Carefully, compassionately: Canadian lessons on assisted dying

BRIEFING PAPER

November 2024

SMF Social Market Foundation

By Gideon Salutin

Opponents of assisted dying in the UK often cite Canada as a country with inadequate procedures and eligibility restrictions. This briefing is designed to evaluate where Canada has gone wrong, how we can learn from those mistakes and explore international examples of best practice.

KEY POINTS

- Deficiencies in procedure and eligibility in Canada can be addressed by following safeguards in place in other countries that have legal assisted dying
- Staff should have appropriate qualifications to assess applications, and adequate training to screen cases
- We need not follow Canada into expanding eligibility to those with nonterminal conditions
 - Advocacy groups warned that the bill unfairly targeted disabled and impoverished people, and lacked safeguards against misuse

RECOMMENDATIONS

- Detailed procedures should be legislated which provide clarity to physicians
 - Clear guidelines should require physicians to evaluate each case
 - Patients should be the first to request assisted dying
 - Oral medication should be the default method for assisted dying
- Active oversight is needed to protect due process
 - Specially trained consultants should be available to assist in complex cases
 - Regional committees should investigate case and penalise bad behaviour
 - Data should be closely monitored, collected and shared
- Alternatives should be available so no one accepts assisted dying for lack of options

BACKGROUND

- Kim Leadbeater MP's Private Members Bill, the <u>Terminally III Adults (End of Life)</u> <u>Bill 2024-25</u> was recently presented to Parliament. The Bill seeks to "allow adults who are terminally ill, subject to safeguards and protections, to request and be provided with assistance to end their own life." The Bill will have its Second Reading on 29th November 2024.
- A similar bill was introduced to the Scottish Parliament in March 2024. <u>The</u> <u>Terminally III Adults (End of Life) Bill 2024-25</u> will allow terminally ill adults in Scotland, who are eligible, to lawfully request and be provided with assistance by health professionals to end their own life.

THE HISTORY OF MEDICALLY ASSISTED DYING IN CANADA

- Medical Assistance in Dying ("MAID") was introduced in Canada in 2016, after the Canadian Supreme Court found that the status quo ante was not compliant with Canadians' constitutional right to life, liberty and security of person.
- The initial 2016 version of Canada's assisted dying policy was relatively restrictive, limiting eligibility only to those with serious and incurable illnesses that was causing them to suffer and have a reasonably foreseeable natural death.
- These restrictions were challenged in the courts, and in 2019 the part of the law which required a foreseeable natural death was ruled unconstitutional. In response the government drafted a new law permitting assisted dying for those who are physically suffering but without a foreseeable natural death, such as those living with cerebral palsy and post-polio syndrome.
- The 2019 bill specifically excluded mental illness from the eligibility criteria until it could be studied further, and the issue is not due to be considered until 2027.

UPTAKE OF ASSISTED DYING IN CANADA

- In 2022 there were 13,241 assisted dying administrations reported in Canada, accounting for 4.1% of all deaths.¹ This would make it the sixth biggest cause of death in the country. Since its introduction in 2016, 44,958 medically assisted deaths have been recorded.
- Uptake has been on an upward trend.

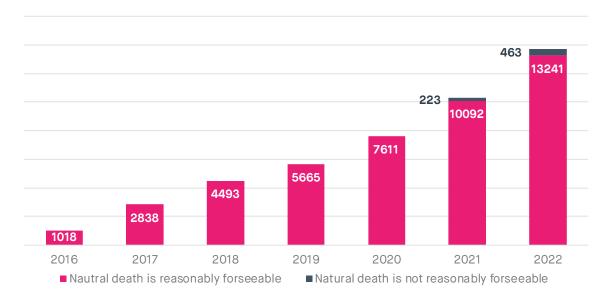
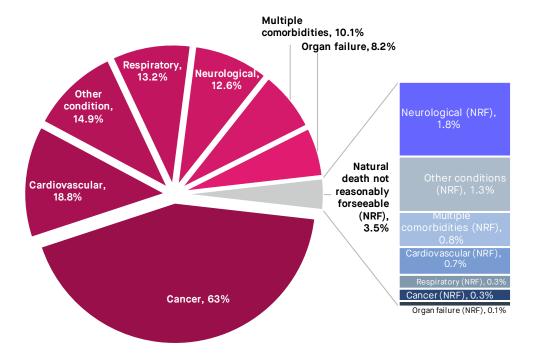


Figure 1: Canada's recipients of assisted dying over time

Source: Health Canada²

- A vast majority of Canada's MAID cases (96.5%) are administered to those where death is reasonably foreseeable. These are known as "track one" cases, and requires two independent medical practitioners to confirm that the individual :
 - has a serious and incurable illness, disease or disability where a **natural** death is reasonably foreseeable
 - is in an advanced state of irreversible decline in capability
 - has enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable
- Since eligibility was expanded in 2021, assisted dying has been provided 686 times to those whose natural death was not reasonably foreseeable, and in 2022 these 'track two' cases represented 3.5% of the total. A majority involve neurological conditions.
- Nearly two-thirds of non-terminal cases have unclear causes, as Canadian statistics list 2.1% of all cases were listed either as "multiple comorbidities" or "other conditions," without expanding on the nature of these diseases.

Figure 2: Underlying medical conditions of those receiving assisted dying in 2022, including those whose natural death was not reasonably foreseeable (NRF)



Source: Health Canada³

Note: The total exceeds 100% because providers were able to select more than one medical condition when reporting

CONCERNS OVER CANADIAN ASSISTED DYING POLICY

- Concerns have been raised over the vague terminology used in the legislation bringing MAID into effect, regarding:
 - Eligibility criteria: How a physician defines a "reasonably foreseeable" and "natural" death is extremely variable. The same is true of "irreversible decline" which theoretically excludes many conditions in which the patient is stable. Defining "intolerable pain" has also proven contentious.⁴
 - Required qualifications of medical practitioners approving MAID: Those MAID applicants whose death is not reasonably foreseeable require one of their assigned medical practitioners to have expertise in the condition causing their suffering, or they must consult an expert. This "expertise" is poorly defined, and does not require any additional education or official degrees.⁵
- The expansion of eligibility requirements for MAID in 2021 has removed a key safeguard that had prevented people without terminal illnesses from accessing it.

ASSISTED DYING IN OTHER JURISDICTIONS

• There are essentially three choices facing policymakers when deciding assisted dying eligibility, illustrated in the table below:

Eligibility	Countries	Explanation
Allow assisted dying for terminal illnesses	Australia ⁱ , New Zealand, United States ⁱⁱ	 Applies to diseases likely to cause the death of an individual Examples include late-stage cancers and cardiovascular conditions Generally restricted to those whose death is expected within a given timeframe. For instance, in the Netherlands, physicians must anticipate death within six months
Allow assisted dying for terminal illnesses and physical suffering	Canada, Colombia, Spain	 Applies to terminal illnesses and diseases causing physical suffering Examples include multiple sclerosis and cerebral palsy Often physicians must show that the illness is irremediable
Allow assisted dying for terminal illnesses, and physical and mental suffering	Belgium, Luxembourg, Netherlands, Switzerland	 Applies to terminal illnesses and diseases causing suffering Examples include diseases causing pain, both mental and physical. Psychiatric conditions like depression may be eligible

- Canada is not unusual in having assisted dying driven by legal rulings rather than legislation. In Japan, Italy and Germany, court judgements have left assisted dying in legal grey areas after decriminalising the practice for doctors but failing to follow this up with clear policy.
- Absent a codified constitution, British policymakers considering assisted dying are unlikely to face the brute force of a legal ruling.^{III6} But foreign experience with opaque laws shows why making clear decisions about eligibility will be essential

ⁱ In Australia assisted dying is legal in every state and territory apart from the Northern Territory.

ⁱⁱ Assisted dying is available only in the following US jurisdictions: Oregon, Washington State, Vermont, California, Colorado, DC, Hawaii, New Jersey, Maine and New Mexico, and it has been decriminalised in Montana

ⁱⁱⁱ A judicial decision had similar implications in Scotland following Ross v Lord Advocate, which clarified that the Scottish law was in line with the ECHR

to protect against misapplications of the policy, create a safe and secure application process, and to reassure the public.

LEARNING FROM CANADA'S MISTAKES

- The UK should put in place clear eligibility criteria for those considering assisted dying. Take the case of Alan Nichols, a 61-year-old from British Columbia, who was hospitalised in 2019 over fears he might be suicidal. Within a month, he had submitted a request for medically assisted dying from within the hospital. Nichols cited hearing loss and seizures that had abated 10 years previously. Despite these circumstances, Nichols' request was approved and he received assisted dying. Afterwards, Nichols' family reported the case to authorities, but were told hospital staff were not liable as Nichols had met the criteria for assisted dying.
- The UK should enact strict guidelines on who can assess and adjudicate on assisted dying applications. Canada was the first country with medically assisted dying to allow nurse practitioners to assess and approve MAID applications alongside licensed physicians. This is concerning for three reasons:
 - i. Nurses' expertise may not be sufficient to make the necessary medical judgements.
 - ii. Second, is their relationship with patients, which can often be emotionally closer than doctors' and risks biasing their opinion.
 - iii. Third, their relationship with doctors: forcing nurses to openly disagree with someone considered their superior puts them in a difficult professional position.
- Case evaluation is not always simple, and many applications will require external support. Many cases in Canada evidence how complex applications can be difficult to decide for individual doctors. As such, it is vital that vulnerable people be protected from assisted dying by ensuring providers have adequate training and clear procedural guidelines to help them follow protocol.

RECOMMENDATIONS

• Parliament should legalise assisted dying for terminal illnesses and, alongside the British Medical Association, design an application process for patients to follow. Following common practice in other countries and as stipulated in the <u>Terminally III Adults (End of Life) Bill 2024-25</u>, this should require the signature of two doctors who can testify that an illness is likely to be terminal within six months. In contrast to the Bill as presented, we find that the patient should have exhausted all reasonable alternative treatments.

• Safeguard area one: clear procedure

- i. Doctors should be required to carry out exhaustive and in-depth investigations into the nature of a patient's suffering. Extremely detailed guidelines are in force in the Netherlands, with legal repercussions for physicians who do not act in accordance with them. Dutch doctors are therefore obliged to do everything in their power to ascertain the true nature of a person's suffering, and are allowed to do so in their own way. Similarly, Belgian doctors are required to have "multiple conversations" spread over "a reasonable amount of time" to ensure all criteria are met.⁷ Therefore, in combination with the British Medical Association, policymakers should work to establish legal guidelines that mandate doctors ask key guestions and require them to reject applications in which they are not confident. Such methods are more invasive, but the cost to designing a less confrontational approach is that vulnerable individuals are not protected. This process is unclear in the current legislation being put before parliament as procedure will be left up to the Secretary of State.
- ii. Physicians should be forbidden from being the first to discuss assisted dying. The Terminally III Adults (End of Life) Bill 2024-25 in the UK does not currently rule this out. Belgian doctors are advised to avoid bringing up assisted dying as it could be interpreted as medical advice, while in New Zealand and the Australian state of Victoria doctors are explicitly forbidden from raising the topic first. Any law or regulation on the subject in the UK must also provide clarity to doctors on how to respond when an individual brings up assisted dying and the appropriate steps which they need to initiate, to ensure they understand the relevant laws and required procedure instead of feeling confused by them. Currently, the legislation being put before parliament allows doctors to be the first to bring up assisted dying.
- iii. Providing assisted suicide rather than euthanasia can help ensure those involved in the process remain comfortable and safe, including the patient themselves. Euthanasia applies to cases where a physician injects or directly administers a lethal drug, and in Canada, this is used in the vast majority of assisted dying cases. In contrast, many American states including Oregon and California see higher uptake of physician-assisted suicide, in which a physician prescribes oral medication for the procedure. Importantly, doctors need not be present for the procedure, and the patient is allowed to take the substance home with them and is allowed to take it when, where and how they wish, allowing for longer reflection time and introspection. The oral protocol acts as an additional safeguard, ensuring that the final choice is autonomous, limiting the role of the physician in their decision. Currently, the legislation uses the oral protocol, but

minimises its benefits by requiring patients schedule an appointment and that a medical professional be present.

• Safeguard area two: active oversight

- i. Introduce specially-trained consultants to administer assisted dying. These are available in Belgium and the Netherlands upon request to assist physicians, patients, and family members and ensure procedure is followed.⁸ These consultants read the medical files, examine the patients, and ascertain whether they meet the conditions for assisted dying.⁹ They are well trained, with at least five years' experience as a physician, have experience in the field of euthanasia, are considered skilful in consultations, and receive roughly 24 hours of training which includes guidance on legal duties and communication. They also meet multiple times a year to discuss cases and air any problems. Teams organised and trained to Dutch and Belgian standards should be assembled regionally across the UK to assist doctors, particularly in the early stages of assisted dying when uncertainty about eligibility will be highest. The current legislation does not create a team of this nature, but this could be added by the Secretary of State.
- ii. Regional committees should be further available after an assisted death to review cases, provide clear guidance for future cases and consequences for clinicians that fail to follow strict guidelines. In some parts of the world, these boards have helped investigate cases that breach legal standards or codes of ethics, and help keep the process reliable and secure.¹⁰ NHS England's regional teams would be ideally placed to develop regional committees to review cases. Like consultants, these are currently not required by the legislation, but could be added.
- iii. Data collection should be administered by regional committees and released annually to prevent disinformation. Safeguards allowing the involvement and analysis of external experts can decrease variation in practice and prevent misapplications of the law while alleviating anxiety about the practice among the public. An annual report is currently required as a provision of the Terminally III Adults (End of Life) Bill 2024-25, but it is unclear what data will be collected, as the paperwork that patients and doctors have to complete to apply for assisted dying do not provide space to give specific information, such as the nature of a person's suffering, their income, or ethnicity.

• Safeguard area three: available alternatives

i. Reasonable alternatives must be exhausted before someone is eligible to receive assisted dying. This is the case in Belgium and the Netherlands.¹¹ This means the physician must be satisfied that there are no routes available to the applicant, such as pain management care or recovery-oriented treatments, which could sufficiently alleviate their condition. This may involve requiring applicants who have not undergone viable treatments to attempt them.¹² Only once a doctor is confident that the individual has exhausted all reasonable treatments should UK doctors allow assisted dying. This is not required under the Terminally III Adults (End of Life) Bill 2024-25 as it stands.

- ii. Improve the provision of palliative care. No one should be forced to use assisted dying because palliative care is not available or is not affordable. In Ontario in 2023, just 51% of non-terminal MAID cases had been offered healthcare services and palliative care in order to relieve their suffering. To protect these individuals from dying for lack of alternatives, resources should be devoted to increasing the provision of palliative care and chronic care support at home, as Austria did when its legislators legalised assisted dying, in order to ensure no one chooses assisted dying when other options are available.¹³ This is not currently required by the legislation.
- iii. Do not offer assisted dying for non-terminal suffering. When it comes to potentially expanding assisted dying to allow cases for non-terminal suffering and mental illness, policymakers should go slow. In Canada, cases of people choosing to die rather than live in poverty or with disabilities are alarming, as are those who have been able to access assisted dying even for conditions which might have alleviated, if given time. This will require terminal illnesses to be clearly defined in law. In addition to clarifying what constitutes a terminal illness, policymakers should require treatment alternatives be exhausted, as is already the case in Dutch and Belgian law.¹⁴ This is included in the current legislation.

SUMMARY OF RECOMMENDATIONS

Area	Safeguard	Status in Terminally III Adults (End of Life) Bill 2024-25
Clear procedure	Guidelines requiring doctors to conduct exhaustive investigations	To be determined by the Secretary of State
	Forbidding doctors from being the first to bring up assisted dying	Not currently included
	Providing the oral protocol by default without requiring doctors be present during the death	Not currently included
Active oversight	Providing consultants available on request to adjudicate complex cases	To be determined by the Secretary of State
	Regional Committees ensuring procedure is being followed	To be determined by the Secretary of State
	Data collection should be mandatory and published annually	Included, however specific data is to be determined by the Secretary of State
Available alternatives	Exhaust reasonable alternatives	Not currently included
	Improve the provision of palliative care	Not currently included
	Do not offer assisted dying for non- terminal suffering	Included

ENDNOTES

¹ Health Canada, "Fourth annual report on medical assistance in dying in Canada 2022" (Government of Canada, October 2023). <u>https://www.canada.ca/en/health-</u> <u>canada/services/publications/health-system-services/annual-report-medical-assistance-dying-</u> <u>2022.html</u>

² Health Canada, "Fourth annual report on medical assistance in dying in Canada 2022" (Government of Canada, October 2023). <u>https://www.canada.ca/en/health-</u> <u>canada/services/publications/health-system-services/annual-report-medical-assistance-dying-</u> <u>2022.html</u>

³ Health Canada, "Fourth annual report on medical assistance in dying in Canada 2022" (Government of Canada, October 2023). <u>https://www.canada.ca/en/health-</u> <u>canada/services/publications/health-system-services/annual-report-medical-assistance-dying-</u> <u>2022.html</u>

⁴ Jocelyn Downie and Jennifer A Chandler, "Interpreting Canada's medical assistance in dying legislation" (Institute for Research on Public Policy, March 2018). <u>https://irpp.org/wp-content/uploads/2018/03/Interpreting-Canadas-Medical-Assistance-in-Dying-Legislation-MAiD.pdf</u>

⁵ Trudo Lemmens, "How Canada's medical assistance in dying law turned euthanasia and assisted suicide into a quasi-universal therapy for suffering" (Institut Droit et Santé, April 2024). <u>https://institutdroitsante.fr/publications/publications-ids/revues-livres/journal-de-la-sante-et-de-lassurance-maladie-jdsam/jdsam-n39-avril-2024/</u>

⁶ The Supreme R (on the application of Nicklinson and another) (AP) (Appellants) v Ministry of Justice (Respondent)" (25 June 2014). <u>https://www.supremecourt.uk/cases/uksc-2013-0235.html</u>. For the equivalent issue in Scotland, see Ross v Lord Advocate, clarified in J Chalmers, "Clarifying the law on assisted suicide? Ross v Lord Advocate" (Edinburgh Law Review, 2017). <u>https://eprints.gla.ac.uk/130144/7/130144.pdf</u>

⁷ Trudo Lemmens, "Charter scrutiny of Canada's medical assistance in dying law and the shifting landscape of Belgian and Dutch euthanasia practice" (Supreme court law review, April 2018). <u>https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3155994</u>

⁸ Barbara Sibbald, "MAiD in the Netherlands led by physicians" (Canadian medical association journal, December 2016). <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5135488/</u>

⁹ Yanna van Wesemael et al, "Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium (BMC Health Services Research, 2009). <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2797003/</u>

¹⁰ Maria Cheng, "Dutch probe 'appalling' euthanasia of dementia patient" (Associated Press, 20 April 2018). <u>https://apnews.com/general-news-8278f8a6224a47e88b46ea434eda26b4</u>

¹¹ Sisco M.P. van Veen et al, "Establishing irremediable physhiatric suffering in the context of medical assistance in dying in the Netherlands: a qualitative study" (Canadian Medical Association Journal, 4 April 2022). <u>https://www.cmaj.ca/content/194/13/E485</u>

¹² David Gibbes Miller and Scott Y H Kim, "Euthanasia and physician-assited suicide not meeting due care criteria in the Netherlands: a qualitative review of review committee judgements" (British Medical Journal Open, October 2017). <u>https://pubmed.ncbi.nlm.nih.gov/29074515/</u>

¹³ BBC News, "New law allowing assisted suicide takes effect in Austria" (BBC, 1 January 2022). <u>https://www.bbc.co.uk/news/world-europe-59847371</u> ¹⁴ Brian L. Mishara and Ad J. F. M. Kerkhof, "Canadian and Dutch doctors' roles in assistance in dying" (Canadian Journal of Public Health, December 2018). <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6964437/</u>