Peter Dowd MP, Clive Efford MP, Sir Roger Gale MP, Carolyn Harris MP, and Esther McVey MP
Chairs, Terminally Ill Adults (End of Life) Bill
3 February 2025

Dear Chairs of the Terminally Ill Adults (End of Life) Bill,

Terminally Ill Adults (End of Life) Bill – written evidence from the British Geriatrics Society

The British Geriatrics Society (BGS) is pleased to be submitting written evidence to the Terminally Ill Adults (End of Life) Bill Committee.

1. About the BGS

1.1. The BGS is the membership organisation for all UK healthcare professionals engaged in the treatment and care of older people. Since 1947 our members have been at the forefront of transforming the quality of care available to older people. Our vision is for a society where all older people receive high-quality patient-centred care when and where they need it. We currently have over 5,300 multidisciplinary members including geriatricians, nurses, GPs, allied health professionals and pharmacists working in acute, primary and community care settings.

1.2. BGS members are specialists in caring for older people at various stages of older age and with complex health conditions common in later life, such as frailty, dementia, and multimorbidity. Therefore, they have extensive skills, capabilities and experience in caring for people near the end of their natural life. A change in the law on Assisted Dying (AD) will have significant impacts on older people, and on the work of healthcare professionals who support them. In 2023, there were 581,363 deaths in England and Wales.[1] 400,042 of these (69%) were in people aged over 75.[1] International data from jurisdictions where AD is legalised demonstrate that most medically assisted deaths are in individuals over the age of 60. For example, in Canada (2022), 85% of medically assisted deaths were in people over the age of 65.[2]

1.3. Given that the significant majority of people who die each year are older people, it is vital to ensure their interests and specific needs are clearly understood in the design of this legislation and the safeguards that accompany it.

1.4. The success of any such legislation and accompanying safeguards is critically dependent on open, transparent engagement and collaboration with those professionals who are currently and most frequently involved in directly supporting and delivering optimal care at end of life. Without engagement or collaboration, AD legislation, and its accompanying safeguards, will not succeed in achieving its declared aims.

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[1] Office of National Statistics, 2024. *Deaths registered in England and Wales: 2023*. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/deathsregistrationsummarytables/2023 (accessed 27 January 2025).
[2] Government of Canada. Fourth Annual Report on Medical Assistance in Dying in Canada. 2022. Available from: https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022 (accessed 31 January 2025).

1.5. Last year, the BGS commissioned a working group of BGS members to review the current evidence, survey the membership, and formulate an updated position statement. The BGS's position statement, opposed to the legalisation of AD, can be found on our website.[3]

2. Prognostication

2.1. The BGS recommends a more precise definition of terminal illness within the bill. The inclusion of "medical condition" within the definition of terminal illness is vague, clinically without meaning and therefore left open to misinterpretation. BGS members are concerned that this term implies the inclusion of frailty, a long-term health condition reflecting increased vulnerability to adverse health outcomes,[4] affecting up to half of the population over the age of 85,[5] which can be noted on a death certificate.

2.2. Frailty is a spectrum disorder which can present non-specifically with lost functional ability. It requires accurate identification, assessment, diagnosis and severity grading. In the early stages, many of its impacts are potentially reversible and even in the advanced stages there is often clinical uncertainty about whether it can be truly considered a terminal illness. Frailty, though increasingly common, does not therefore fit neatly into a definable disease category, and there is genuine clinical uncertainty as to whether it represents a terminal illness, denoting people eligible in this bill, or a disability, making people ineligible.[6]

2.3. Despite this, data shows that frailty is cited as the main reason for AD in 5.7% of cases in Canada.[7] Additionally, there is an established link between frailty and feeling a burden to others,[8] meaning many older people with treatable clinical frailty may choose an assisted death to avoid burdening their family, which we view as unacceptable. **The BGS recommends an amendment that explicitly excludes frailty within the definition of a terminal illness to safeguard older people with this condition from harm.**

2.4. The recognition of end of life and treatment decisions towards the end of life are complex, requiring substantial training and experience. Studies suggest that doctors are fairly accurate at predicting prognosis of less than 14 days or more than a year, but the timeframe in between is challenging.[9] This is

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[3] British Geriatrics Society, 2024. BGS Position Statement on Assisted Dying (Physician Assisted Suicide and Voluntary Active Euthanasia). Available: https://www.bgs.org.uk/positionAD (Accessed 22 January 2025).
[4] Rockwood K, 2018. 'Fifteen years of progress in understanding frailty and health in aging'. *BMC Medicine* Nov 27; 16(220). doi: https://doi.org/10.1186/s12916-018-1223-3
[5] Clegg A, Young J, Iliffe S, Olde Rikkert M, and Rockwod, K, 2013. 'Frailty in elderly people', *Lancet* Mar 2;381(9868):752-62. doi: https://doi.org/10.1016/s0140-6736(12)62167-9.
[6] Hopkins S, Price A, and Etkind S, 2025. 'Why we need to consider frailty in the assisted dying debate' [manuscript submitted for publication].
[7] Government of Canda, 2023. F*ourth annual report on Medical Assistance in Dying in Canada 2022*. Available at: www.canada.ca/en/health-canada/services/publications/health-system-services/annual-reportmedical-assistance-dying-2022.html (accessed 22 January 2025).
[8] Rodríguez-Prat A, Balaguer A, Crespo I, and Monforte-Royo C, 2019. 'Feeling like a burden to others and the wish to hasten death in patients with advanced illness: A systematic review.' *Bioethics* May; **33**: 411–20. doi: https://doi.org/10.1111/bioe.12562.
[9] Orlovic M, Droney J, Vickerstaff V, Rosling J, Bearne A, Powell M, Riley J, McFarlane P, Koffman J and Stone P, 2023. 'Accuracy of clinical predictions of prognosis at the end-of-life: evidence from routinely collected data in urgent care records'. *BMC Palliative Care* April 26;22(51). Doi: https://doi.org/10.1186/s12904-023-01155-y

especially the case for those with two or more long-term conditions[10] and those with clinical frailty, where the potential for reversibility of suffering is difficult to determine.

2.5. The bill currently defines terminal illness as those expected to die in the next six months, and the BGS urges the committee to consider the significant margins of error entailed in providing accurate prognostication for older people nearing end of life. This will lead to either premature AD or inadequate time to maintain effective safeguards.

2.6. The media and public attention around the bill have focused on alleviating suffering to patients. However, there is no mention of suffering within the bill. Instead, the bill focuses on life expectancy. It is important that the motivating reasons behind an individual's wish to have an assisted death are fully understood and reported by the coordinating medical practitioner. This allows for all alternative care and support to be fully explored before proceeding with AD. **The BGS recommends an amendment to include the requirement for medical practitioners to discuss the underlying reasons a patient may be requesting AD beyond just life expectancy, and that this is recorded**.

3. Conscientious objection

3.1. A survey of BGS members found that most respondents (52%) were not willing to professionally engage in the process of AD.[11] The current draft bill does not provide adequate protections for healthcare professionals who wish to conscientiously object from taking part in any part of the AD process. Clause 4, page 2, line 33 states that medical practitioners "must" refer patients to another medical practitioner if they are unwilling or unable to conduct the preliminary discussion. This means that those with conscientious objection retain involvement in the process, which does not adequately protect those with moral, ethical or religious objections. This clause also directly contradicts clause 23, page 16. **The BGS strongly recommends the removal of clause 4, page 2.**

4. Multidisciplinary team and carers

4.1. The bill is entirely framed around an outdated medical model of healthcare and does not refer to the role of the wider multidisciplinary team, instead focusing on the role of medical practitioners. Many older people will not have a strong or continuous relationship with a medical practitioner and often a nurse or an allied health professional may take on this role. Senior decisions are not always taken by doctors, and consultant nurses often lead palliative care teams.

4.2. Similarly, social care professionals play a significant role in the lives of older people requiring care and provide an important link to healthcare services. There is no recognition or guidance within the draft bill regarding the role of the wider multidisciplinary healthcare team or social care providers. **The BGS recommends that if medical practitioners are the only professionals to**

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[10] Age UK, 2023. *The State of Health and Care of Older People, 2023*. Available at: https://www.ageuk.org.uk/siteassets/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age-uk-briefing-state-of-health-and-care-july-2023-abridged-version.pdf (accessed 22 January 2025).

[11] British Geriatrics Society, 2025. *BGS Position Statement on Assisted Dying (Physician Assisted Suicide and Voluntary Active Euthanasia)*. Available: https://www.bgs.org.uk/positionAD (accessed 22 January 2025).

be allowed to discuss AD with patients or assist with the process, this is explicitly noted within the bill. If not, guidance is needed on how the wider multidisciplinary team and the social care sector may assist older adults seeking an assisted death.

5. Palliative and end of life care

5.1. Repeated reference is made within the bill to "*available* palliative, hospice or other care", requiring a medical practitioner to discuss these options with the patient. Palliative and end of life care services are under-resourced in the UK and many people who may require these services are unable to access them. In the worst cases, the lack of older people's service resourcing has led to neglectful care in some settings, including abuse and societal negativity about ageing.[12] [13] Together, these factors can be expected to influence the decision-making and choice of older people, especially towards the end of their lives. The BGS is concerned that older people may be influenced to choose AD because of the lack of palliative and end of life care available. **The BGS strongly recommends the committee considers the presence or absence of good palliative and end of life care in influencing older people's decision-making around AD.**

5.2. The debate around AD and media coverage of the bill has skewed the debate, leaving many with a distorted understanding of when and how most people die. Most people die in older age at the end their natural lifespan rather than from single conditions, such as cancer. Better provision of end-of-life care could enable more people to die well with supportive care in a place of their choosing based on what matters to them. BGS priorities for end-of-life care can be found in our position statement on AD. A key component of end-of-life care is advance care planning, a structured discussion with patients and their families or carers about their wishes and thoughts for the future.

5.3. Since the bill passed its second reading, BGS members have raised concerns about patients unwilling to take part in advance care planning discussions, as they associate it with AD due to media coverage of this bill. The BGS strongly urges the committee to separate the issue of AD from palliative and end of life care. Patients should not be denied good palliative and end of life care because they fear this will lead to discussions around AD. Allowing death due to natural causes at the right time instead of continuing unwanted interventions aiming to prolong life is distinct from the intentional ending of life. Patients need to be clear of this distinction and allowed to make an informed choice without fear of disempowerment or coercion to shorten natural life expectancy.

6. Resourcing

6.1. AD will add additional demands on the older people's healthcare workforce if it is provided through the NHS. The BGS has long called for more geriatricians and an increase in the wider workforce to care for an ageing population.[14] If

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[12] Lafferty A, Fealy G, Downes C, and Drennan, J, 2016. '. Lafferty, A. Fealy, G. Downes, C. Drennan, J. 2016. 'The prevalence of potentially abusive behaviours in family caregiving: findings from a national survey of family carers of older people', *Age and Ageing*, 45(5), 703–707. doi: https://doi.org/10.1093/ageing/afw085.

[13] Centre for Ageing Better, 2024. *Ageism: Key Facts and Stats*. Available at: https://www.agewithoutlimits.org/ageism-key-stats-facts (accessed 22 January 2025).

[14] British Geriatrics Society, 2023. *The case for more geriatricians: Strengthening the workforce to care for an ageing population*. Available: https://www.bgs.org.uk/MoreGeriatricians (accessed 22 January 2025).

AD is legalised, this further increases the workforce needed to ensure the healthcare needs of an ageing population are met and to support older people considering AD. Alongside assessments, the bill states in clause 18, page 12, subsection 9, that the coordinating doctor must stay with the patient until the person has administered the substance and died, or it is determined that the procedure has failed. Evidence suggests that time to death after administrating lethal drugs is highly unpredictable, ranging from one minute to 108 hours.[15] Whilst this may be necessary, it will require significant clinical resource. The BGS urges the committee to consider the impact this bill will have on NHS resourcing and clinicians' time**. The BGS recommends that additional funds must be made available to ensure that the service is adequately resourced, and that funding and workforce is not diverted from other healthcare services.**

7. Coercion and control

7.1. BGS members have concerns that they will not be able to detect coercion and control. A review of international data in jurisdictions where AD is legalised tells us that this is a significant risk, with 35% of people accessing AD in Western Australia[16] and 59% of people accessing AD in Washington, USA[17] citing being a burden as a reason for choosing AD. This is especially true for older people who often feel pressures associated with getting older, such as requiring care, and the need to give up their home. It is imperative that robust procedures are in place to safeguard older people from harm. **The BGS recommends that training is provided to all healthcare professionals on how to detect coercion and control, and that the committee considers that this may be the role of a non-clinical expert.**

8. Mental ill health

8.1. About half a million people over the age of 65 experience anxiety and depression.[18] There is not adequate provision within the current draft of the bill to screen for mental health disorders which may exist alongside a terminal illness. If the mental health condition is treated, this may prevent some from requesting AD. **The BGS recommends an amendment outlining that patients must be screened for existing mental health conditions.**

9. Documentation

9.1. The documentation outlined in the schedule of the bill is not in line with current best practice for documenting significant conversations and the consent process. The GMC produces guidance on decision-making and

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[15] Worthington A, Finlay I and Regnard C, 2022. 'Efficacy and safety of drugs used for 'assisted dying'. *British Medical Bulletin*, May 4;142(1): 15-22. doi: https://doi.org/10.1093/bmb/ldac009.
[16] Washington State Department of Health, 2023. *2022 Death with Dignity*. Available: https://doh.wa.gov/sites/default/files/2023-10/422-109-DeathWithDignityAct2022.pdf (accessed 22 January 2025).
[17] Cahill, E, Lewis L, Barg F, and Bogner H, 2009. '"You Don't Want to Burden Them": Older Adults' Views on Family Involvement in Care' *Journal of Family Nursing*. May 27;15(3):295–317. doi: 10.1177/1074840709337247
[18] Age UK, *Large numbers of older people could do with some mental health support - but are less likely than younger groups to receive it.* Available: https://www.ageuk.org.uk/latest-press/articles/2022/large-numbers-of-older-people-could-do-with-some-mental-health-support---but-are-less-likely-than-younger-groups-to-receive-it/ (accessed 22 January 2025)

consent, which we recommend the committee considers.[19] **The BGS recommends a standardised electronic template as part of a national database system where all decision and conversations about AD are recorded.** The schedule should include the reason for requesting AD, treatment options discussed, and the risks and benefits of the proposed course of action. Assessment and documentation focused on mental capacity to decide about AD should be robust and include time spent with the patient, details of discussions, who was present during discussions, and questions asked.

9.2. More detail is needed within the bill in the event of one of the independent doctors refusing to sign paperwork. The bill explains the process for referring the person to another practitioner if this happens but fails to consider whether that refusal may be valid or its rationale. **BGS strongly recommends accurate documentation of this process, including why the signature was refused, and the bill needs to be amended to allow for valid reasons of refusal**.

Thank you for the opportunity to contribute written evidence on the Terminally Ill Adults (End of Life) Bill which we urge the committee to consider. However, we would very much welcome the opportunity to discuss these matters in more detail. Please contact Lucy Aldridge (l.aldridge@bgs.org.uk), BGS Policy Co-ordinator, to arrange this.

Yours Sincerely,

Professor Jugdeep Dhesi
BGS President

Professor Martin Vernon
Co-chair, BGS Ethics and Law SIG

Dr Andrew Stanners
Co-chair, BGS Ethics and Law SIG

[19] General Medical Council, 2020. *Decision making and consent*. Available: https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---decision-making-and-consent-english_pdf-84191055.pdf (accessed 22 January 2025).