Question 1 – Overarching question

The purpose of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to introduce a lawful form of assisted dying for people over the age of 16 with a terminal illness.

Which of the following best reflects your views on the Bill?

- Fully support
- Partially support
- Neutral/Don't know
- Partially oppose
- Strongly oppose

It is important to first contextualise our response to this Survey, Scottish Care is a membership organisation and the representative body for independent sector social care services in Scotland. We represent over 350 organisations, which totals almost 1000 individual services, delivering residential care, nursing care, day care, care at home and housing support services.

As a membership organisation, we recognise this Bill evokes deeply personal views and raises significant moral and ethical questions. Given the diverse perspectives within our membership, we do not take a formal position on this matter. Our primary commitment remains in supporting our members in delivering the highest quality of care to those who seek their services, regardless of the choices those individuals make.

We understand that the passage of this Bill could have profound implications for our members and the people they support. It is crucial that these potential impacts and the complexities they entail are thoroughly considered during the legislative process. To this end, we are engaging with this survey to highlight some of the concerns and challenges that may face the social care sector. The insights given are to ensure that the Assisted Dying for Terminally Ill Adults (Scotland) Bill addresses the practical realities and needs of those providing and receiving care within the social care network.

Which of the following factors are most important to you when considering the issue of assisted dying?

- Impact on healthcare professionals and the doctor/patient relationship
- Personal autonomy
- Personal dignity
- Reducing suffering
- Risk of coercion of vulnerable people
- Risk of devaluing lives of vulnerable groups
- Sanctity of life

- Risk of eligibility being broadened and safeguards reduced over time
- Other, please specify

We have chosen this option as we recognise that the factors listed above are deeply interrelated, both philosophically and practically. As such, it is neither feasible nor meaningful to attempt to rank these factors in order of importance, or outrightly choose three. It is crucial to openly acknowledge that making decisions in this context may involve balances between different considerations.

It is equally important to stress that these balances are a natural part of the decision-making process, and protections must be put in place to ensure those making these decisions are not vilified or unfairly criticised. We must approach this Bill with empathy and understanding, recognising the complex nature of the choices that may arise.

Question 2 – Eligibility

The Bill proposes that assisted dying would be available only to terminally ill adults.

The Bill defines someone as terminally ill if they 'have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death'.

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

Eligibility – Terminal illness

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

- No-one should be eligible for assisted dying
- Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill
- Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right
- Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill
- Assisted dying should be available to people who are terminally ill, and to people in some other categories.
- Other – please provide further detail

  We expand on our choice in the next box.

If you have further comments, please provide these

There are significant concerns about the Bill's definition for people who fall within the 'terminally ill' category. The current definition is too vague, this will likely lead to subjective judgments having to

be made by medical professionals, therefore, creating room for potential inconsistencies in how eligibility is assessed across different regions. There is also concern about the risks of inaccurate diagnoses, undetected coercion, and the impact of fluctuating mental capacity on seriously ill patients, all of which could compromise the integrity of the decision-making process.

Eligibility – minimum age

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

- No-one should be eligible for assisted dying.
- The minimum age should be lower than 16
- The minimum age should be 16
- The minimum age should be 18
- The minimum age should be higher than 18
- Other – please provide further detail

We do not hold an official stance on this matter.

If you have further comments, please provide these

Question 3 – The Assisted Dying procedure and procedural safeguards

The Bill describes the procedure which would be in place for those wishing to have an assisted death.

It sets out various procedural safeguards, including:

- examination by two doctors
- test of capacity
- test of non-coercion
- two-stage process with period for reflection

Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?

- I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle
- The procedure should be strengthened to protect against abuse
- The procedure strikes an appropriate balance

- The procedure should be simplified to minimise delay and distress to those seeking an assisted death
- Other – please provide further detail

If you have further comments, please provide these

The procedural safeguards set out in the Bill need to be strengthened to ensure sufficient protection for those who choose this process and furthermore to ensure there is clarity around expectations at every step. At the stage of "examination by two doctors," the Bill should clearly define the required level of medical expertise for eligibility assessments due to the critical nature of these decisions. Additionally, reasonable steps need to be put in place to highlight how this requirement will be met in practice, especially considering the existing NHS waiting lists. Clear guidelines and training for medical practitioners are necessary to assess and document the absence of coercion effectively. Furthermore, the Bill must address the challenges of cognitive decline, such as dementia, which complicates assessments of decision-making capacity, and ensure that patients provide truly informed consent. There needs to be appreciation of the fluctuating nature of capacity.

It is essential to consider not only procedural safeguards but also the contextual factors that may increase an individual's vulnerability when completing this process, for instance such as poor access to services which could influence an individual's decision. The Bill should explicitly outline if an individual has been able to explore avenues which address their needs and required relief. The choice provided by this Bill should not be positioned as an immediate option without first exploring alternative avenues. Additionally, special attention must be given to vulnerable populations, such as residents in nursing and care homes, who may feel pressured to choose assisted dying due to perceived burdens or a lack of specialist resource to provide the care they need.

There is a critical need to invest in high-quality palliative and end-of-life care (PEOLC) services, including in care homes and homecare settings. While assisted dying is distinct from PEOLC, access to excellent PEOLC should be considered a fundamental safeguard in this Bill. The availability of good PEOLC towards the end of life is essential to ensuring that no one feels compelled to choose assisted dying due to limited care options. Therefore, substantial investment in PEOLC should accompany and precede the enshrinement of this Bill, as this could reduce risks to vulnerable individuals. The Bill's current provisions on discussing available PEOLC are vague, particularly regarding the circumstances in which such discussions might be deemed "inappropriate." There is also a lack of clarity on how assessments should be conducted when PEOLC is not available. Telling a patient that care to address their suffering is unavailable could profoundly impact their sense of dignity and decision-making. Furthermore, it is crucial to determine what reliable and up-to-date information sources assessing doctors will use to verify the availability of PEOLC.

Question 4 – Method of dying

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

Which of the following most closely matches your opinion on this aspect of the Bill?

- It should remain unlawful to supply people with a substance for the purpose of ending their own life.
- It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill
- It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer.
- Other – please provide further detail

We are alarmed about the lack of detail in the Bill regarding the scenario of medical complications arising from the administration of the necessary substance. In such cases, the individual may follow the expected path, or the process could become more protracted and difficult. If this becomes the case, what expectations will be placed on involved staff and what resources will be provided for them to meet this adequately. There is concern that the medical and care staff who would be involved in supporting individuals in their last moments will be unprepared for the unexpected. This does not only call into question the consistency of care applied but also the distressing impact it might have on involved staff.

If you have further comments, please provide these

Question 5 - Health professionals

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

- Medical professionals should not be involved in assisted dying, as their duty is to preserve life, not end it.
- The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out.
- Assisting people to have a “good death” should be recognised as a legitimate role for medical professionals
- Legalising assisted dying risks undermining the doctor-patient relationship
- Other – please provide further detail

If you have further comments, please provide these

The Bill lacks sufficient recognition of the impact on those facilitating assisted dying, particularly in the already challenging social care sector, who may be required to support individuals in their final moments. This could further strain, recruitment and retention challenges within the sector. The psychological and emotional toll on healthcare professionals, especially those in communal settings like care homes, must be acknowledged, as their involvement could cause them significant moral distress. The Bill should mandate their access to support through counselling and debriefing.

Furthermore, high-quality, complex training is crucial for all health and social care professionals involved, covering areas such as PEOLC, legal aspects, safeguarding, human rights, and difficult conversations with individuals and families. The financial impact to resource such training needs to be considered, to highlight what level of care can be expected.

Conscientious objection is another critical issue, as some staff may have moral or religious objections to participating in assisted dying. The Bill's current provisions do not offer adequate protection for these objectors, particularly those indirectly involved in the process. Conversely, professionals who do participate may face legal and emotional challenges, such as potential court involvement if a family does not support the individual's decision, which could be highly stressful even if the outcome is favourable. The Bill must address these practical concerns to ensure that the rights and well-being of all parties are respected and protected.

Question 6 - Death certification

If a person underwent an assisted death, the Bill would require their underlying terminal illness to be recorded as the cause of death on their death certificate, rather than the substance that they took to end their life.

Which of the following most closely matches your opinion on recording the cause of death?

- I do not support this approach because it is important that the cause of death information is recorded accurately
- I support this approach because this will help to avoid potential stigma associated with assisted death
- Other – please provide further detail

We do not hold an official stance on this matter.

If you have further comments, please provide these

Question 7 – Reporting and review requirements

The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person's medical record.

It also proposes that Public Health Scotland should collect data on; requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.

The Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.

Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

- The reporting and review requirements should be extended to increase transparency
- The reporting and review requirements set out in the Bill are broadly appropriate
- The reporting and review requirements seem excessive and would place an undue burden on frontline services
- Other – please provide further detail

If you have further comments, please provide these

A vigorous reporting and review process is crucial to enable effective care and support for those enforcing their rights under this Bill. There are additions that can be made to the outlined requirements which increase the fulfilment of the intention behind the Bill.

To ensure a comprehensive understanding of an individual's choice under this Bill, the assessment phase should include an exploration of the reasons and motivations behind an individual's request. This understanding is vital not only for ensuring that individuals are making informed and voluntary decisions but also for identifying any underlying issues, such as unmet care needs or external pressures, that might be driving these requests. This aspect of assessment should then be fed into the reporting and review cycle to ensure that the Bill stays true to its purpose and issues of unmet needs are addressed. Without this level of scrutiny, there is a risk that factors influencing decisions will be misunderstood, potentially leading to unintended and harmful outcomes.

Furthermore, the lack of precision in the Financial Memorandum raises concerns about the adequacy of the resources allocated to support individuals through this process. As part of the reporting regime, it is essential to document the resources required—including staffing, training, and support services—to ensure individual needs are being met. With several hospitals currently operating at full capacity, it is likely that there will be an increased reliance on social care services, which are already under strain. These services must be sufficiently supported and resourced to handle the additional responsibilities that the Bill may impose. Ensuring this support is crucial for maintaining the quality of care and for preventing additional strain on the social care system.

Additionally, the Bill should require the recording of any untoward incidents or complications that arise during the assisted dying process. This includes medical complications, issues related to the administration of life-ending substances, and any distressing or prolonged experiences that deviate from the expected course. Recording such incidents is essential for ongoing evaluation and improvement of the process, ensuring that it remains as safe, efficient, and compassionate as possible. Without this level of detail, it will be difficult to identify and address potential weaknesses in the system, which could lead to harm or a loss of public trust in the process.

In summary, a more robust and detailed reporting regime is necessary to ensure that an individual's passage through the process is thoroughly monitored, well-regulated, and adequately resourced. This would involve not only tracking the outcomes of assisted dying requests but also understanding the motivations behind them, documenting the resources used, and recording any incidents that occur. Such measures are essential for safeguarding both the individuals involved and the integrity of the public health system.

Question 8 – Any other comments on the Bill

Do you have any other comments in relation to the Bill?

The increasing prevalence of assisted dying among older populations, as seen in various countries, raises significant ethical and societal concerns. In contexts like Canada and Europe, a growing number of elderly individuals are opting for assisted dying due to reasons such as loss of autonomy, severe chronic conditions, and unbearable suffering. This trend necessitates a careful consideration of how society values older people and what constitutes a valuable contribution in old age. It also highlights the potential for social and individual coercion, where older individuals might feel pressured to choose assisted dying, whether due to perceived burdens on their families or limited care options.

The experiences from countries like the Netherlands, Belgium, Luxembourg, and Canada demonstrate that as assisted dying becomes more normalised, there is often a broadening of eligibility criteria. This evolution raises concerns about the impact on various care settings, which already face challenges related to public perception, misunderstandings, and stereotypes. Without clarity and consistent communication with the public, the legalisation of this Bill could exacerbate these challenges, leading to further stigmatisation or misinterpretation of the important work that is carried out in care settings.

In Canada, for instance, the expansion of eligibility for Medical Assistance in Dying (MAID) to include those whose only medical condition is a mental illness reflects how legal frameworks can evolve in response to societal and legal pressures. Such expansions could lead to ethical dilemmas, particularly regarding the protection of vulnerable populations, therefore it is important to ensure that the rights in this Bill are supported by comprehensive PEOLC. A sector which needs increased investment to adequately meet the needs of current and future generations.

The Bill demonstrates a lack of practical and contextual understanding of what assisted dying may mean within a social care setting. Care homes have a communitarian nature and are settings where long term relationships are developed between resident and staff and with other residents. If someone makes the decision to be assisted ion their dying then that decision impacts the whole community, both psychologically and practically. There will also be impact on other families and relatives as well as a whole cohort of staff who may support the individual.

PEOLC remains a crucial consideration. There is a strong obligation to provide high-quality care to all individuals, particularly those nearing the end of life. As an organisation we are concerned that the options made available under this Bill might detract from efforts to improve PEOLC. This then potentially may lead to premature decisions to end life as a perceived solution to suffering. In Scotland, most care provided to individuals with deteriorating health, is generalist PEOLC offered by health and social care professionals across various settings, including homes, care facilities, and hospitals. Ensuring equitable access to such care is essential to prevent assisted dying from becoming a default option due to limited support. Furthermore, the support which service providers are expected to deliver to individuals at every stage during this process, needs to be clearer. While their involvement is suggested, it is unclear what level of support will be required and how this support will be adequately resourced by the Government. This level of clarity will ensure that expectations can be adequately fulfilled, monitored and reviewed.

The allocation of resources presents significant challenges, particularly in publicly funded health and social care systems. Assisted dying must never be perceived, whether explicitly or implicitly, as a cost-saving measure. In Scotland, the health and social care systems are designed to address different needs within the community, and they must work in harmony to provide comprehensive care. When parts of this system, such as PEOLC, are disproportionately underfunded and unable to meet the growing demand, it creates an implicit understanding that these services or those who rely

on them are less important or unnecessary. This perception weakens these services as viable options for individuals, potentially pushing people towards assisted dying as the only accessible alternative. Ensuring equitable funding and support across all areas of health and social care is essential to maintain a balanced approach that respects the diverse needs of all individuals in the community.

Additionally, the impact on families must be carefully considered. The decision for assisted dying can have profound emotional and psychological effects on family members, they will also require ethical care that includes robust support both before and after the procedure. Moreover, the public perception of assisted dying can influence societal views on the value of life, particularly for the elderly and disabled. There is a risk that normalising assisted dying could lead to a devaluation of these demographics, further marginalising vulnerable groups.

In summary, the concerns raised around this Bill involve navigating a complex balance. While respecting individual autonomy is crucial, it must be carefully weighed against; the need to protect vulnerable populations, ensure informed consent, uphold high standards of PEOLC, address the emotional impact on staff and families, navigate legal and ethical dilemmas, and remain aware of cultural and societal implications. Ensuring that adequate resources, including funding for PEOLC, are available is essential. This will help support the rights under this Bill to remain a truly autonomous choice, rather than becoming an implied suggestion or expectation, and ensure individuals are fully supported in their end-of-life care decisions.