricted to its citizens or permanent residents only.

Residency requirement ensures that only the legitimate residents of England and Wales could access assisted dying and not the foreign visitors who are trying to exploit this procedure. It can be argued that the ADB's safeguard in residency requirement is adequate as a terminally ill person with a 6-month life expectancy will not be able to satisfy the 12-month residency requirement due to imminent death. However, there are methods to prove 12 months residency even without residing physically for 12 months in a particular country. For example, residency in Oregon could be proved by possession of an Oregon driver's licence, ownership or lease of property in Oregon or filing an Oregon tax return for the most recent tax year.¹⁴³ A person who satisfied any

¹³⁷ Above n 25 s 9(1)(b)(iii).

¹³⁸ Above n 30 s 16(1)(b)(ii).

¹³⁹ Above n 7 cl 1(2)(c)(iii).

¹⁴⁰ Above n 25 s 9(1)(b)(i)-(ii); Above n 30 s 16(1)(b)(i).

¹⁴¹ Gareth Iacobucci, 'Number of people travelling to Switzerland for assisted dying doubles in four years' [2014] BMJ 349.

¹⁴² Ibid.

¹⁴³ Above n 34 s 3.10.

of these requirements before having a terminal illness could prove the satisfaction of residency requirements. Although this example is from Oregon, the meaning of 'ordinarily resident in England and Wales' and the evidentiary requirements were not mentioned in the ADB; hence, open to wide interpretation.

Using the Oregon example in satisfying residency requirements, a person who owns an income-generating property in England and Wales is required by law to file a tax return regardless of citizenship or residency status. Thus, 2 evidentiary requirements could be satisfied by this person, such as the ownership of property and filing the relevant tax return if these proofs could be used in the UK to prove residency. The terms used in the ADB's residency requirements are open to various interpretations. To avoid this loophole in the ADB, the meaning of 'ordinarily resident in England and Wales' must be defined, and specific documents must be provided to prove residency. These documents should be exclusive for permanent residents who currently reside in the UK, such as visa issued by the Home Office's UK Visas and Immigration department, current tenancy agreement or shire rates notice, and bank statements or utility bills from the past 12 months. Some Australian government agencies are using these documents to prove a person's visa status and proof of current physical residency.¹⁴⁴

4.2 Conclusion

Currently, the ADB's terms on residency requirements make it vulnerable to exploitation of foreign individuals; hence, it needs to reinforce the safeguard in this concern. The ADB should be confined to the citizens and permanent residents only to avoid medical tourism in assisted dying and preserve the government's responsibility to its people. This could be done by producing an instrument that is accurately directed to the concerned individuals. The ADB should refer to other legislation related to immigration and citizenship to formulate an appropriate definition of terms that will serve the country's best interest and its people. Creating methods to prove permanent

¹⁴⁴ Australian Department of Home of Affairs website <<https://immi.homeaffairs.gov.au/visas/permanent-resident/evidence-of-residency-status>> accessed 6 August 2021; Medicare (Services Australia) website <<https://www.servicesaustralia.gov.au/individuals/subjects/documents-enrol-medicare-if-youre-permanent-resident>> accessed 6 August 2021.

residency that is sufficiently distinct to exclude other methods available to non-residents will minimise those who want to take advantage of assisted dying.

CHAPTER 5: CODES OF PRACTICE AND OTHER SAFEGUARDS

5.1 Conscientious objection

There are several personal and professional reasons for HCP not wanting to participate in assisted dying. The ADB specified that HCP are not compelled to participate in assisted dying,¹⁴⁵ which is also the principle in Australia.¹⁴⁶ Personal discomfort, wrongful death, unsafe legislation and contrary to medical practice are the reasons of some HCP in Victoria who did not participate in assisted dying.¹⁴⁷ This gives HCP the right to act freely based on their personal and ethical beliefs.¹⁴⁸ There are also emerging arguments in Canada where institutional conscientious objection should be applied to a faith-based healthcare organisation.¹⁴⁹ However, it is suggested that institutional conscientious objection is unacceptable as healthcare organisations are accepting public funds; hence, a pragmatic compromise mechanism should be implemented.¹⁵⁰ On the other hand, the concept of conscientious objection in Western countries is based on Christian conscience only, and not on other faiths such as Islam, where treating the opposite sex is also a ground for refusal of treatment.¹⁵¹ Therefore, granting a conscientious objection to assisted dying could create a slippery slope to other medical procedures.

Contrary to the other terms in the ADB, a wide definition or interpretation of conscientious objection could resolve these different arguments and beliefs. A strict interpretation could undermine both the patient and HCP's interests. The definition

¹⁴⁵ Above n 7 cl 5.

¹⁴⁶ Above n 25 s 7; Above n 30 s 9.

¹⁴⁷ Casey M. Haining, Louise A. Keogh and Lynn H. Gillam, 'Understanding the reasons behind healthcare providers' conscientious objection to Voluntary Assisted Dying in Victoria, Australia' [2021] 18 *Journal of Bioethical Enquiry* 277, 281.

¹⁴⁸ Andrew McGee, 'Voluntary assisted dying: should conscientious objection be unconditional?' [2020] 50(2) *Journal of Pharmacy Practice and Research* 117, 118.

¹⁴⁹ Jeffrey Kirby, 'Should institutional conscientious objection to assisted dying be accommodated?' [2021] 4 *Canadian Journal of Bioethics* 15.

¹⁵⁰ *Ibid* 19.

¹⁵¹ Julian Savulescu and Udo Schuklenk, 'Doctors have no right to refuse medical assistance in dying, abortion or contraception' [2017] 31(3) 162, 164-165.

should maintain the balance between the HCP's exercise of their beliefs and the patient's interest. It is desirable if the ADB will refer to GMC's Good Medical Practice guide¹⁵² for a balanced description of conscientious objection. In this document, the HCP could decline from performing a particular medical procedure and refer the patient to a different practitioner. At the same time, the GMC's guide prohibits the HCP from condemning the patient due to its choices and beliefs. Overall, the ADB's provision in conscientious objection is a balanced safeguard for both the HCP and TIP. However, a minor refinement in the terms of conscientious objection would reinforce this safeguard.

5.2 Withholding or withdrawing of treatment

Paternalism in medical practice is considered as a thing of the past, especially in Western medicine where it is largely regarded as unethical.¹⁵³ However, according to a survey conducted to 1,000 medical practitioners in the US, 51% of these doctors are willing to withhold or withdraw treatment, especially to terminally ill patients or those suffering from dementia.¹⁵⁴ This is an alarming result considering the vast amount of available public information against medical paternalism. It can be assumed that doctors might find it challenging to manage these patients due to their futility. The most vulnerable groups to paternalism are the children, unconscious and psychiatrically ill individuals due to their inherent faculty weakness.¹⁵⁵ Therefore, there should be some safeguards protecting vulnerable who have withdrawn or withheld their treatment as this could be used to mask assisted dying.

It can be argued that there are capacity and age requirements to access ADB; hence, minors and mentally incapable individuals could not consent to assisted dying. However, the reality is the majority of medical practitioners are prepared to withdraw or withhold treatment.¹⁵⁶ Whether the doctors will actually perform this action, they still

¹⁵² General Medical Council, 'Good Medical Practice' (2013) para 52.

¹⁵³ Robert J. Sullivan, Lawrence W. Menapace and Royce M. White, 'Truth-telling and patient diagnoses' [2001] 27 *Journal of Medical Ethics* 192.

¹⁵⁴ Neil J. Faher, Pamela Simpson, Tabassum Salam et al, 'Physicians' decisions to withhold and withdraw life-sustaining treatment' 166 [2006] *Arch Intern Med* 560.

¹⁵⁵ Colin Gavaghan, 'You can't handle the truth; medical paternalism and prenatal alcohol use' [2009] 35(5) *Journal of Medical Ethics* 300.

¹⁵⁶ *Ibid* n 154.

have the capacity to do so. Patients and their carers trust their physicians. It will not be surprising if they listen to their doctor's advice that might lead to indirect encouragement to access assisted dying. Once the treatment is withheld or withdrawn, its result will be the same as assisted dying; however, without the positive action of administering the lethal medicine. Therefore, it would be sensible to include a provision in the ADB that will specifically address this situation and apply a different procedure that will safeguard these vulnerable individuals.

5.3 Prescription and administration of medicine

The ADB allows the HCP to assist the TIP in ingesting or self-administering the lethal drug.¹⁵⁷ However, the decision to self-administer this medicine and the final act of doing so must be taken by the TIP.¹⁵⁸ This method will work only for individuals who are physically capable of performing the final act of self-administration of the medicine, but not for those who are physically incapable. In Victoria, individuals who are incapable to self-administer the medicine could apply for a practitioner administration permit.¹⁵⁹ Aside from physical incapability, the practitioner administration permit could only be granted if the TIP still possess capacity and the request to access voluntary dying is enduring.¹⁶⁰ Limiting access to assisted dying is one way to maintain its safeguards. However, the ADB would defeat its purpose if it is only limited to individuals with the physical ability to self-administer the medicine. A provision allowing the assistance of the HCP in the administration of the medicine should be added in the ADB.

The prescription of the medicine is not yet finalised in the ADB.¹⁶¹ Therefore, it is recommended to examine other jurisdictions that could be adopted by the ADB. In Western Australia, the rules for prescribing, supplying, and disposing of medicine are adequately described in the legislation.¹⁶² In this legislation, it is reiterated that the TIP has no obligation to take the medicine. This provision will constantly remind the TIP

¹⁵⁷ Above n 7 cl 4(4).

¹⁵⁸ Above n 7 cl 4(4)(c).

¹⁵⁹ Above n 25 s 48.

¹⁶⁰ Above n 25 s 48(3).

¹⁶¹ Above n 7 cl 4(7).

¹⁶² Above n 30 ss 69-81.

that there is no coercion in taking the medicine and would be a valuable addition to the ADB's safeguard.

5.4 Mandatory reporting for breach

Similar to other jurisdictions, there is a monitoring provision in the ADB that observe the safe operation of assisted dying procedures.¹⁶³ However, a mandatory provision for the possible breach of the assisted dying procedures could increase the safeguards of the ADB. This directive is effective for other offences like child sexual abuse.¹⁶⁴ For instance, in Western Australia, the HCP could be penalised for not reporting a suspected sexual abuse to minors.¹⁶⁵ This mandatory reporting is extended to court personnel if they reasonably believe that a child suffers actual or potential harm.¹⁶⁶ The introduction of this mandatory reporting substantially increased the identification of child sexual abuse cases in Western Australia in the last 7 years since its implementation.¹⁶⁷ It can be argued that a similar directive could potentially increase the ADB's safeguard. Reasonable suspicion of a possible breach is sufficient to trigger a report and further investigation. Due to this effect, it can be assumed that the persons involved would take reasonable care in implementing the process. The positive obligation to report under the law and its corresponding penalty for failure to comply might also compel the parties to carry out the procedure accordingly.

5.5 Conclusion

Both the interests of the patients and HCP must be satisfied to justify conscientious objection. The ADB should protect vulnerable individuals from paternalism that would result in concealed assisted dying through withholding or withdrawing of treatment. Likewise, physically frail yet mentally capable individuals must not be discriminated against in accessing assisted dying. Due to these controversial issues associated with assisted dying, mandatory reporting would be a reasonable inclusion in the ADB. This

¹⁶³ Above n 7 cl 9(1).

¹⁶⁴ Ben Mathews, Xing Ju Lee and Rosana E. Norman, 'Impact of a new mandatory reporting law on reporting and identification of child sexual abuse' 56 [2016] Child Abuse & Neglect 62, 76.

¹⁶⁵ Children Community Services Act 2004 (Western Australia) s 124 B

¹⁶⁶ Family Court Act 1997 (Western Australia) s 160.

¹⁶⁷ Above n 164.

could be achieved by creating balanced and impartial provisions in the ADB that would serve the best interest of the involved parties.

CONCLUSION

The constant introduction of the ADB in Parliament could signify the public demand for assisted dying. This claim is supported by the several hundred individuals from the UK travelling to Dignitas every year to end their life. However, it is surprising that this bill could not successfully progress beyond the committee stage after being presented 7 times in Parliament for the last 8 years. One of the possible assumptions for this failure is the ADB's safeguards. In comparison to other jurisdictions with assisted dying laws, the ADB's safeguards are not adequate to protect the TIP. Some of the necessary provisions to ensure adequate safeguards in the ADB are either missing or insufficient.

Examples of the ADB's inadequacies are lack of mandatory specialist involvement in assessing capacity and diagnosing terminal illness, fewer request requirements in accessing assisted dying, possible procedure availability to non-UK permanent residents or citizens, and unclear rules regarding physician administration of medicine for physically incapable individuals. Even though the mandatory reporting for breach is not present in other jurisdictions, its addition will reinforce the ADB's safeguards. The addition of provisions that would result in concealed assisted dying through withholding or withdrawing treatment should be considered in the ADB. Unequivocal criteria to avoid medical tourism should be implemented to assure that UK citizens will not be disadvantaged and to minimise the government's potential liability.

Substantial changes to the bill that reflect adequate safeguards to the TIP has not been presented yet in Parliament. Therefore, introducing a completely revised bill focusing on TIP's safety could increase the chance of the ADB becoming law.

In addition, considering the HCP's safeguards would be a holistic way to protect all the parties in assisted dying. Although there is no guarantee to pass the ADB, presenting a comprehensive bill in Parliament has not been tried, and this would be worth the try.

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