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# Terminally Ill Adults (End of Life) Bill

**LEGAL BRIEFING** By Roger Kiska, Legal Counsel Christian Legal Centre

### Overview

- 1. On 11 November 2024, Bill 012 2024-2025, a Private Member's bill was introduced by Kim Leadbeater, MP, with the legislative aim of legalizing assisted suicide. Pursuant to s. 24 of the proposed law, the bill would amend s.2 of the Suicide Act 1961, decriminalising suicide when performed under the remit of the bill. The proposed law would also remove any form of civil liability for ending one's life unnaturally within the terms set out in the bill. Ss. 24 and 25 make further allowance for courts to find no liability, either criminally or civilly, in instances where assisted suicide is occasioned under terms not covered in the Act.
- 2. To be eligible, an individual must have mental capacity to make the decision, must be over the age of 18, must be diagnosed with a terminal illness where the reasonable prognosis is that the person will succumb to natural death within the coming six months, and must be resident in England or Wales for at least 12 months prior to their making their initial declaration requesting to die by artificial means.
- 3. The process dictates that a registered medical professional, defined as someone who has the training, qualifications and experience as the Secretary of State may specify by regulation, must assess the individual seeking to die, ensuring that they meet the criteria enumerated above in paragraph 1. The registered medical practitioner cannot be someone who will benefit financially from the death of the individual or be a named beneficiary in their will. That medical practitioner, after proving the identity of the individual, must witness the signing of their first declaration (which is prescribed in form by schedule 1 of the bill). The medical practitioner [the coordinating doctor], must thereafter fill out a form as prescribed by schedule 2 of the bill, a copy of which they present to the patient, and refer the individual to an independent doctor for further assessment.

- 4. This is followed by a mandatory 7-day period of reflection, after which the independent medical practitioner must carry out a second assessment to confirm or reject the assessment of the coordinating doctor. Should the consulting doctor reject the assessment, the coordinating doctor may refer the individual to a different independent doctor. Should the assessment of the second doctor also reject the results of the coordinating doctor's initial assessment, the process ends. Should the consulting doctor, either initially or after re-assessment by a second doctor, confirm the findings of the coordinating doctor, declarations similar to those done by the consulting doctor are drafted, witnessed and signed. The individual may then petition the High Court for permission to end their life by artificial means.
- 5. Should the person wishing to end their life be physically unable to sign their own name in relation to both that person's first and second declaration, a proxy may do so. A proxy is defined by the bill as someone who has personally known the individual making the declaration for at least 2 years, or a "person who is of good standing in the community."
- 6. The High Court may, but need not, hear from and question the person seeking assisted suicide. They must, however, hear from and question either (or both) the consulting and/or independent medical practitioner. They may also consult third persons to report about relevant matters relating to the person petitioning the court to end their lives.
- 7. Should the High Court reject the application, a right of appeal to the Court of Appeal arises under the Bill. Shall either the High Court or Court of Appeal make a declaration that the individual has met the statutory criteria to end their life, and following a second period of reflection (14 days), and after the coordinating doctor assesses whether the individual still meets the statutory criteria and still wishes to end their life, the coordinating doctor will provide the person with an approved life-ending substance. The bill does not enumerate which substance can be used to end life. According to s. 20 of the bill, the Secretary of State would define which substances would be approved by regulation. It is noteworthy that there is no universal drug or drug cocktail which can guarantee a painless quick death. Research bears this fact out.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> See e.g.: Ana Worthington et al., "Efficacy and Safety of Drugs Used for 'Assisted Dying'," Br Med Bull. 2022 May 4, 142(1): 15-22.

- 8. The bill makes no allowance for appeals of a positive decision in favour of the petitioner. Nor, more importantly, does it create a right of challenge from family or friends who might contest the decision. Their only recourse would be a judicial review, which is prohibitively expensive for most, and would offer little chance of success given the deference shown to findings of fact once determined by a competent court of first instance. Moreover, if the statistical prevalence of requests to die evidenced in other jurisdictions with similar legislation are borne out in England and Wales, the High Court could receive hundreds of petitions to die annually. The only way for the already over-burdened judicial system to deal with such requests would be either a judicial backlog mooting the entire point of the bill or a system where such requests are merely rubber stamped.
- 9. The person wishing to end their life, either alone or with the assistance of the doctor (or another registered medical professional named by the coordinating doctor), will self-administer the life ending substance. The coordinating doctor, or medical practitioner named by the coordinating doctor, must be present in the room as the individual self-administers the substance. They must also be present until the individual dies, albeit there is no requirement to be in the room with them.
- 10. A final declaration is then made by the doctor, regardless of whether the individual has changed their mind about taking the substance or the suicide has failed, which must be recorded.
- 11. At any point, the individual seeking to end their life may cancel their earlier declarations, either orally or in writing. However, at no point is the patient, or any of the stakeholders involved in ending the individual's life, including the court, under a requirement to inform that person's next of kin about their intention to end their life. The only requirement levied upon a stakeholder, pursuant to s. 9(2)(f), is for either the coordinating doctor or independent doctor to consider advising the individual about informing their next-of-kin about their decision. It is reasonable to surmise that where an individual is not willing to share their desire to end their life with their closest family, that it is fair to question their commitment to their decision to end their lives. The lack

<sup>&</sup>lt;sup>2</sup> Infra fn. 7.

of provision for such a safeguard requiring disclosure to next of kin is therefore noteworthy.

### **Assisted Suicide: The Slippery Slope**

12. Perhaps the most significant obstacle to legislating assisted suicide is that in every jurisdiction where it has been done, unacceptable abuses have occurred. So have assisted suicide laws, internationally, expanded from their original intent, to encompass such things as depression, disability, economic disadvantage and child euthanasia. Already pressure is mounting among Labour MPs and campaigners to expand the bill to include those without terminal illnesses.<sup>3</sup> The logic of allowing voluntary assisted suicide would also support non-voluntary euthanasia to alleviate suffering or as being in the best interests of the patient.<sup>4</sup> Precedent for this is amply evidenced below in relation to the Netherlands<sup>5</sup> and domestically in a number of recent high profile Court of Protection cases.<sup>6</sup>

Australia: New South Wales

13. In New South Wales, in November 2023, legislation came into force allowing for assisted suicide for the terminally ill who had a prognosis of 6 months or less. That is a parallel threshold to that proposed by the Leadbeater bill. 12 months was mandated for those with neurodegenerative conditions who are experiencing unbearable suffering. Within the first 3 months of legalisation, an astounding 517 people made requests to die, with 130 of them completing the process and dying by taking a doctor-prescribed substance to end their lives.<sup>7</sup>

Belgium

<sup>&</sup>lt;sup>3</sup> Camilla Turner, "Extend assisted dying to those without terminal illnesses, say Labour MPs," The Telegraph, 05 October 2024, at: <a href="https://www.telegraph.co.uk/politics/2024/10/05/widen-access-to-assisted-dying-say-labour-mps/">https://www.telegraph.co.uk/politics/2024/10/05/widen-access-to-assisted-dying-say-labour-mps/</a> (accessed 18<sup>th</sup> November 2024).

<sup>&</sup>lt;sup>4</sup> See e.g.: John Keown, "Physician Assisted Suicide: Improving the Quality of the Debate," Policy Exchange, November 2024, available at: <a href="https://policyexchange.org.uk/publication/physician-assisted-suicide-republished/">https://policyexchange.org.uk/publication/physician-assisted-suicide-republished/</a> (accessed 18 November 2024).

<sup>&</sup>lt;sup>5</sup> Para. 20.

<sup>&</sup>lt;sup>6</sup> Paras. 37ff.

<sup>&</sup>lt;sup>7</sup> Mostafa Rachwani, "More than 130 patients in NSW died through voluntary assisted dying in program's first three months," The Guardian, 28 June 2024, at: <a href="https://www.theguardian.com/australia-news/article/2024/jun/28/nsw-voluntary-assisted-dying-laws-statistics-report">https://www.theguardian.com/australia-news/article/2024/jun/28/nsw-voluntary-assisted-dying-laws-statistics-report</a> (accessed 15th November 2024).

- 14. In 2022, the European Court of Human Rights, in a Belgian assisted dying case originally filed by the author of this legal opinion <sup>8</sup>, found a violation of the Convention's right to life provision, in that the Belgian Commission responsible for ensuring the suitability of applicants for assisted suicide, a role essential to protecting the vulnerable, lacked independence and was susceptible to abuse. <sup>9</sup> The applicant was the son of a woman who had undergone assisted dying by lethal injection. She had suffered depression for 20 years, which was exacerbated by a recent break-up with her long-term partner. The Applicant's mother's psychiatrist, as well as other psychiatrists, refused to sign off on the request for assisted suicide on the grounds that they felt that she could still be helped. Eventually she approached 'Dr D', who referred her to a psychiatrist who eventually signed her off as meeting the criteria for assisted suicide. During this period, the Applicant's mother gave a donation of €2500 to 'Dr D's' association LEIF. He also served on the committee which approved the assisted suicide. Mr Mortier was at no point notified prior to his mother's death that she had been approved for the life ending injection or as to when it would take place.
- 15. The Belgian system has become so zealous in the area of assisted dying that in 2014, if became the first country in the world to extend euthanasia to children without any age limit.<sup>10</sup>

#### Canada

16. Similar safeguarding concerns have occurred in other jurisdictions as well. In Canada, in October of this year, a psychiatrist involved in drafting a national euthanasia training curriculum testified to a parliamentary committee that the legislated safeguards for assisted dying in Canada were impotent. She further noted that the Canadian populace, and even legislators, were likely unaware of just who was qualifying for assisted suicide. The reality is that in Canada people are seeking euthanasia because of credit card debt or poor housing or difficulty obtaining medical care. While they may suffer from medical conditions, the underlying reason for their desire to die relates to

<sup>&</sup>lt;sup>8</sup> ECHR, *Affaire Mortier c Belgique*, application no. 78017/17, judgment of 04 October 2022. Original application available at: <a href="https://adfmedialegalfiles.blob.core.windows.net/files/MortierApplication.pdf">https://adfmedialegalfiles.blob.core.windows.net/files/MortierApplication.pdf</a> (accessed 15th November 2024).

<sup>&</sup>lt;sup>9</sup> Paras. 177-178.

<sup>&</sup>lt;sup>10</sup> See: Section 3, Law of 28 May 2002 on Euthanasia, amended by the Law of 13 February 2014.

<sup>&</sup>lt;sup>11</sup> Alexander Raikin, *No Other Options*, The New Atlantis, 16 December 2022, Winter 2023, available at: <a href="https://www.thenewatlantis.com/publications/no-other-options">https://www.thenewatlantis.com/publications/no-other-options</a> (accessed 15 November 2024).

material or emotional matters not intimately related to their physical health.<sup>12</sup> There are also numerous shocking examples from Veterans Affairs Canada, where veterans who had asked for help with PSTD<sup>13</sup> and another a ramp for her wheelchair<sup>14</sup> were asked by caseworkers if they would like to apply for euthanasia.

#### **Switzerland**

17. Studies about the euthanasia regime in Switzerland have similarly nefarious outcomes. In a published study conducted between 2003-2014, researchers discovered that the crude rate of assisted suicide more than tripled during the study period. The vast majority of those who ended their lives were older, had no children and had no religious affiliation. <sup>15</sup> Precisely stated, the majority of applicants were elderly individuals who lacked key elements allowing for human flourishing or an otherwise meaningful life.

18. In 2023 alone, assisted suicide rates rose by 11%. 16

#### Netherlands

19. A 2021 study analysing euthanasia deaths in the Netherlands found that the number of euthanasia deaths in the country has consistently risen since 2006. The percentage of deaths ascribed to euthanasia in the Netherlands between 2002 and 2019 has literally doubled. Evidence suggests, the study argued, that those who attend church are less likely to wish to prematurely end their life through assisted suicide.<sup>17</sup> This is consistent

<sup>13</sup> Michael Lee. "Canadian soldier with PTSD outraged when CA suggested euthanasia," New York Post, 22 August 2022, at: <a href="https://nypost.com/2022/08/22/canadian-soldier-with-ptsd-outraged-when-va-suggested-euthanasia/">https://nypost.com/2022/08/22/canadian-soldier-with-ptsd-outraged-when-va-suggested-euthanasia/</a> (accessed 15 November 2024).

<sup>&</sup>lt;sup>12</sup> Ibid

<sup>&</sup>lt;sup>14</sup> Tom Yun, "Paralympian trying to get wheelchair ramps say Veterans Affairs suggested euthanasia," CTV News, 03 December 2022, at: https://www.ctvnews.ca/politics/paralympian-trying-to-get-wheelchair-ramp-says-veterans-affairs-employee-offered-her-assisted-dying-1.6179325 (accessed 15 November 2024).

<sup>&</sup>lt;sup>15</sup> Nicole Steck, Christopher Junker, Marcel Zwahlen, *Increase in assisted suicide in Switzerland: Did the socioeconomic factors change? Results from the Swiss National Cohort*, 2017, *BMJ Open* 2018;8:e020992. doi: 10.1136/bmjopen-2017-020992.

<sup>&</sup>lt;sup>16</sup> "Swiss assisted suicide rates rose 11% in 2023," SwissInfo.Ch, 08 February 2024, at: <a href="https://www.swissinfo.ch/eng/life-aging/swiss-assisted-suicides-rose-11-in-2023/49198616">https://www.swissinfo.ch/eng/life-aging/swiss-assisted-suicides-rose-11-in-2023/49198616</a> (accessed 15th November 2024).

<sup>&</sup>lt;sup>17</sup> Groenewoud AS, Atsma F, Arvin M, *et al.* "Euthanasia in the Netherlands: a claims data cross-sectional study of geographical variation", *BMJ Supportive & Palliative Care* (14 January 2021): doi: 10.1136/bmjspcare-2020-002573...

with the aforementioned 2017 Swiss study about lack of meaning being a root cause of the desire for premature death.

- 20. An earlier study done in 2005 suggested that as many as 19.8% of euthanasia deaths are illegally certified as death by natural causes. <sup>18</sup> Moreover, the Dutch courts have also allowed for the killing of an estimated 15 to 20 newborns per year. Dutch doctors have gone from euthanizing the terminally ill to the chronically ill, to people with serious disabilities, to the emotionally and mentally ill. <sup>19</sup>
- 21. The United Nations Human Rights Committee has criticized the Netherlands on numerous occasions for its lack of scrutiny or safeguards relating to assisted dying applications.<sup>20</sup>

### **Conscientious Objection**

22. The draft bill also has compatibility issues with Article 9 of the European Convention on Human Rights, which protects freedom of thought, conscience and religion. While Article 23 of the draft bill suggests that no medical practitioner is obliged to participate in ending a life under the law, a plain reading of S. 4(5) does require some level of compelled participation even where a conscientious objection exists:

A registered medical practitioner who is **unwilling** or unable to conduct the preliminary discussion mentioned under subsection (3) **must**, if requested by the person to do so, **refer them** to another registered medical practitioner whom the first practitioner believes is willing and able to conduct that discussion. [emphasis added]

23. This would apply to anyone with *Grainger* compliant beliefs against assisted dying, regardless of whether they believed referral was participation in the process of ending someone's life or not. This is a *de facto* interference with that medical practitioner's Article 9 rights, and any such interference would be subject to a proportionality analysis.

<sup>&</sup>lt;sup>18</sup> Agnes Van der Heide *et al.*, "End-of-life Practices in the Netherlands under the Euthanasia Act," (2007) 356:19 *New England Journal of Medicine* 1957.

<sup>&</sup>lt;sup>19</sup> Wesley J Smith, "*Euthanasia Spreads in Europe*," National Review, 26 October 2011, at: <a href="https://www.nationalreview.com/2011/10/euthanasia-spreads-europe-wesley-j-smith/">https://www.nationalreview.com/2011/10/euthanasia-spreads-europe-wesley-j-smith/</a> (accessed 15<sup>th</sup> November 2024).

<sup>&</sup>lt;sup>20</sup> See e.g.: Human Rights Committee, Concluding Observations: Netherlands, CCPR/C/NLD/CO/4 (2009) and CCPR/CO/72/NET/(2001).

Moreover, under the bill as currently drafted, it is clear that Christian hospices would also be required to refer people to registered medical practitioners who they know would be willing to assess a person for assisted suicide, if the person being consulted at the hospice are themselves a registered medical practitioner as defined by regulation.<sup>21</sup>

24. Rights of conscience are explicitly recognised in international law, and among the commitments the United Kingdom has accepted through the treaty and convention ratification process. The Grand Chamber of the European Court of Human Rights has itself explicitly affirmed rights of conscience for sincerely held religious and moral beliefs as falling within the gambit of Article 9 of the Convention.<sup>22</sup>

## 25. The Grand Chamber based its reasoning on several premises:

- (a) That where conscientious objection was not for a personal benefit, but was based on a sincerely held religious or philosophical belief, a system should have been put in place whereby violence would not be done to that belief;
- (b) A refusal to allow conscientious objection fails to strike a proper balance between the interests of society as a whole and the fundamental rights of the individual;
- (c) Democracy does not simply mean that the views of the minority must be subordinated to those of the majority;
- (d) And that far from creating inequalities or discrimination in a democratic society, provision of rights of conscience ensure a cohesive and stable pluralism and promote religious harmony and tolerance in society.<sup>23</sup>
- 26. A lack of protection for conscience is significant given that those in the medical profession closest to those in end-of-life situations have consistently and overwhelmingly opposed legalising assisted suicide. A 2014 survey by the Royal College of General Practitioners bears this fact out. Interestingly, the majority of

<sup>&</sup>lt;sup>21</sup> See infra paras. 27-29 regarding the definition of a registered medical practitioner.

<sup>&</sup>lt;sup>22</sup> ECHR, Bayatyan v. Armenia [GC], (2012) 54 E.H.R.R. 15.

<sup>&</sup>lt;sup>23</sup> *Id*.at § 124, 126.

respondents who opposed legislating in favour of physician assisted death were those who specialised in fields closely related to end-of-life cases such as palliative medicine, oncology and geriatric medicine. <sup>24</sup> In a 2019 survey by RCGP, 89% of respondents who opposed legalisation did so on the basis of patient vulnerability, 66% opposed because of moral considerations, and 54% opposed because of their religious beliefs. <sup>25</sup> For the avoidance of doubt, the position of the RCGP is shared by the British Medical Association (2016), the Association for Palliative Medicine of Great Britain (2015), and the Royal College of Practitioners (2014). <sup>26</sup>

### The Definition of Registered Medical Practitioner

- 27. The bill also is potentially misleading as to exactly who will be allowed to assess an individual for assisted suicide, or to provide a life-ending substance or supervise death. While the bill uses the terms coordinating doctor and independent doctor, the statutory language also heavily refers to 'registered medical practitioners', instead of doctors, when referring to the relevant medical professionals permitted to fulfil the statutory obligations stemming from the proposed law. As evidenced throughout the bill<sup>27</sup>, this means that anyone whom the Secretary of State defines as being a registered medical practitioner by regulation will be permitted to fulfil that role.
- 28. The ability to stretch statutory language to mean anything the Secretary of State chooses it to mean is perhaps best evidenced by the 2022 amendments of the Abortion Act 1967 to include a person's home as a place where an abortion can take place. S.1(3) requires that abortions can only take place in a hospital, or a place approved by the Secretary of State. With the introduction of telemedicine abortions during covid, the Secretary of State defined the home of a woman seeking an abortion as such a place. This became primary law with the adoption of Ss. 3B and 3D of the 1967 Act. The whole

<sup>&</sup>lt;sup>24</sup> Royal College of General Practitioners, "Assisted Dying Consultation Analysis." RCGP, 2014. Available at: <a href="www.rcgp.org.uk/policy/rcgp-policy-areas/~/media/Files/Policy/Assisted-Dying-Consultation/Assisted%20Dying%20 Consultation%20Analysis.ashx">www.rcgp.org.uk/policy/rcgp-policy-areas/~/media/Files/Policy/Assisted-Dying-Consultation/Assisted%20Dying%20 Consultation%20Analysis.ashx</a> (accessed 05 January 2023).

<sup>&</sup>lt;sup>25</sup> RCPG, 2019 Assisted Dying Membership Consultation, Unweighted Data Tables (11 March 2020), at: <a href="https://www.rcgp.org.uk/getmedia/e8972bc8-a11e-4c79-aaeb-54689beceff2/RCGP-assisted-dying-membership-consultation-unweighted-tables-march-2020.pdf">https://www.rcgp.org.uk/getmedia/e8972bc8-a11e-4c79-aaeb-54689beceff2/RCGP-assisted-dying-membership-consultation-unweighted-tables-march-2020.pdf</a> (accessed 15 November 2024).

<sup>&</sup>lt;sup>26</sup> Karen Porter and Katharine G Warburton, *Physicians' views on current legislation around euthanasia and assisted suicide: Results of surveys commissioned by the Royal College of Physicians*, Future Healthcare Journal, 2018, Vol. 5 No 1:30-4. Available

at: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6510045/pdf/futurehealth-5-1-30.pdf">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6510045/pdf/futurehealth-5-1-30.pdf</a> (accessed 15 November 2024).

<sup>&</sup>lt;sup>27</sup> See for e.g.: Ss. 5(3)(a); 8(6)(a); 19(2)(b).

safeguarding purpose of defining a hospital as the primary place to have an abortion was thus lost.

29. Similarly, an almost identical definitional authority would be vested in the Secretary of State to define what a registered medical practitioner is. Just as a home can be made interchangeable with a hospital, so too can whatever the Secretary of State defines as being a registered medical professional be interchangeable with a doctor.

#### The Proxy Issue

30. S. 15 of the bill creates a further danger of abuse. The bill allows for a person to use a proxy if they are unable to physically sign their own name to a declaration. S. 15(5)(b) allows for anyone with good standing in the community to serve as a proxy. This definition completely undermines the safeguards of s. 15(5)(a), which would define a proxy as someone who has known the person seeking to end their life for at least 2 years. The vagueness of "a person who is of good standing in the community" could literally mean anyone, including an assisted suicide campaigner.

#### Mental Capacity, Coercion and Life-Expectancy Prognoses

31. Perhaps the most significant shortcoming of the bill relates to the issue of mental capacity and coercion. While s. 26 prescribes criminal penalties for those who entice someone to end their lives by dishonesty, coercion or pressure, the bill contains a remarkably limited amount of safeguards against unconscious bias in favour of assisted suicide or other abuses. S. 9(3)(b) for example, notes that where either (or both) the consulting and independent doctor have doubts as to the mental capacity of the individual seeking assisted death, they do not have to refer the patient for a mental evaluation to determine capacity. Moreover, the Secretary of State may, but is not obliged to, produce a code of practice relating to assessing mental capacity and/or recognising and taking into account the effects of depression or other mental disorders that may impair a person's decision-making.

- 32. Nor does the draft bill make provisions definitively protecting against doctor shopping. Granted s. 10(3) does not allow a consulting doctor the ability to further refer an individual to an independent doctor for assessment following 2 failed assessments by independent doctors; however, that is only a partial safeguard. And while there are provisions requiring the individual seeking death to be resident in England or Wales for 12 months prior to the request and to be a registered patient with a general medical practice in England or Wales (Ss. 1(1)(c-d)), there is no requirement for the coordinating doctor to have any history with that individual. In other words, nothing in the law prevents a person who has failed in an attempt with one coordinating doctor to receive approval to die, to simply continue to find coordinating doctors to start the whole process over again.
- 33. Third, no safeguard exists to prevent a registered medical practitioner from introducing the theme of assisted dying into a consultation. To the contrary, s. 4(2) of the bill makes specific allowance for it: "But nothing in subsection (1) prevents a registered medical practitioner exercising their professional judgement to decide if, and when, it is appropriate to discuss the matter with a person." The bill therefore makes it possible for a doctor, who holds a position of trust and disproportionate influence over a patient, particularly those who are vulnerable, to lead that person towards choosing assisted suicide.
- 34. Fourth, s. 2(1)'s definition of terminal illness lacks the precision, foreseeability and clarity needed to pass Convention muster. 28 The bill defines someone who is terminally ill as a person having "an inevitably progressive illness, disease or medical condition which cannot be reversed by treatment" and where that person is **reasonably** expected to die within 6 months of their diagnosis. However, a good number of conditions which can be treated and controlled, but can nevertheless be progressive and irreversible, could fall within Ms Leadbeater's definition of terminal illness. The definition therefore begs the question of whether conditions like diabetes could fall within the parameters of the bill. It is that level of uncertainty which could lead the bill to be ruled incompatible with the Convention under s. 3 of the Human Rights Act 1998, for failing to be prescribed by law.

<sup>&</sup>lt;sup>28</sup> Cf. Sunday Times, 30 Eur. Ct. H.R. (ser. A) at 31.

- 35. Moreover, prognoses about life expectancy can be unreliable. While modern medicine is capable of amazing things, the reality is that accurate, evidence-based tools to determine life expectancy up to a period of six months are lacking.<sup>29</sup> A government review of the Liverpool Pathway put it bluntly: "diagnosing imminent death is a far more imprecise science than people realise."<sup>30</sup> Such short comings, in real time, were evidenced in the diagnosis of Alfie Evans, discussed at length below at paragraphs 48 and following.
- 36. Fifth, neither the courts nor medical practitioners can be trusted to act in a way which safeguards life over choosing death. Recent history has shown, overwhelmingly so, that in end-of-life cases, there is an almost unbending predilection for choosing death. The Christian Legal Centre has supported a number of families and patients in high-profile end-of-life cases where both the carers involved and the courts have run roughshod over the wishes of family to preserve life. It must be remembered that in each case where a decision is made by the High Court or Court of Protection to issue orders ending life sustaining treatment and care, it was the hospital who filed the claim seeking to end life. Judges, for their part, have almost unanimously sided with physicians and hospitals against families and patients.
- 37. The case of Sudiksha Thirumalesh is instructive.<sup>31</sup> Sudiksha was 19 years old and suffering from a degenerative mitochondrial disease. The disorder affected her hearing, sight, muscles, and organs. She had wanted to restart experimental nucleoside treatment for her condition in Canada. She was conscious and able to communicate. Despite her condition, she was preparing for her A levels and willing to die trying to live.<sup>32</sup>
- 38. Her doctors at the University Hospitals Birmingham NHS Foundations Trust took Sudiksha to the High Court, seeking an order to remove life sustaining treatment and care. Using the same provisions of the Mental Capacity Act 2005 which govern the bill (s. 3), the hospital was successful in arguing that Sudiksha lacked capacity to make her

<sup>&</sup>lt;sup>29</sup> See. e.g.: Paul KJ Han et al., "Development of a Prognostic Model for Six-Month Mortality in Older Adults with Declining Health," J Pain Symptom Manage. 2011 Nov 8;43(3):527–539.

<sup>&</sup>lt;sup>30</sup> Baroness Julia Neuberger et al., "More case, less pathway: A review of the Liverpool Pathway," produced by Williams Lea (July 2013), p. 20, at:

https://assets.publishing.service.gov.uk/media/5a75153340f0b6397f35d87d/Liverpool\_Care\_Pathway.pdf (accessed 18th November 2024).

<sup>&</sup>lt;sup>31</sup> Hemachandran & Anor v Thirumalesh & Anor [2024] EWCA Civ 896.

<sup>&</sup>lt;sup>32</sup> Paras. 11 and 32.

own medical decisions on the sole basis that she refused to be deterred by her prognosis and wanted to live.<sup>33</sup> In coming to her finding, the judge in the case rejected the reports of the two consultant psychiatrists and opinion of the Official Solicitor stating that they believed Sudiksha had the requisite mental capacity to make her own decisions, and instead relied entirely on her medical team's evidence that she lacked capacity.<sup>34</sup> While the Court of Appeal reversed the finding, it was only after Sudiksha's untimely death. The case serves as a stark warning as to the dangers of doctors and judges determining capacity.

39. A number of other cases similarly evidence the presumption in favour of ending life by judges responsible for making such decisions. They also highlight the dangers of dogmatically relying on the prognoses of doctors relating to the end-of-life findings:

### Archie Battersbee<sup>35</sup>

40. The story of Archie Battersbee captured the hearts and garnered the prayers of millions of people around Britain and the world. Archie, a 12-year-old boy from Southend, Essex, suffered a serious head injury while at home in April and had been convalescing at Royal London Hospital in Whitechapel. Weeks into his care, the hospital brought the matter to the Court of Protection seeking an order allowing them, over Archie's parents objection, to deliver a brain stem test to determine if he was clinically dead. Archie's parents, Hollie Dance and Paul Battersbee, supported by the Christian Legal Centre, had challenged the hospital arguing that Archie had not been given enough time to recover and that a brain stem test is notoriously inaccurate. Despite an order from the UN Committee on the Rights of Persons with Disabilities to refrain from taking any measures which would end Archie's life while it reviewed the substantive merits of his emergency complaint to their Committee, the Court of Appeal wilfully ignored the request and moved ahead with plans to end Archie's life. While the Convention on the Rights of Persons with Disabilities is an unincorporated treaty in UK law, the UK has

<sup>&</sup>lt;sup>33</sup> Paras. 107-108.

<sup>&</sup>lt;sup>34</sup> Paras. 117-118.

<sup>&</sup>lt;sup>35</sup> Barts Health NHS Trust v Dance & Ors (Re Archie Battersbee) [2022] EWCA Civ 935. Available at: https://www.bailii.org/cgi-

nevertheless ratified the Optional Protocol submitting itself to the Committee's complaints' procedure. Archie passed away on 06 August 2022.

'Baby A'36

- 41. 'Baby A', as he is described in court documents, was born healthy. Eight weeks into his young life, he was found by his father to be unconscious and unresponsive. On the way to the hospital, Baby A suffered a heart attack and lost circulatory function for nearly 30 minutes. He was admitted to Queen Elizabeth Hospital, which is overseen by the Guy's and St. Thomas' NHS Foundation and began undergoing tests. The Trust brought the matter to the Family Division of the High Court seeking an order allowing them to remove ventilation.
- 42. Remarkably, 'Baby A', before the first hearing, and two weeks after he was declared dead by Queen Elizabeth Hospital, was seen by a nurse to breath on his own and move. During the first trial, the hospital admitted the mistake and suggested that nothing of this sort had ever happened before (an opinion that is demonstrably false as many cases of people waking after being diagnosed brain dead have been documented). Nevertheless, after numerous appeals, it was determined by the courts that it was in the best interests of 'Baby A' that all life sustaining care for the infant was discontinued until his inevitable death which took place in October 2022.

R.S.<sup>37</sup>

43. In early November 2020, RS suffered a heart attack. In the absence of blood flow, RS sustained brain damage as a result of a lack of oxygen. Within a few days of being admitted, doctors at University Hospital Plymouth NHS Trust concluded that it was in his best interests that all life sustaining care, including hydration and nutrition, be withdrawn. At the end of November, an application was made to the Court of Protection to resolve the dispute between RS's mother and other members of his family, both in Poland and in the UK, who insisted that he be kept alive. Despite the direct intervention

<sup>&</sup>lt;sup>36</sup> Guy's And St Thomas' NHS Foundation Trust v A & Ors [2022] EWHC 2422 (Fam). Available at: https://www.bailii.org/cgi-

bin/format.cgi?doc=/ew/cases/EWHC/Fam/2022/2422.html&query=(title:(+Guy%27s+))+AND+(title:(+St.+))+AND+(title:(+Thomas%27+)) (accessed 15 November 2024).

<sup>&</sup>lt;sup>37</sup> University Hospitals Plymouth NHS Trust v RS & Anor [2020] EWCOP 70. Available at: https://www.bailii.org/ew/cases/EWCOP/2020/70.html (accessed 15 November 2024).

of the Polish government, RS was also ordered to have all life sustaining care ended until his eventual death on 27<sup>th</sup> January 2021.

# Alfie Evans<sup>38</sup>

- 44. Alfie Evans was born in Liverpool on 09 May 2016. Although born healthy, Alfie suffered from an incredibly rare mitochondrial disorder and his health deteriorated. In July 2016, he had his first hospital referral. On 14 December 2016, Alfie was admitted to Alder Hey Children's Hospital in Liverpool. His parents Tom Evans and Kate James dutifully remained at Alfie's bedside throughout the entire ordeal.
- 45. In mid-December 2017, the Alder Hey Children's NHS Foundation Trust filed an application to the Court of Protection to discontinue life sustaining care. During the hearing in early February, Tom Evans, who was 21 years old at the time and had left school at the age of 16, represented himself, while the Trust was represented by Queen's Counsel. Given the disparity in legal representation and the immense difficulty in having a layman cross-examine medical experts, the result was that the Court, on 20 February 2018, wrote a medically damning report together with an end-of-life plan for Alfie.
- 46. A unique element of the case was that the parents were pushing out videos on social media of Alfie doing things that the judgment suggested he was incapable of doing. During this same period, the Vatican's Bambino Gesu paediatric hospital agreed to take on the care of Alfie, while Poland offered air transport for Alfie and the family to Italy. During the course of appeals, the Italian government, in its zeal to prevent Alfie's death, granted him Italian citizenship on 23 April 2018.
- 47. Despite everything, the Court of Protection nevertheless refused the parents' wishes to remove the child to a different hospital, instead withdrawing Alfie's ventilation on the same day with a significant police presence at the hospital to prevent anyone trying to preserve Alfie's life.
- 48. What is not often discussed in this case is just how wrong the initial judgment was about Alfie's ability to survive off ventilation, which could in part be ascribed to the disparity

<sup>&</sup>lt;sup>38</sup> Alder Hey Children's NHS Foundation Trust v Evans & Anor [2018] EWHC 308 (Fam), available at: <a href="https://www.bailii.org/ew/cases/EWHC/Fam/2018/308.html">https://www.bailii.org/ew/cases/EWHC/Fam/2018/308.html</a> (accessed 11 January 2023).

in legal representation at the initial hearing leading to legal factual findings which were not in accord with the actual real-life facts of the situation:

"It is unlikely that he can breathe without assistance." (Prof Cross, para 16)

"Alfie's inability to breathe is a consequence of the disease and not likely from the medication administered." (Prof Haas, para. 21)

"He is completely dependent on mechanical ventilation to preserve his life." (Dr M, para. 25)

"Alfie is one hundred per cent dependent on ventilator support." (Dr R, primary medical expert for Alder Hey, para. 30)

"Withdrawing of treatment will immediately lead to his death...." (Prof Haas, para. 43)

"It is the ventilator that has been keeping him alive for many months, he is unable to sustain his own respiratory effort." (Hayden J., para. 61)

- 49. Despite the certainty expressed by the experts and Justice Hayden of Alfie's immediate death, Alfie Evans survived without ventilation until 28 April 2018, five days after ventilation was removed, during which time he was significantly deprived of hydration and nutrition with the goal of ending his life.
- 50. As with the Charlie Gard case, the courts extended the reasoning of the Supreme Court in in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67 (para 22) that it would be "*lawful to withhold or withdraw*" care to also mean that it is permissible to prevent parents, vis-à-vis police force, from receiving alternative care which is on offer.

### The Need for Legislative Restraint

51. Nicklinson & Anor R (on the application of) (Rev 1) [2014] UKSC 38 highlighted the Supreme Court's concern about protecting the vulnerable from assisted suicide. The judgment underscored the importance of legislating in accordance with respecting Article 2 of the Convention (right to life), and having a responsible legislature make a fully informed decision on the matter. Past parliamentary reviews have consistently rejected assisted dying due to the potential risks of abuse. The existing framework for palliative care, when adequately funded, can provide relief without necessitating

- assisted suicide. The bill, therefore, diverts focus from addressing the root causes of end-of-life suffering, such as inadequate care infrastructure.
- 52. The State's duty under Article 2 extends beyond preventing coercion; it requires affirming life's intrinsic value. Legalising assisted dying risks normalising the idea that some lives are less worth protecting.

#### Conclusion

- 53. The Terminally Ill (End of Life) Bill raises significant concerns, both morally and legally, about unnaturally ending the life of another. The bill is replete with imprecise language and loopholes allowing for abuse of the process to obtain assisted suicide. History has shown that where assisted dying is legal, safeguards often erode, leading to a broadening of eligibility criteria. Vulnerable individuals, including the elderly, disabled, or economically disadvantaged, are put at risk and could feel implicit pressure to choose death to avoid being perceived as a burden as the scope of the law broadens.
- 54. Similar legislation, only recently adopted in New South Wales, shows just how dangerous such legislation is. The residents of England and Wales deserve legislators who value their lives and seek to enrich them with better palliative care options. Medical professionals should be trained to enable their patients to see their value and detect depression, rather than steer patients towards assisted suicide.
- 55. For the reasons set out in this opinion, the proposed law should be rejected.