



Our **duty** of care

Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

A RESPONSE TO THE MEDICAL ADVISORY GROUP REPORT

JANUARY 2023

Liam MacArthur, MSP, established a Medical Advisory Group (MAG) to consider the implementation of assisted dying in Scotland. Their report was published at the end of 2022. This report represents an important contribution to the debate. Our Duty of Care (ODOC) is a group of healthcare professionals who are concerned about assisted dying and have concerns about the process taken by the MAG and its conclusions. This briefing paper sets out some of the concerns and observations arising from this report and offers some alternative research and references to the recommendations in the MAG report.

The thoughtful consideration of this proposed Bill by MSPs is very welcome. It is hoped that this summary response to the Medical Advisory Group report can help MSPs in those deliberations.

THE PROCESS OF THE MEDICAL ADVISORY GROUP

- ▶ The Advisory group members were **predominantly in support of assisted dying**.
- ▶ **The invited evidence was only from those supporting assisted dying**.
- ▶ The report **implies that extensive evidence is available on assisted dying**, although even official reports vary widely with regards the available data and much missing information.^{1,2}

REPORT CONCLUSIONS

Incorrect Claims of Medical Support

- ▶ The report claims increasing medical support for assisted dying (p15), but makes no mention that:
 - a. There is **no support for change from the Royal College of Physicians** (London)(2020): *"...the RCP clarifies that it does not support a change in the law to permit assisted dying at the present time."*³
 - b. There is **no support from the British Geriatrics Society**.⁴
 - c. There is **continuing opposition by the Royal College of General Practitioners** and the **World Medical Association**.^{5,6}
 - d. The **UK Association for Palliative Medicine and many other UK specialities are opposed**.^{7,8}
- ▶ Assisted dying jurisdictions are described as if there is widespread adoption (p4), but in reality the **vast majority of countries, comprising 96% of the world's population have not legalised assisted dying**.

Unclear Eligibility Criteria

- ▶ The term **'end-of-life care'** is used throughout the report, **overlooking evidence that early palliative care can prevent much pain anguish and loneliness.**^{9, 10, 11, 12} Unfortunately, such early support is offered infrequently within the NHS and the **report makes no mention of this lack of balance in care.**
- ▶ **The proposed eligibility criteria are vague.** The report recommends including young people (p11 and 39) and individuals refusing treatment (p40). This makes a 16yr old young person with capacity refusing treatment for anorexia or juvenile diabetes eligible for an assisted death.¹³

Assisted Dying Safeguards Do Not Make a Safer System

- ▶ The report states that *'more safeguards don't necessarily make a safer system'* (p27). Safeguards are essential in protecting the vulnerable. However, the report makes no mention that **safeguards have been repeatedly weakened or removed in every jurisdiction that has introduced assisted dying,** usually on the grounds of being discriminatory.¹⁴
- ▶ Legislation is not static. Evidence shows that **single case rulings and doctors' changing practice rapidly undermine safety for the vulnerable.**^{15, 16, 17}

Unsubstantiated Claims or Ignored Facts

- ▶ **Vulnerable individuals:** The report states *"...there is no evidence that it will disproportionately impact patients in vulnerable group"*. (p48). This **makes no mention of the increasing reports and evidence of the misuse of assisted dying in the poor, lonely, disabled and those unable to access care.**^{14, 18, 19}
- ▶ **Number of assisted deaths:** The report estimates up to 580 assisted deaths per year, based on the assumption that no more than 1% of the population get an assisted death (p21). This ignores the 4.8% rate in British Columbia which has a similar population to Scotland with remote and rural communities- this level was reached within 6 years.²⁰
- ▶ **Clinical Time involved in Assisted Dying:** Australian experience in Victoria is that each assisted death takes 60 hours of healthcare professional time.²¹ **Scotland would have to find at least 8,500 extra clinical sessions** and the report makes no mention of the impact this would have on current healthcare.
- ▶ **Palliative care:** The report claims that despite Scotland having excellent palliative care *"...many people still experience no relief from pain and suffering as they die.."* (p32) **Every day, over 320 people in the UK, including vulnerable groups, cannot access specialist palliative care.**^{22, 23} To date, promises of extra funding for palliative care in Scotland have not been met. The report's view that there has been *"...increased investment in palliative care"* in assisted dying jurisdictions (p31) does not mention the **stalled growth in Dutch and Belgian palliative care services since 2012,**²⁴ and **low rankings for end-of-life care in countries that have assisted dying legislation.**²⁵
- ▶ **Pain and symptom medication:** *"...administering medication to relieve pain and suffering, which may have the unintended consequence of hastening death"* (p32). This statement **disregards repeated evidence that such treatments do not hasten death.**^{26, 27, 28}

Flaws in the Proposed Decision-Making Processes

- ▶ **Assumptions about current assessment skills:** *“The group considered the satisfaction of capacity and coercion assessments to be one of the foremost safeguards of Mr MacArthur’s proposal.”* (p45) In reality, **no healthcare professional is routinely trained to detect coercion.** The report’s proposal that they can be trained to do so conflicts with the fact that **capacity assessment remains poor despite over a decade of capacity legislation,**²⁹ and that **loneliness and depression are often missed.**^{30, 31, 32}
- ▶ **Inexperienced doctors can assess patients:** the report recommends allowing newly qualified doctors to make assessments and that they *“... Need not be a specialist in the disease, illness, or condition that the patient has.”* (p10) This **removes a key safeguard of ensuring a patient receives expert, realistic and individualised advice about their care options.**
- ▶ **No safeguard against discrimination or professional coercion:** the group propose that some patients will receive ‘assistance’ in the decision making (p12). This is vaguely defined on p44, including the use of a proxy, but **discounts the serious potential for discriminatory or coercive influence through conscious or unconscious bias.**^{33, 34}
- ▶ **Assessments can be online:** *“... teleconference may overcome access issues for some patients.”* (p12) In remote and rural communities, this **further compromises safeguards to assess capacity, exclude coercion and depression.**
- ▶ **Removal of cooling off period:** the group propose that the decision time can be reduced to 48hrs *“if the patient is expected to die with the 14-day window.”* (p13) **This overlooks evidence that even terminal diagnoses and prognoses can be wrong.**^{35, 36, 37}

Navigator Service Promoting Assisted Dying

- ▶ The report proposes an assisted dying service: *“The purpose of an assisted dying care navigator service would be to provide support, assistance, and information in relation to assisted dying to patients and their families, friends and carers, and healthcare practitioners.”* (p50). There is **no mention in the report of the dangers of blurring the boundary between suicide promotion and suicide prevention.**³⁸

Limited Conscientious Objection

- ▶ The group makes it clear that doctors, nurses, pharmacists and organisations will have **limited power to refuse to participate** in assisted deaths:
 - a. Training will be mandatory (p10) and its content mandated by the health secretary. (p19)
 - b. Only professionals directly involved can refuse (p10)
 - c. There will be a duty to refer a patient to an assisted dying practitioner or service (p10)
 - d. Policies and employment contracts will ensure organisations cannot refuse to participate (p10).

Assisted Death Process

- ▶ **No mechanism is proposed for approving lethal drugs:** The group was comforted by claims that “...further information will be available..” (p53) despite the fact that **no lethal drug has ever been approved by any regulatory authority anywhere in the world.**³⁹ The report makes no recommendation on how or who would do this.
- ▶ **Misinformation on problems:** “The group was reassured that the likelihood of an assisted death not going to plan was minimal.” (p54) **This disregards the 9.3% complication rate in Oregon in 2021.**⁴⁰ The group quote a median time to death in Oregon of 32 minutes (p56), omitting the fact that some have taken up to 104 hours to die and that in Washington state 19% took more than 2 hours to die.⁴¹
- ▶ **No advice on managing complications:** The report gives no advice on what a practitioner should do if a patient vomits, has a seizure, takes hours or days to die, or fails to die, all problems reported in Oregon with oral lethal drugs. The only advice given by the group is that “... the assisting practitioner to carry a medical IV kit to administer medication to the patient if the self-ingestion did not work for any reason.” (p54) In other words, **to manage complications, doctors must expect to default to euthanasia without legal cover.**

REFERENCES

- 1 Worthington A et al. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. *BMJ Palliative and Supportive Care* 2022; 0:1-7. <https://spcare.bmj.com/content/early/2022/12/30/spcare-2022-003944>
- 2 Sleeman K, Owen GS. Assisted dying: we must prioritise research. *BMJ Opinion*, 2021, Sept 8. <https://blogs.bmj.com/bmj/2021/09/08/assisteddying-we-must-prioritise-research/>
- 3 Royal College of Physicians of London. RCP clarifies its position on assisted dying. <https://www.rcplondon.ac.uk/news/rcp-clarifies-its-position-assisted-dying>
- 4 British Geriatrics Society. Physician Assisted Suicide, 2021. <https://www.bgs.org.uk/resources/physician-assisted-suicide>
- 5 Royal College of General Practitioners. Assisted dying RCGPs 2020 decision. <https://www.rcgp.org.uk/representing-you/policy-areas/assisted-dying>
- 6 World Medical Association. WMA statement on Physician-assisted suicide, 2019. <https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/>
- 7 Association for Palliative Medicine Position Statement (PDF) [The Association for Palliative Medicine \(apmonline.org\)](https://www.apmonline.org)
- 8 BMA Physician-assisted dying survey, 2021. <https://www.bma.org.uk/advice-and-support/ethics/end-of-life/physician-assisted-dying/physician-assisted-dying-survey>
- 9 Gómez-Batiste X, Murray S, Thomas K, Blay C, Boyd K, Moine S, et al. Comprehensive and integrated palliative care for people with advanced chronic conditions: an update from several European initiatives and recommendations for policy. *Journal of Pain and Symptom Management*. 2017;53(3):509-17. <https://pubmed.ncbi.nlm.nih.gov/28042069/>
- 10 Murray SA, Kendall M, Mitchell G, Moine S, Amblàs-Novellas J, Boyd K. Palliative care from diagnosis to death. *BMJ*. 2017;356. <https://www.bmj.com/content/356/bmj.j878>
- 11 Oluyase AO et al. Hospital-based specialist palliative care compared with usual care for adults with advanced illness and their caregivers: a systematic review. Southampton (UK): NIHR Journals Library; 2021 May. PMID: 34057828. <https://pubmed.ncbi.nlm.nih.gov/34057828/>
- 12 Temel JS et al. Effects if early integrated palliative care in patients with lung and GI cancer: a randomised controlled trial. *Journal of Clinical Oncology*, 2017; 10(35): 834-41. <https://pubmed.ncbi.nlm.nih.gov/28029308/>
- 13 Gaudiani JL, Bogetz A, Yager J. Terminal anorexia nervosa: three cases and proposed clinical characteristics. *Journal of Eating Disorders*, 2022; 10: 23-36. <https://jeatdisord.biomedcentral.com/articles/10.1186/s40337-022-00548-3>
- 14 Zhu YY. Why is Canada euthanising the poor? *The Spectator* 31 December 2022. <https://www.spectator.co.uk/article/most-read-2022-why-is-canada-euthanising-the-poor/>

REFERENCES

- 15 Snijdewind MC et al. Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases. *Journal of Medical Ethics*, 2016; 44(5): 292-6. <https://jme.bmj.com/content/44/5/292.short>
- 16 Vissers S et al. Assisted dying request assessments by trained consultants: changes in practice and quality - Repeated cross-sectional surveys (2008– 2019). *BMJ Supportive & Palliative Care* 2022; 0: 1-11. <https://spcare.bmj.com/content/early/2022/06/29/spcare-2021-003502.info>
- 17 Webster P. Worries grow about medically assisted dying in Canada. *Lancet*, 2022; 400: 801-2. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(22\)01733-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(22)01733-0/fulltext)
- 18 Cecco L. Are Canadians being driven to assisted suicide or healthcare crisis? *The Guardian*, 11 May 2022. <https://www.theguardian.com/world/2022/may/11/canada-cases-right-to-die-laws>
- 19 Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012– 2016). *BMC Medical Ethics*, 2018; 19: 17. <https://bmcmethics.biomedcentral.com/articles/10.1186/s12910-018-0257-6>
- 20 Third annual report, Medical Assistance in Dying in Canada 2021. Ottawa: Health Canada. <https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html>
- 21 Rutherford J et al. What the doctor would prescribe: physician experiences of providing voluntary assisted dying in Australia. *Omega- Journal of Death and Dying*, 2021; 0(0): 1-3. <https://pubmed.ncbi.nlm.nih.gov/34282961/>
- 22 Hospice care in the UK. London: Hospice UK, 2016. <https://www.hospiceuk.org/publications-and-resources/hospice-care-uk-2017-numbers-insight>
- 23 Adam E et al. The palliative care needs of adults with intellectual disabilities and their access to palliative care services: a systemic review. *Palliative Medicine*, 2020; 34(8): 1006-18. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7596767/>
- 24 Arias-Casais N et al. Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliative Medicine*. 2020, Vol. 34(8) 1044–1056. <https://journals.sagepub.com/doi/10.1177/0269216320931341>
- 25 Finkelstein EA et al. Cross country comparison of expert assessments of the quality of death and dying 2021. *Journal of Pain and Symptom Management*, 2022; 63(4): e419-e429. <https://www.sciencedirect.com/science/article/pii/S0885392421006734>
- 26 Yokomichi N et al. Effect of continuous deep sedation on survival in the last days of life of cancer patients: A multicenter prospective cohort study. *Palliative Medicine*, 2022; 36(1): 189–199. <https://journals.sagepub.com/doi/abs/10.1177/02692163211057754>
- 27 Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. *Archives of Internal Medicine*, 2003; 163: 3414. <https://jamanetwork.com/journals/jamainternalmedicine/article-abstract/215069>
- 28 Zylberberg et al. Opioid prescription is associated with increased survival in older adult patients with pancreatic cancer in the United States: a propensity score analysis. *JCO Oncology Practice*, 2022; 18(5): e659-e668. <https://ascopubs.org/doi/abs/10.1200/OP.21.00488?journalCode=op>
- 29 Select Committee on Mental Capacity Act 2005- Report. *Mental Capacity Act 2005: post-legislative scrutiny*. <https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm>
- 30 Faisal-Cury A et al. Depression underdiagnosis: Prevalence and associated factors. A population-based study. *Journal of Psychiatric Research* 151 (2022) 157–165. <https://www.sciencedirect.com/science/article/abs/pii/S002239562200228X>
- 31 Lloyd-Williams M. Difficulties in diagnosing and treating depression in the terminally ill cancer patient. *Postgraduate Medical Journal*, 2000; 76: 555-8. <https://pmj.bmj.com/content/76/899/555>
- 32 Lee W. et al. Caring for depression in the dying is complex and challenging- survey of palliative physicians. *BMC Palliative Care*, 2022; 21: 11. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-022-00901-y>
- 33 Marcelin JR et al. The impact of unconscious bias in healthcare: how to recognize and mitigate it. *Journal of Infectious Diseases*, 2019; 220(S2): S6273. https://academic.oup.com/jid/article/220/Supplement_2/S62/5552356
- 34 Care Quality Commission. *Protect, respect, connect: decisions about living and dying well during COVID-19*. CQC 2021. <https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19>
- 35 Memorandum by the Royal College of Pathologists. *House of Lords Report 86-II (Session 2004–05), Prognosis - para 118*. <https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm#a29>
- 36 Downar J et al. The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis. *CMAJ*, 2017; 189(13): E484-93. <https://pubmed.ncbi.nlm.nih.gov/28385893/>
- 37 Warriach HJ et al. Accuracy of physician prognosis in heart failure and lung cancer: comparison between physician assessments and model predicted survival. *Palliative Medicine*, 2016; 30(7): 684-9. <https://pubmed.ncbi.nlm.nih.gov/26769732/>
- 38 Jones DA. Assisted dying and suicide prevention. *Journal of Disability and Religion*, 2018; 22(3): 298-316. <https://www.tandfonline.com/doi/abs/10.1080/23312521.2018.1486773?journalCode=wrhd21>
- 39 Worthington A et al. Efficacy and safety of drugs used for ‘assisted’ dying’. *British Medical Bulletin*, 2022; 1-8. <https://academic.oup.com/bmb/article/142/1/15/6580517>
- 40 Oregon Death with Dignity Act: 2021 Data Summary. Oregon Health Authority (Public Health Division), 2022. <https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>
- 41 2020 Death with Dignity Act Report. Centre for Health Statistics, Washington State Department of Health, 2021. <https://doh.wa.gov/you-and-your-family/illness-and-disease-z/death-dignity-act/death-dignity-data>