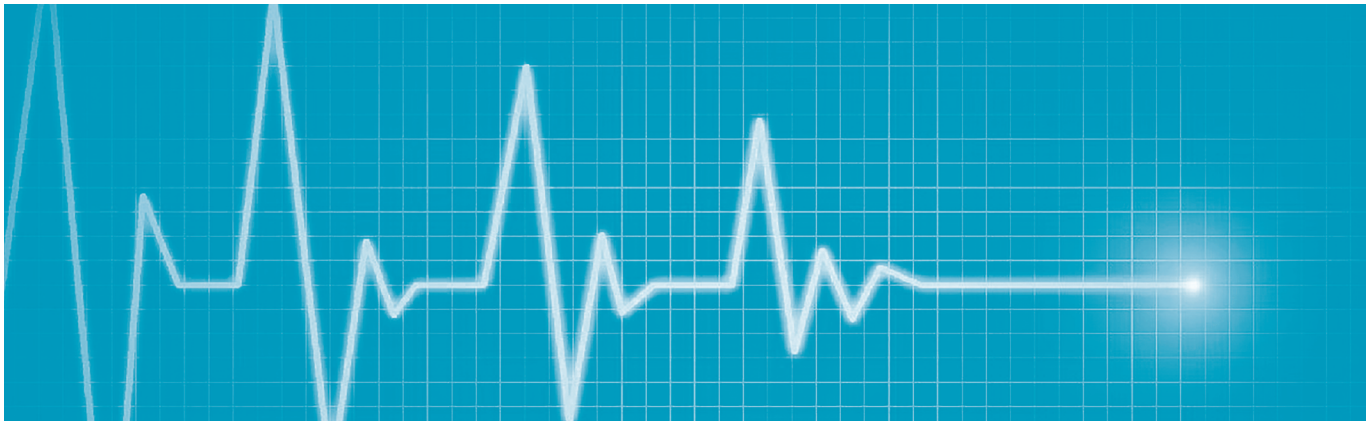
WRITTEN EVIDENCE

Hourglass Written Evidence:



The Terminally Ill Adults (End of Life) Bill

February 2025

Hourglass
Safer ageing · Stopping abuse

About Hourglass

The Hourglass mission is simple: to end the harm, abuse and exploitation of older people. Every year, more than a million older people across the UK experience physical, sexual, emotional/psychological, financial/economic abuse and neglect.

This is a truly damning indictment of how our society views and fails to value many older people. Hourglass is the only UK-wide charity dealing with the issue and has been doing so since 1993. Over that time our work has touched the lives of tens of thousands of people, shaped government policy and amplified the issue in national press. That is why Hourglass is so vital.

Hourglass operates Europe's only 24/7 helpline for older victims, their families and care practitioners, and it's a lifeline for them. We collaborate with key stakeholders and other frontline organisations to nurture a safer ageing agenda. We also have created programmes that change lives and ways of thinking.

Our specially trained Community Response Independent Domestic Violence Advisors (IDVAs), Independent Sexual Violence Advisors (ISVAs) and Domestic Abuse (DA) Officers specialise in helping people over 60 affected by abuse, providing tailored and specialist support and addressing the safety of victims at risk of harm from current or former intimate partners or family members, to secure their safety and provide the necessary support to recover from the harm suffered. This is an often-emotional job and, whilst there are many success stories and recoveries, abuse of this type is often a life-shortening experience.

Hourglass's View on the Terminally Ill Adults (End of Life) Bill

Overarchingly, Hourglass has a neutral view on the proposed Terminally Ill Adults (End of Life) Bill. We understand and support the need for older people to be able to make choices regarding their own lives and deaths and have autonomy over decision making in this sphere and any others.

However, we are concerned by elements of the Bill revolving around safeguarding, oversight and regulation, and we are anxious to ensure that older people are not at risk of coercion, abuse, and pressure to end their lives on account of the Bill.

AUTONOMY OF CHOICE

Hourglass's commitment and call for a Safer Ageing Society by 2050, as outlined in its recent **manifesto**, specifically lays down an aim to "foster an environment where the safety and dignity of ageing individuals are guaranteed."[1] While assisted dying may seem antithetical to notions of keeping older adults safe and allowing for safer ageing, assisted dying legislation may well fit in a dignity consensus, and allow the dignity of choice for older people, especially in cases of terminal illness.

A key concept raised by those supportive of assisted dying is that it allows a person with capacity but in need of medical support, the right to choose, and the key moral autonomy to determine for themselves when and how they die, the ethical principle of a "right to die."[2] As a participant from a recent Health and Social Care Select Committee roundtable on the subject contended:

> ***"As my life starts to end and the myriad increasing comorbidities multiply, I want to die while I'm able to choose and act preserving my dignity and self-respect."[3]***

When concerning assisted dying support for terminally ill older people rather than that of "intolerable suffering", the choice is not between living and dying, but between dying at a time and place not of one's choosing, or dying at a time and place of one's choosing. People already have recognised freedom to accept or decline some life ending decisions in clinical and non-clinical contexts, including the right to refuse lifesaving treatments, or to make a Do Not Resuscitate order. As such, assisted dying could be seen as an extension of these existing rights.

Even with advanced modern medicine and palliative care, pain is not extinguished from the ageing process. The provision and standard of palliative care can be variable across the UK and it must be recognised that older people should not have to make a choice between sub-optimal end of life care and assisted dying. Another prominent argument around the legislation of assisted dying is that forcing people to suffer unbearable physical and mental pain

and distress is contrary to modern ethics around health and wellbeing. As Shaw and Morton note, "permitting assisted dying enables consenting patients to avoid negative quality-adjusted life years (QALYs), enabling avoidance of suffering."[4] Hourglass argues that the choice to extinguish pain for those with terminal illnesses is one aspect of the dignity of choice and autonomy, and can fit within a safer ageing society.

NECESSITY OF SAFEGUARDING

Hourglass underlines that there are valid concerns around the risk of coercion and abuse, adequate safeguarding measures, and the potential for ageist positioning of older people as burdens or "others" within an assisted dying context.

A fear that older or vulnerable people will see themselves or be seen as a burden, or wherein older people's lives may be stigmatised or seen to be devalued in an assisted dying context is an apt one. In 35.3% of cases of assisted dying in Canada in 2021,[5] "perceived burden on family, friends and caregivers" was cited as a reason for suffering, while 48% of people who have pursued assisted dying in Oregon since 1998 cited being a "burden on family, friends/caregivers" as an end-of-life concern.[6]

As Hourglass sees with calls to its helpline concerning coercive control as a form of abuse affecting older victim-survivors, there is a high risk that pressure and coercion could follow. This could be both by families seeking economic gain and thus compelling an older person to feel that there is an obligation to end their lives, or by medical, health care or legal personnel. There are valid concerns linking the application of DNRs and assisted dying, as seen most recently during the pandemic when some older, disabled, and vulnerable patients were given DNRs by medical professionals without their consent or their families being informed, fundamentally breaching their human rights.[7]

All older adults who wish to consider assisted suicide must be fully informed about all of their options and a shared decision-making model should be employed throughout the process.

Abuse of older people in all its forms isn't widely understood or taken seriously. This lack of understanding constitutes a barrier to seeking help, and often ensures that perpetrators have an easier time getting way with acts of harm and abuse.

This is particularly evident in economic abuse cases, which continue to rise. Findings from Hourglass's three recent "Growing Old in the UK" surveys between 2020 and 2024 show that 26% of respondents did not see "taking items from an older person's home without asking" as an abusive act. The same proportion did not see "family members trying to change the Wills of older relatives" as abuse, while 24% of respondents did not see "using a Power of Attorney over an older relative for personal financial gain" as an abusive act either. Hourglass research also identified that over the last three years, economic abuse cases received by the Hourglass 24/7 helpline showed financial losses by older victim-survivors across the UK totalled over 53 million pounds (£53,124,100).

This illustrates a serious concern that older people's assets and livelihoods are not seen as their own and illuminates a key fear that assisted dying legislation will add another way for perpetrators to coerce and abuse for financial gain.

The key concern for Hourglass is around robust safeguarding measures and having the necessary regulatory framework for assisted dying, and whether any safeguarding measures could adequately protect older people in the case of coercion and abuse, especially around issues of mental capacity. In the majority of international jurisdictions where assisted dying is legal, at least two doctors make independent assessments. Other safeguards in jurisdictions where assisted dying is linked to a terminal diagnosis include a requirement to make repeated requests to access assistance, multiple assessments over a period of time, a requirement to have a set period of time left to live, and a "cooling off period" between the application to access assisted dying, and the administration of the procedure.[8]

While in a jurisdiction such as Canada (which has been criticised in some quarters for the liberal eligibility criteria, allowing assisted dying in cases of "intolerable suffering" because of extreme poverty, or homelessness for instance[9],) where assisted dying is allowed in cases of "intolerable suffering" and where a natural death is not foreseeable, "[an] individual has to be informed of "appropriate means to relieve" their suffering, including counselling services, mental health and disability support services, community services, and palliative care. Other safeguards include a mandatory 90-day wait time between a request and being able to access assisted dying."[10]

Concerns have been raised about the potential for medical professionals to pressure vulnerable groups including older people to participate in assisted dying post potential legislation. Hourglass argues that this risk is not restricted to the medical profession, but extends to the social care and legal profession. Baroness Finlay suggests a safeguarding process wherein medical professionals' involvement is limited, and decisions are made by the courts:

> ***"If assisted dying were to be legalised, consideration of requests should be placed in the hands of a scrupulously impartial body with experience of assessing evidence from a range of expert sources, including doctors, psychiatrists, social workers and others, as well as from applicants themselves, and reaching an overall judgement. This points clearly to the courts and, given the gravity of what is involved, to the High Court. Doctors would provide the Court with information***

> ***on the strictly-medical aspects of a request, a role they already play in other contexts. But it would be for the Court, and for the Court alone, to consider the overall picture in light of evidence from this and other sources and to be the sole arbiter of whether a request should proceed."***[11]

Hourglass is extremely concerned with recent movements around the Bill by Kim Leadbeater MP to take away a level of safeguarding and judicial scrutiny, as was originally outlined in the Bill, and replace a High Court Judge's oversight of the process with a panel of medical experts. While Hourglass understands that medical practitioners are the experts in this area, the additional safeguarding at a judicial level is essential to ensure that supplementary scrutiny and enquiry are available in every case of assisted dying. Hourglass would prefer it if both an expert panel and a subsequent judicial decision were laid out as safeguards, much as Baroness Finley advocates for above, and concurs with the need for a judicial scenario as laid out by Catherine Atkinson in her amendment:

> Clause 12, page 8, line 15, leave out subsections (4) and (5) and insert— "(4A) Rules of Court must secure that in relation to an application under subsection (1), the High Court must— (a) prescribe a procedure which in relation to each application appoints a person (the Official Solicitor in cases in brought in England and Wales) to act as advocate to the Court, (b) hear from and question, in person— (i) the person who made the application for the declaration, (ii) the coordinating doctor, (iii) the independent doctor, and (c) consider hearing from and questioning, in person— (i) persons properly interested in the welfare of the person who made the application for the declaration and other persons they are close to, and (ii) any other person who has provided treatment or care for the person being assessed in relation to that person's terminal illness."

Member's explanatory statement - this amendment would require court rules to be made that would ensure an adversarial court process, by appointing an advocate to the court. It would also require them to hear from the person seeking assistance to end their life and both assessing doctors, and to consider also hearing from family members and others involved in the person's care.

TRAINING AND COMPETENCY

Hourglass is also anxious that the proposed Bill is currently lacking in any specific focus around preventing coercive control, psychological, economic and domestic abuse. As such, Hourglass wholeheartedly supports the amendments around training laid down by Jess Asato, and would argue that this training be mandatory, regular, competency assessed and extended to all professions which interact with the implementation of the proposed Bill. Robust and regular adult safeguarding training must include how to recognise abuse, and crucially, how to report it.

> Clause 5, page 3, line 25, at end insert— "(4A) Regulations under subsection (3)(a) must specify that training in respect of domestic abuse, including coercive control and financial abuse is mandatory."

Member's explanatory statement - this amendment would require the registered medical practitioner acting as the coordinating doctor to have undertaken training on domestic abuse, including coercive control and financial abuse.

> Clause 8, page 5, line 29, at end insert— "(8A) Regulations under subsection (6)(a) must specify that training in respect of domestic abuse, including coercive control and financial abuse is mandatory." Member's explanatory statement. This amendment would require the registered medical practitioner acting as the independent doctor to have undertaken training on domestic abuse, including coercive control and financial abuse.

> Clause 19, page 13, line 32, at end insert— "(5A) Regulations under subsection (2)(b) must specify that training in respect of domestic abuse, including coercive control and financial abuse is mandatory."

AND BY KIM LEADBEATER:

> Clause 5, page 3, line 23, at end insert— "(3A) The Secretary of State must by regulations make provision about the training, qualifications and experience that a registered medical practitioner must have in order to act as the coordinating doctor. (3B) The regulations must include training about— (a) assessing capacity; (b) assessing whether a person has been coerced or pressured by any other person. (3C) Subject to that, the regulations may in particular provide that the required training, qualifications or experience is to be determined by a person specified in the regulations."

As well as the amendments outlining safeguards around the separation of interviews and the qualification of supporting doctors laid down by Meg Hillier:

> Clause 7, page 4, line 15, at end insert— "(2A) The coordinating doctor must take the report required under subsection (2B) into account in making an assessment under paragraph (2)(b), (f) and (g). (2B) One or more qualified persons must have conducted a separate interview with the person and made a report to the coordinating doctor on the matters specified in subsection (2C).
>
> (2C) The matters that must be covered in the report required under subsection (2B) are— (a) any evidence of duress or coercion affecting the person's decision to end their life,

(b) any difficulties of communication with the person interviewed and an explanation of how those difficulties were overcome, and (c) the capacity of the person interviewed to understand the information given to them under paragraph (9)(2), (b), (c) and (d).

(2D) A person shall be taken to be qualified to conduct an interview under subsection (2B) if that person— (a) is a registered medical practitioner who— (i) is registered in the specialism of psychiatry in the Specialist Register kept by the General Medical Council, or (ii) has such training, qualifications and experience as the Secretary of State may by regulations specify, (b) has not provided treatment or care for the person being assessed in relation to that person's terminal illness, (c) is not a relative of the person being assessed, (d) is not a partner or colleague in the same practice or clinical team as the coordinating doctor, (e) did not witness the first declaration made by the person being assessed, and (f) does not know or believe that they— (i) are a beneficiary under a will of the person, or (ii) may otherwise benefit financially or in any other material way from the death of the person. (2E) Before making regulations under subsection (2D)(a), the Secretary of State must consult such persons as they consider appropriate. (2F) Regulations under subsection (2D)(a) are subject to the negative procedure."

Hourglass would like to see greater clarity on the determination of capacity, mandatory training for those undertaking capacity assessments as well as the defined professions which can determine capacity, as this should not rest solely with GPs. This inclusion in the Bill will help to prevent the involvement of inappropriate professions or professionals at an inappropriate level, becoming involved in decision making.

Clause 8, page 5, line 16, at end insert "or conducted the interview under subsection (7) (2B)".

Member's explanatory statement - this amendment is linked to Amendment 14 and ensures that the independent doctor cannot be the same person who undertakes the assessment that would be required under that amendment.

CAPACITY

Hourglass has also been concerned with amendments such as those laid down by Sarah Olney MP concerning changes to the meaning of capacity underlined within the Mental Capacity Act 2005, specifically:

To move the following Clause - “Ability to make decision”. The person is to be considered as having the ability to make a decision to request assistance to end their life if they can fully understand, use and weigh the relevant information in accordance with regulations made by the Secretary of State under affirmative resolution.”

Member's explanatory statement -this new clause defines the concept of ability which is intended to replace the concept of capacity. This new clause is intended to replace Clause 3.

Clause 1, page 1, line 4, leave out "capacity" and insert "ability".

This replaces the concept of capacity based on the Mental Capacity Act and replaces it with a new concept of ability which is defined in NC1.

While Hourglass still sees the misunderstanding of the concept of capacity and the threat of abuse and neglect from medical professionals and others, twenty years of dedicated training around the concept have ensured a level of understanding across the medical, legal and social care sectors. Hourglass is concerned that any movement and change to the definition of capacity will weaken safeguards and allow loopholes to appear.

CONCLUSION

Hourglass as an organisation has a neutral view on the Bill, reflecting our belief in and need for a safer ageing society where the “dignity of ageing individuals are guaranteed,” and as such the dignity of choice and autonomy for older adults who wish to end their lives in this way. Hourglass has many concerns about the lack of safeguarding measures within the Bill, and the concern that older people will be coerced, abused, or manipulated into assisted dying for matters of financial or economic gain for their families, or that older people will feel they are a burden to their families and society as they grow older and consider assisted dying as a way to relieve that thought.

Hourglass is pleased to see amendments by MPs that develop and grow safeguarding measures to necessary levels; however, the charity remains seriously concerned about recent changes to the proposed legislation around judicial scrutiny and reserves the right to change its organisational view on the Bill.

Older people deserve the same independence and autonomy as any other demographic but this must be viewed against the widespread lack of knowledge of the increasing abuse of older people across the UK. Any decisions must be made within a safeguarding context. Abuse is not always clearly characterised as coercion by the abused and is often covert, subtle and insidious.

Hourglass would be pleased to offer further insight and explanation as required.

[1] We Are Hourglass (2024) “Manifesto: A Safer Ageing Society by 2050.” 3.

[2] British Medical Association (2021) “Key arguments used in the debate on physician-assisted dying”. 2

[3] Quoted in House of Common’s Health and Social Care Committee (2024) “Assisted Dying/ Assisted Suicide Second Report of Session 2023–24.” https://committees.parliament.uk/work/6906/assisted-dyingassisted- suicide/publications/. 53

[4] David Shaw, Alec Morton (2020). “Counting the cost of denying assisted dying” Clinical Ethics, Volume 15, Issue 2, https://doi.org/10.1177/1477750920907996

[5] Health Canada, (October 2023) “Fourth annual report on Medical Assistance in Dying in Canada 2022”.

[6] Oregon Public Health Division Center for Health Statistics, (March 2023) “Oregon Death with Dignity Act 2022 Data Summary.”

[7] Independent (March 2024) “Covid patients wrongly issued with ‘do not resuscitate’ orders, watchdog finds” https://www.independent.co.uk/news/health/do-not-resuscitate-patients-pandemic-covid-b2512054.html

[8] House of Common’s Health and Social Care Committee (2024) “Assisted Dying/ Assisted Suicide Second Report of Session 2023–24.” https://committees.parliament.uk/work/6906/assisted-dyingassisted- suicide/publications/

[9] The Guardian (2022) “Are Canadians being driven to assisted suicide by poverty or healthcare crisis?” https://www.theguardian.com/world/2022/may/11/canada-cases-right-to-die-laws

[10] Government of Canada, (2024) ‘Medical assistance in dying’, https://www.canada.ca/en/health- canada/services/health-services-benefits/medical-assistance-dying.html

[11] Baroness Finley (2023) “Written evidence submitted by Baroness Ilora Finlay and Mr Robert Preston to the Health and Social Care Select Committee.”

Hourglass

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OATH
OLDER AGE TOMORROW'S HOPE

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