# Terminally Ill Adults (End of Life) Bill

#### Key issues

- from Report Stage Day 1
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## Key issues from Report Stage Day 1

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# Key issues from Report Stage Day 1

Very few of the issues in the Bill were addressed on Day 1, yet MPs will be asked to make decisions on Day 2 with little understanding of the issues. This briefing covers 7 of the most significant areas of concern. Where arguments against the amendment were offered on Day 1, we have provided a response.

# 1. Ensuring assisted dying is freely chosen - Doctors must not suggest Assisted Dying (NC1)

The Bill permits any doctor to raise the option of ending the patient's life, no matter how young or vulnerable the patient. NC1 ensures assisted dying is something freely chosen and patient-initiated, protecting vulnerable individuals from implicit pressure in clinical settings. Even neutral mentions by doctors can feel like recommendations due to power imbalances, risking trust, especially among disabled or vulnerable patients.

#### 2. A higher standard of proof is needed (NC9)

72% of the public want proof that those seeking assisted dying are not being pressured. This Bill's "balance of probabilities" (51%) test isn't enough for this irreversible act. NC9 requires certainty at the end from both the approval panel and the doctor administering the lethal substance, using a tiered approach to prevent coercion or error while keeping initial checks less stringent.

# 3. Assisted Dying must be for terminal illness, not societal failure (NC16)

Public opinion opposes assisted dying eligibility based on "quality of life" issues like poverty or depression. Yet, this Bill allows assisted dying even if the wish stems from depression, lack of care, or feeling like a burden - not from the illness itself. If someone wants to die because society has failed them, our duty is to fix the failure, not to offer lethal substances. NC16 clarifies that a "settled wish to die" must stem from terminal illness, not societal failures.

# 4. The Mental Capacity Act falls short (amendments 81, 24, 17, 102, 32)

The Bill leans too heavily on the Mental Capacity Act (MCA) - simply whether an individual can understand, retain, use and weigh information - a legal test that was never designed for decisions about ending life. MCA capacity doesn't exclude severe mental illness or suicidal thoughts, which experts, including the Royal College of Psychiatrists, deem unsafe. Amendments 81, 24, 17, 102, and 32 strengthen safeguards to ensure decisions are free from impaired judgment or treatable suffering.

# 5. Palliative care must be an option (amendments 80, 30, 31)

The Bill leaves the door open for assisted death for someone who might have been helped had they received proper, timely care. One in four people die without needed palliative support. Access is patchy, and worse for disadvantaged groups. Without addressing this, "choice" is simply illusory. Amendments 80, 30 and 31 aim to tie eligibility to cases where every effort has been made to explore effective palliative care, ensuring assisted dying is not a default due to systemic failings.

# 6. Protecting our hospices (NC17, NC18, amendment 16)

Hospices must have a clear legal right to opt out of assisted dying. Other countries protect this; this Bill would make England and Wales outliers. As the Bill stands, hospices risk legal action, workforce loss, and damage to community trust. Most hospices rely on charitable funding and already face staff shortages. Effectively forcing involvement could spark an exodus of palliative care professionals and deter patients who are worried about being pushed towards assisted dying.

# 7. Default position is to exclude family (amendments 33, 10, 47, 8, 23)

Family and loved ones are explicitly excluded from this process. The only reference is that doctors may, if they consider it appropriate, suggest patients discuss their request with next of kin or those they are close to. If they have not, or do not intend to, there is no requirement to explore why. This applies no matter how young or vulnerable the patient. The default of family exclusion risks patient isolation, and missed opportunities where the family might help to identify coercion, pressure or some remedial factor that is driving the decision, as well as ignoring the emotional impact on families or dependents blindsided by a loved one's death.

To secure assisted dying for those who want it, this Bill results in:

**EVERY** terminally ill person's choices being changed; **EVERY** doctor being empowered to raise it; **ALL** losing the default of help to the end; **ALL** being expected to make a decision; **ALL** being vulnerable to internal and external pressure.

## Ensuring assisted dying is freely chosen - Doctors must not suggest Assisted Dying (NC1)

#### THE ISSUE

This Bill allows any doctor to raise assisted dying with a patient, irrespective of how vulnerable the patient is. Allowing doctors to initiate the discussion in this way risks subtle pressure within the unequal doctorpatient dynamic. This threatens patient autonomy, particularly for vulnerable groups, and could undermine trust in healthcare.

#### WHY IT MATTERS

- . The power imbalance in medical situations is stark. Dr Rachel Clarke warned that raising assisted dying could lead vulnerable patients to question whether their life is deemed "not worth living." Professor Brassington's evidence to the Committee notes that a doctor's suggestion carries implicit endorsement, as doctors rarely propose harmful options. This is especially concerning for terminally ill patients, who face heightened risks of depression and suicidal thoughts. Even if presented as one option among many, including assisted dying in the "menu" may be interpreted as a recommendation, undermining genuine autonomy. NC1 ensures patients initiate these discussions, protecting their freedom from unintended influence.
- Maintaining Trust, Especially Among Minority and Disability Groups.

The trust between a patient and their doctor is paramount. Patients must feel confident that their doctor's sole focus is their care and well-being. Dr Jamilla Hussain's evidence highlighted existing mistrust within some ethnic minority communities due to experiences of racism in healthcare. If doctors can initiate discussions about assisted dying, it risks entrenching these fears, leading to patients from these communities avoiding necessary care. Similarly, Disability Rights UK has voiced concerns that disabled people might feel pressured if doctors suggest assisted dying, given that their lives are sometimes devalued within healthcare settings. NC1 helps preserve the integrity of this trust by ensuring the patient is in control of initiating this specific conversation.

#### **Practical Concerns for Doctors:**

The Bill already distinguishes assisted dying from standard medical treatment by disapplying Montgomery case-law (clause 5(1)), which requires doctors to inform patients of all options. Yet, the British Medical Association's neutral stance and the Medical Defence Union's concerns highlight a "worst of both worlds" scenario: doctors face complaints whether they raise assisted dying or not. NC1 provides clarity, ensuring doctors only discuss assisted dying when prompted by patients, avoiding ethical and legal conflicts.

#### **Evidence from Other Jurisdictions:**

In jurisdictions like Oregon and Canada, where doctors can initiate discussions, reports indicate patients sometimes feel steered toward assisted dying, particularly when palliative care is limited. NC1 aligns with stricter safeguards in places like Victoria, Australia, where patient-led requests are prioritised to protect autonomy.

#### ADDRESSING CONCERNS

#### Patients will still have access to information:

The Bill, as introduced by the sponsor, already provides that doctors are not under any duty to raise it (clause 5(1)). NC1 doesn't deny information to the patient, it simply ensures the *request* for that specific information is patient-led to avoid the risk of implicit pressure. NC1 also does not prohibit the State from running a public information campaign about assisted dying; what it prohibits is doctors proactively raising it with their patients, given the risk of implicit pressure that this carries. And as Dr Alexandra Mullock noted, public awareness of a legalised assisted dying process is likely to be high, meaning patients won't be ignorant of its existence.

#### This will protect vulnerable minority groups:

For many vulnerable groups, the primary concern is not a lack of awareness of assisted dying, but the risk of being steered towards it due to existing healthcare inequalities, societal biases, or a lack of adequate support and palliative care. NC1 is a protective measure for these groups, ensuring that the conversation only begins if they truly wish to explore it, thereby promoting genuinely equitable and autonomous decision-making, rather than access potentially driven by vulnerability.

#### It will strengthen the doctor-patient relationship:

NC1 is designed to strengthen trust by removing a potential source of anxiety and misinterpretation. Patients, especially vulnerable ones, need to trust that their doctor is unequivocally focused on their care and improving their quality of life. Allowing doctors to initiate discussions about assisted dying could, for some, introduce an element of fear or suspicion that their life is being devalued, thereby damaging, not enhancing, the therapeutic relationship. NC1 provides clarity and removes ambiguity for both doctor and patient in this

If a patient indirectly indicates that they wish to discuss assisted dying, the doctor will be

NC1 does not "gag" doctors from responding to patient needs. If a patient indicates, even non-verbally or indirectly, that they wish to discuss assisted dying, a doctor can and should explore this sensitively (the text of NC1 says "unless that person has first raised it", it does not require that this raising consists of a particular form of words). NC1 prohibits the doctor from introducing the topic unprompted when there has been no such indication from the patient. Skilled medical professionals are adept at understanding and responding to patient cues; NC1 respects this while preventing unsolicited suggestions.

#### THE AMENDMENT

- · NC1 provides that no doctor or health professional shall raise the subject of assisted dying with a person "unless that person has first raised it".
- . Supporting NC1 is not about opposing the principle of assisted dying for those who meet strict criteria and genuinely desire it. It is about ensuring the robustness of the safeguards within the Bill, particularly at the very first point of contact on this sensitive issue. It strengthens the Bill by addressing a key area of public and professional concern, ensuring that the choice, if made, is demonstrably the patient's own.

# 2. Ensuring certainty when ending a life: the standard of proof (NC9)

#### THE ISSUE

The Bill's reliance on the "balance of probabilities" (51% certainty) for assessing eligibility, consent, and absence of coercion is insufficient for the irreversible act of helping end a patient's life. NC9 introduces a "beyond reasonable doubt" standard at the final stages to ensure certaiznty and protect vulnerable individuals, which means that one must be "sure".

#### **WHY IT MATTERS**

· The public expect proof of lack of pressure:

More in Common polling found that the most important safeguard for the public is that there is some form of proof that the person seeking assisted dying is not being pressured. The Bill's current "satisfied" standard, confirmed by Ministers as the "balance of probabilities," risks errors in life-ending decisions. NC9 establishes a tiered approach: doctors conducting initial assessments use the "balance of probabilities" test but can flag if they have doubts, while the Assisted Dying Review Panel and the doctor providing the lethal substance must be satisfied "beyond reasonable doubt" that the criteria are met and this is the individual's settled wish. This ensures rigorous scrutiny where it matters most.

· Since death is irreversible, we must be sure:

A "beyond reasonable doubt" standard compels thorough examination, reducing risks of coercion or misjudged capacity slipping through. It aligns with the gravity of assisted dying, ensuring lethal drugs are only administered when eligibility is unequivocal. Without this, subtle pressures or uncertainties could lead to irreversible errors, particularly for vulnerable patients.

• Impact on Vulnerable Groups:

Vulnerable patients, including those with mental health conditions or disabilities, are at higher risk of subtle coercion or misinterpretation of their wishes. NC9's higher standard ensures decision-makers rigorously assess capacity and intent, protecting against decisions driven by external pressures or societal biases.

For civil matters of exceptional gravity, "beyond reasonable doubt" has been established as a
reasonable test:

The House of Lords in *Re* B (2008) confirmed that "beyond reasonable doubt" is appropriate for civil matters of exceptional gravity, like assisted dying. European inquisitorial systems successfully apply this standard to complex decisions. In contrast, jurisdictions like Oregon, using lower standards, report cases where coercion concerns were overlooked, highlighting the need for NC9's clarity.

#### ADDRESSING CONCERNS

Questions of life and death require the utmost certainty:

The House of Lords in Re B (2008) case clarified that there are two distinct standards of proof, and that the criminal standard ("beyond reasonable doubt") can and should be applied in civil proceedings of exceptional gravity. Assisted dying is unequivocally such a case. Relying on an undefined "flexibility" when lives are at stake creates unacceptable risk. Parliament must legislate for certainty.

- The criminal standard is appropriate for complex issues like capacity or an inquisitorial panel:

  For complex matters requiring a definitive 'yes' or 'no,' such as capacity, asking "Are you sure?" is arguably simpler and safer than calculating probabilities. Furthermore, an inquisitorial panel, which investigates rather than presides over adversaries, is well-suited to applying a "beyond reasonable doubt" standard to its own findings. Many European inquisitorial criminal systems successfully use this standard.
- It will make the process safer by allowing for greater opportunities to investigate matters:

  NC9 is carefully tiered. It only applies "beyond reasonable doubt" at the final approval by the Panel and the ultimate check by the administering doctor. The initial medical assessments operate on the balance of probabilities, allowing cases with flagged doubts to proceed for the Panel's more stringent review. This is a proportionate, not obstructive, approach to safeguarding.

#### THE AMENDMENT

- NC9 requires assessing doctors to decide on an application on the civil standard of proof but to flag any
  aspects on which they are not sure. The Panel can then investigate those concerns and must be sure that the
  person is eligible before approving the application. Similarly, the doctor providing the lethal drugs for the final
  act must be sure that there has been no last-minute change of mind.
- NC9 is a vital strengthening of the Bill's safeguards, providing necessary clarity and ensuring that decisions of such irreversible magnitude are made with the highest possible degree of certainty. But if, as Dr Neil Shastri-Hurst suggests, requiring this high degree of certainty would make the Bill unusable and freeze the entire process, then the Bill's fundamental safety, not just the standard of proof it employs, is what must be questioned.

TERMINALLY ILL ADULTS (END OF

# TERMINALLY ILL ADULTS (END OF LIFE) BILL

### A settled wish to die: Assisted Dying must be for terminal illness, not societal failure (NC16)

#### THE ISSUE

The Bill does not explicitly link the wish to die to the terminal illness, allowing eligibility for those driven by external factors like depression, financial hardship, or feeling like a burden. NC16 ensures the wish to die is rooted in the terminal illness, not societal or personal pressures.

#### **WHY IT MATTERS**

#### Public trust:

More in Common polling shows Britons oppose eligibility based on "quality of life" issues like homelessness or heartbreak. NC16 excludes motivations such as feeling like a burden, mental disorders, disabilities (unrelated to the terminal illness), financial struggles, lack of care, or suicidal ideation. This ensures assisted dying addresses terminal suffering, not solvable problems.

#### Preventing a "Duty to Die":

A significant concern is that vulnerable individuals might feel, or be made to feel, that they are a burden on their families or on the NHS/state. NC16(a) directly addresses this. Data from jurisdictions like Oregon and Canada show a concerning percentage of individuals citing "being a burden" as a reason for requesting assisted death, a figure that has often increased over time. As Lord Sumption noted, the issue is not just overt pressure, but the assumptions people make about societal attitudes. This Bill must not inadvertently create a "duty to die."

#### **Ensuring Choices Are Not Driven by Lack of Care or Support:**

NC16(d) and (e) ensure that choices are not driven by desperation due to financial hardship, inadequate housing, or a lack of access to necessary medical treatment, palliative care, or social support. If a person wishes to die because they cannot get the care they need to live with dignity, the failure lies with service provision, not with the individual's desire to live. Assisted dying should not become a cheaper or quicker alternative to comprehensive care and support.

#### **Protecting Those with Treatable Mental Health Conditions:**

NC16(b) and (f) safeguard individuals whose wish to die may be substantially driven by a mental disorder, such as depression, or by suicidal ideation, rather than a settled response to their terminal illness. In a number of US states young women have been assisted to end their lives on account of eating disorders and they were all assessed to have mental capacity. As the Royal College of Psychiatrists has pointed out, a person can have capacity under the Mental Capacity Act but still have their judgment significantly impaired by depression. The focus should be on treating such conditions, not facilitating death.

#### **Distinguishing Disability from Terminal Illness:**

NC16(c) ensures that the wish to die is rooted in the terminal illness itself, not in societal or personal difficulties associated with a pre-existing disability separate from the terminal prognosis. This addresses concerns from disability rights groups that disabled individuals might be disproportionately steered towards assisted dying.

#### **Upholding True Autonomy:**

True autonomy means making a free and informed choice, unclouded by external pressures or remediable conditions. NC16 ensures that the "clear, settled and informed wish" required by the Bill is genuinely about the patient's response to their terminal illness and its consequences, not a reaction to solvable problems or untreated conditions.

#### ADDRESSING CONCERNS

The Bill already requires trained professionals to make nuanced judgments, this adds some flesh to

Assessing motivations is indeed complex, but it is not beyond the capability of trained professionals. Doctors and the proposed Panel are already tasked with making nuanced judgments regarding capacity, coercion, and whether a wish is "clear, settled, and informed." NC16 adds a specific, crucial dimension to this assessment. The term "substantially motivated" provides a necessary threshold, guiding professionals to explore whether the desire to die is primarily a symptom of, for example, untreated depression or lack of housing, rather than an autonomous response to the terminal illness itself. To ignore clear indicators that a request stems from such remediable factors would be a failure of care.

#### This upholds true patient autonomy:

True patient autonomy is compromised if the decision to end one's life is driven by treatable conditions (like depression or inadequate pain relief), correctable circumstances (like lack of social care or financial hardship), or an internalised feeling of being an avoidable burden. NC16 is not about paternalistically overriding a genuinely autonomous wish related to terminal illness; it is about ensuring that the "autonomy" being exercised is not an illusion shaped by despair, neglect, or remediable suffering. The state has a profound interest in protecting life and ensuring that assisted dying does not become a response to societal failings.

The State should not endorse feeling like a burden as a valid primary driver for state-assisted death: While individuals may have these feelings, and some proponents of assisted dying may argue this is a "legitimate reason", the state should not endorse feeling like a burden as a valid primary driver for stateassisted death. The Falconer Commission itself acknowledged the "real risk that some individuals might come under pressure... [from] self-imposed pressures that could result from the individuals having low self-worth or feeling themselves to be a burden on others". NC16 ensures the focus remains on the suffering arising from the terminal illness, not on alleviating perceived burdens on family or public services.

#### The existing safeguards on capacity and coercion are insufficient:

A person can have legal capacity and not be subject to overt coercion, yet still be driven to request assisted dying by factors NC16 seeks to address. For instance, someone with capacity might request to die due to untreated, severe depression or because they lack access to adequate palliative care. NC16 acknowledges that capacity and absence of overt coercion alone do not guarantee that a wish to die is a settled, informed, and truly autonomous response to the terminal illness itself. It ensures a deeper inquiry into the reasons

The Sponsor (Kim Leadbeater MP) repeatedly stated during Committee that the people she intends this legislation for (terminally ill adults) are not suicidal: "I will say on the record that the term "suicide" is not accurate for the cases we are talking about. The people we are dealing with are not suicidal. They very much want to live; they do not want to die, but they are dying. It is important that we have that on the record." (Col 318); "it is clear to me that the terminally ill people I have met would not describe themselves as suicidal at all. They want to live, but the fact is, they are dying—that is a very important distinction to make." (Col 165). On that basis this amendment would not undermine that policy intent, but would instead ensure that the Bill is properly focused on those it is intended for and protects others from unintended consequences.

#### THE AMENDMENT

- NC16 states that a person does not have a settled wish to end their life if they are substantially motivated by:
  - Not wanting to be a burden on others or public services
  - A mental disorder (including depression)
  - A disability (other than the terminal illness itself)
  - Financial considerations, including lack of adequate housing
- Lack of access, or delayed access, to necessary treatment or services
- Suicidal ideation (distinct from a settled wish to end life due to terminal illness).
- NC16 directs doctors and the Panel to thoroughly explore the motivations behind a request, ensuring that the decision is made for the right reasons. And it allows action to be taken where the wish to die is due to remedial factors. By supporting NC16, Members can significantly strengthen the Bill's safeguards, ensuring it achieves its compassionate aims without creating unintended pathways to death for the vulnerable or those lacking adequate support.

# 4. The Mental Capacity Act falls short (amendments 81, 24, 17, 102, 32)

#### THE ISSUE

The Bill's fundamental reliance on the Mental Capacity Act 2005 (MCA) as the primary framework for assessing a person's capacity to decide to end their own life is a significant flaw that undermines the proposed safeguards. This approach is insufficient and poses an unacceptable risk to vulnerable individuals. Experts across legal and medical fields, including the Royal College of Psychiatrists, have voiced grave concerns that the MCA, as currently applied in the Bill, is neither sufficient nor appropriate for such an irreversible decision.

#### **WHY IT MATTERS**

- Reliance on the MCA without significant adaptation is problematic because the Act was not designed for this
  context and because a person can have legal capacity under the Act while still suffering from serious mental
  disorders or other factors that impair their judgment and desire to live.
- The MCA was never intended to govern decisions about ending one's own life.

  It was enacted to protect individuals who lack capacity in decisions about their care or finances, and to guide others making decisions on their behalf. Applying it to a person's decision to end their life is an "entirely novel test" in an "uncharted territory" with "no experience" or precedent. The Royal College of Psychiatrists explicitly states that the MCA "does not provide a framework for assessing decisions about ending one's own life". Professor Gareth Owen, Professor of Psychological Medicine, Ethics and Law at King's College London, states that the decision to end one's own life is "unsettled or conceptually much more profound or novel" and that applying the MCA puts you "into an area where there is no experience of the central capacity question under consideration". Alex Ruck Keene KC, a barrister specialising in mental capacity law, agrees that this is a "novel context" for MCA application.
- A person can meet the MCA's definition of capacity while suffering from mental disorders that significantly impair their judgment or influence their desire to die.
  The Royal College of Psychiatrists clarifies that under the Bill, "a person with a co-occurring mental disorder that is impacting their wish to end their own life would not necessarily be deemed ineligible" if they retain MCA capacity. The Bill only excludes those whose mental disorder impairs capacity itself. This concern is echoed by Professor Allan House, Professor of Liaison Psychiatry, who states that assessing capacity needs to go "beyond merely assessing mental capacity and the presence of severe mental illness". Professor Gareth Owen notes that conditions like sub-clinical mood problems or anxiety could potentially impair judgment without necessarily meeting the threshold for lacking capacity under the strict MCA definition.
- Mental disorders can bias decision-making even when legal capacity is technically present. The MCA requires a clear link between a mental impairment and the *inability* to make a decision. If this specific causation isn't met, a person can be deemed to have capacity even if their decision-making is clouded by their mental disorder. As Alex Ruck Keene KC points out, a person could appear unable to understand information, but if that inability isn't caused by a recognised impairment, they could still be deemed capacitous under the MCA. This highlights a critical gap where impaired judgment, not directly causing an inability to understand/retain/use/weigh information but biasing the decision, might not be captured by the MCA.
- Terminal illness increases the risk of suicide and depression, which are often treatable. Dr Annabel Price notes that about 20% of terminally ill patients have diagnosable depression, and around 10% have a wish to hasten death, with this wish strongly linked to feeling suicidal. Experts emphasise that treating depression can alleviate the wish to die. Relying solely on the MCA means someone with treatable depression could be deemed capacitous and eligible for assisted dying. Amendment 102 (R Smith) is a crucial safeguard against this, requiring a check for "remediable suicide risk factors" before a preliminary discussion can even take place.

#### The MCA mandates a presumption of capacity.

Section 1(2) of the MCA requires that a person must be assumed to have capacity unless it is established that they lack it. This places the burden on the assessing doctors and panels to *disprove* capacity, rather than requiring positive confirmation of capacity for this momentous decision. The Royal College of Psychiatrists views this "presumption of capacity may be problematic in the context of AD/AS given the consequence... would be the person's death". Amendment 24 (Francis) directly addresses this flaw by proposing to disapply this presumption of capacity.

#### The MCA explicitly allows for "unwise decisions."

The Act states that a person is not to be treated as lacking capacity merely because they make a decision that others might deem unwise. This dangerous principle means someone could be assessed as having capacity under the MCA to choose assisted dying, even if that decision is profoundly influenced by despair or mental illness and is considered unwise by others.

#### The MCA's requirement to support decision-making has perverse implications.

The Act requires taking all practicable steps to help a person make a decision before concluding they lack capacity. In the context of assisted dying, this could necessitate discussing information, including the "likely consequences" of ending one's life, which might alarmingly include perceived benefits such as relieving financial burdens on family.

#### The reliability of capacity assessment under the MCA is questionable, especially in complex situations.

Experts warn that the MCA is often poorly understood by healthcare professionals. Dr Rachel Clarke, an NHS doctor and trainer, states that despite teaching capacity assessments, they are "often the case that they are very poorly conducted". Professor Alan Thomas, Professor of Old Age Psychiatry, highlights that a doctor's own values can influence their judgment. Professor Gareth Owen notes that while the MCA may be reliable in routine decisions, "in areas of decision making where the decision itself is unsettled or conceptually much more profound or novel... you cannot expect there to be such levels of reliability". Dr Annabel Price of the Royal College of Psychiatrists confirms this, stating there is "questionable confidence in the consent processes, of which mental capacity is part, in relation to the decision to end one's life" among experienced practitioners. Amendment 17 (Spencer) seeks to raise the standard for this specific decision by requiring the capacity assessment to include a detailed understanding of prognosis certainty, treatment options, palliative care, and the nature of the assisted dying substance.

#### · Capacity can fluctuate in terminally ill patients.

Factors like physical illness, fatigue, medication side effects, and psychological distress can cause a person's capacity to change over time. The standard application of the MCA needs significant adaptation to account for these fluctuations in a context where the decision is irreversible.

#### The Bill does not mandate a separate mental health assessment to identify impaired judgment unrelated to capacity.

While referral to a psychiatrist is allowed if there is doubt about capacity, the Bill does not automatically require assessment for mental disorders that could impair judgment even if capacity is present. This is a notable difference from safeguards in other jurisdictions like Oregon, California, and Victoria, which often require psychological evaluations if a mental health condition *might* be present.

#### THE AMENDMENTS

- Parliament must strengthen the safeguards around capacity and mental health by supporting amendments that address these critical issues:
  - Amendment 81 (Paul) proposes removing Clause 3 entirely, advocating for a wholly different approach to capacity assessment for assisted dying.
  - b. Amendment 24 (Francis) is essential for reversing the presumption of capacity, requiring clinicians to actively establish capacity rather than assuming it exists.
  - Amendment 17 (Spencer) enhances the standard of the capacity assessment itself by specifying the detailed information that must be understood by the applicant.
  - d. Amendment 102 (R Smith) introduces a vital check for remediable suicide risk factors like treatable depression or other issues, ensuring that requests stemming from solvable problems are identified before the process begins.
  - e. Amendment 32 (Spencer), linked to Dr Ben Spencer's arguments for stronger assessments, addresses the issue of undue influence, a form of impaired judgment that must be rigorously checked.

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# 5. Palliative care must be an option (amendments 30, 31 and 80)

#### THE ISSUE

Supporters of the Bill argue that assisted dying is necessary for those people palliative care cannot help; people experiencing unbearable suffering that cannot be alleviated. However, if this is not to become a push towards assisted dying for all who are terminally ill, equal thought must be given to those who can be helped. They should have an equal guarantee to palliative care options, so that they have a genuine choice and are not simply pushed to end their lives early due to lack of alternatives. Without addressing this, the "choice" will be simply illusory, narrowed further by funding and commissioning decisions. Amendments 80, 30 and 31 aim to tie eligibility to cases where every effort has been made to explore effective palliative care, ensuring assisted dying is not a default due to systemic failings.

#### **WHY IT MATTERS**

Someone could qualify for assisted dying under the Bill even if their pain and suffering could be
relieved by adequate palliative care, but they lack access to it.
The availability and quality of palliative care services in England and Wales is acknowledged to be uneven,
with reports of unmet need and variation in provision. Dr Sarah Cox, President of the Association for Palliative
Medicine of Great Britain and Ireland, stated that palliative care is currently inadequate and needs massive
improvement so that the Bill offers patients a real choice. She also highlighted that 25% of people who die in

this country, over 100,000 people a year, do not have the palliative care they need.

- Without adequate palliative care, the choice of an assisted death is not a free one. Sam Royston from Marie Curie pointed out that if people cannot choose to access palliative care, they cannot make a free choice about the care and support they receive. Professor David Jones concluded that evidence indicates palliative and end-of-life care deteriorating in quality and provision following the introduction of assisted dying in several jurisdictions.
- Without adequate palliative care, the Bill only leads the patient down one route—to die.
  Inequitable access exists, with poorer provision for those from minoritised communities and low
  socioeconomic backgrounds, as highlighted by Dr Jamilla Hussain. The current drafting means that a person
  could potentially qualify not because palliative care cannot help them, but because they are not receiving
  adequate palliative care, possibly due to systemic failings.

#### **PROPOSED AMENDMENTS**

- Amendment 80 clarifies that assisted dying is for those cases where a person is experiencing "severe
  pain and discomfort that cannot be reasonably relieved to the person's satisfaction through palliative
  care". The intention behind this amendment is to ensure that the Bill applies only to the "very small group of
  people who may benefit from it, not the larger group who just need adequate palliative care to give them the
  comfortable, dignified death they deserve". It aims to align the Bill's legal criteria with the stated intention.
- Amendments 30 and 31 would mean that someone is only eligible for assistance in ending their own life under this Act if they have relevant and available palliative care options.

# PARLIAMENT AT ITS BEST?

"I think the government has been quite irresponsible—if it really wants this change to pass—by trying to do it through private members' legislation...Commons scrutiny is being left to solve a whole range of problems it isn't equipped to deal with—like how to produce legislation that most people would see as fair to those who want the option ... [and] others who may feel under pressure—whether to preserve their inheritance, or because carers are, you know, pushing them to the edge."

#### Jill Rutter,

Senior Fellow, Institute for Government, March 2025

## Protecting our hospices (NC17, NC18 and amendment 16)

#### THE ISSUE

Hospices must have a clear legal right to opt out of assisted dying. Other countries protect this; this Bill would make England and Wales outliers. As the Bill stands, hospices risk legal action, workforce loss, and damage to community trust. Most hospices rely on charitable funding and already face staff shortages. Effectively forcing involvement could spark an exodus of palliative care professionals and deter patients who are worried about being pushed towards assisted dying.

#### **WHY IT MATTERS**

- Without a right to opt out it may deter people from hospice and palliative care.
- For decades, modern palliative medicine and hospice care have striven to encourage early access to services, battling a cultural tendency to associate hospice with "admitting defeat". Toby Porter, Chief Executive of Hospice UK, in his oral evidence, highlighted the risk that if hospices were involved in assisted dying, it "would just reinforce an inaccurate perception about hospice and palliative care: the myth that you are helped along your way by doctors in hospices and hospitals". This could further deter individuals from seeking the vital support and comfort that palliative care offers, ultimately undermining efforts to improve endof-life discussions and services.
- Some hospices may explicitly want to provide a "safe space" where patients do not fear that assisted dying will be suggested as an option.
  - This is particularly important because the Bill gives every doctor the right to raise at their discretion assisted dying. An explicit legal right to refuse to permit assisted dying on their premises would allow institutions to establish a clear policy, which is crucial for transparency with both patients and staff. This ensures that employees are aware of and adhere to the institution's stance, preventing "legal and ethical minefields" and allowing for the matching of "right employees with the right hospices".
- Impact on the already fragile workforce within the hospice and palliative care sector.
  - There is a national shortage of palliative care staff, and a significant majority of palliative care consultants hold strong views against assisted dying. Their opposition is rooted in the World Health Organisation's definition of palliative care, which explicitly states it should "neither hasten nor prolong death". Toby Porter told the Committee that there is a risk that if these professionals felt they "could not keep their distance from assisted dying" in a hospice setting, it could lead to an "exodus of skilled and valuable health and social care practitioners". Such a loss of specialist consultants would severely impair hospices' ability to provide essential care.
- There are serious concerns that the Bill allows Ministers to make what public funding there is conditional on providing assisted dying.
  - The case of the Irene Thomas hospice in British Columbia, which lost its public funding and was taken over after refusing to offer assisted dying, serves as a stark warning. This is not scaremongering, but rather has been foreshadowed in the UK context, with Kit Malthouse asking at Committee "Should they still be able to deny what is a legal service, if they are in receipt of public funds?"
- An explicit legal right to decide whether or not they permit assisted dying on their premises would allow institutions to establish a clear policy, which is crucial for transparency with both patients and staff.

This ensures that employees are aware of and adhere to the institution's stance, preventing "legal and ethical minefields" and allowing for the matching of "right employees with the right hospices". This institutional optout is consistent with precedents in other jurisdictions like California and New Zealand, where healthcare entities and hospices can choose not to offer assisted dying services. This also acknowledges the impact on the broader "community" within a hospice; an assisted death takes place in the shared "home" of other residents and staff, impacting others.

- Negative impact on financial and community support vital for hospices.
  - UK hospices are financially vulnerable, with 65% to 70% of their funding coming from charitable donations. Assisted dying is controversial, with strong feelings on both sides. There's a legitimate concern that if hospices were forced to offer assisted dying, some community members might cease funding them, and conversely, if they refused, others might withdraw support. This presents a significant "strategic and operational challenge", where hospices need the ability to make careful decisions for themselves.
- If England and Wales does not allow such an opt-out, it would be an outlier.

Other countries have given hospices, care homes and other facilities the right to opt out of involvement with assisted dying and legal protection if they choose to do so. England and Wales will be outliers. They include Canada, Netherlands, Belgium, Australia (Victoria, Western Australia, Tasmania, South Australia, Queensland, New South Wales), New Zealand, Spain, United States (Oregon, Washington, Vermont, California, Colorado, Hawaii, New Jersey) and Austria. Without legal protection, hospices are likely to be dragged into the courts because MPs have failed to make clear in law that they can opt out.

#### PROPOSED AMENDMENTS

This New Clause would ensure that the public funding a hospice receives is not to be affected by whether or not they provide assisted dying, and that in allocating funding, a public authority cannot consider whether they do provide assisted dying or not. As Together for Short Lives have said, "the statutory funding that a provider organisation receives to deliver health and or social care to people with life-limiting or life-threatening conditions should in no way depend on whether or not they decide to offer assisted dying."

TERMINALLY ILL ADULTS (END OF LIFE) BILL

This New Clause ensures that care homes and hospices are free to decide whether and to what extent they wish to provide assistance under this Act or allow it on their premises. It does not implement either an optout or an opt-in basis but ensures that such organisations have complete freedom to decide whether to be involved and, if so, to what extent. This is to reflect the fact that many hospices might want to be involved at the initial stage of the process but not the final act. This New Clause ensures that hospices and care homes have the space and autonomy to make those decisions.

This amendment would make it clear that no hospice or care home is required to permit the provision of assisted dying on their premises.

# 7. The default position is to exclude family (amendments 33, 10, 47, 8, 23)

#### THE ISSUE

Family are mentioned only in passing in the Bill. Doctors may, if they consider it appropriate, suggest patients discuss their request with next of kin or those they are close to. The family do not even have a right to be notified after the death. The exclusion of family raises concerns about patient isolation, undetected coercion, and the emotional impact on families blindsided by a loved one's death. Simply requiring doctors to ask if the person has informed their family strikes a balance between a person's right to privacy and addressing these concerns.

#### **WHY IT MATTERS**

- With so many choosing assisted death because they feel that they are a burden, the opportunity for family to provide reassurance or step in may be material to the patient's decision.
   People aged under 25 are especially vulnerable because they are still maturing; their parents or former guardians should always be informed that there has been a decision to grant an assisted death.
- The exclusion of family by default is very dangerous in terms of abusive relationships.
   It's very common for an abusive partner to try to isolate the victim from their close friends and family. Some level of required notification would mean that it was much harder for a controlling partner to push someone through this process without it being exposed.
- Families often hold vital information about a patient's history, mental state, or circumstances—such as coercion or resolvable feelings of being a burden—that assessors may miss.
  For example, 45.1% of Track 1 and 49.8% of Track 2 MAiD patients in Canada's 2023 report cited feeling like a burden as a reason for their request, a sentiment that family discussions might alleviate. In Oregon, this figure rose from 13% in 1989 to 52% between 2017-2023. Not asking whether patients have spoken to their families about wishing to die, enhances the risk that the process will fail to detect coercion by someone outside the immediate family, such as a new partner.
- In the Court of Protection, much less serious applications than an application for an assisted suicide require notification of at least three persons "likely to have an interest in being notified".

  An indicative list is given which is supposed to be worked along in order, (first there are spouses, next anyone with whom the applicant lives as a spouse, next parents, then children, then siblings, then wider relatives). If some of the closest relatives are unsuitable then others can be notified.
- In several countries where assisted dying is legal, cases have emerged where family members were
  not informed until after the procedure, even when the individual suffered from mental health issues
  like depression.

For instance, in January 2025, Anne, a 51-year-old from Wales, ended her life at a Swiss clinic without her family's knowledge, despite their belief she was depressed after her son's death; the clinic failed to notify them beforehand, contrary to prior assurances. Similarly, in Canada in October 2021, Donna Duncan's daughters learned of her assisted death via text message hours after her release from a psychiatric unit, where she had been suicidal and starving herself post-car crash, with her daughters claiming she was "fast-tracked" to die. In a 2017 Belgian case, Tom Mortier's mother, who had severe depression, died by euthanasia, and he was only informed the next day; he later won a European Court of Human Rights case due to flaws in the post-death investigation, though not for the lack of prior notification.

Bereaved families, unaware of the decision, may face clinical grief disorders, depression, or PTSD.
 UK charity AtaLoss warns that discovering an assisted death without prior warning will be similar to the trauma of suicide, intensifying bereavement. Third, cultural and systemic factors highlight the need for family inclusion. Dr Jamilla Hussain's evidence from ethnic minority groups (Pakistani, Roma, Black Caribbean) emphasises that family and community provide hope, and exclusion risks misinterpreting support as coercion. Racialised communities also fear systemic biases pushing vulnerable individuals toward assisted dying, a concern amplified if families are sidelined.

#### THE AMENDMENTS

#### Amendments 33 and 10 (Asato)

require the assessing doctor and the Panel to ask the person whether they have discussed their request with family and friends and to discuss their reasons for not doing so if they have not. It therefore strikes a balance between informing the family but in a way that respects privacy.

#### Amendment 47 (Wright)

requires that people with an interest in the welfare of the patient (such as their family members) be notified that they have made an application so that they can present any information that they have to the Panel. This rule is modelled on the Court of Protection which requires notification of three such persons (Practice Direction 9B). The amendment does not specify a number of people to be notified but allows the Commissioner to issue a Practice Direction.

#### Amendment 8 (Atkinson)

requires that the Panel must consider hearing from persons with an interest in the welfare of the applicant (such as their family) and from others who provide care for them in relation to their terminal illness.

#### Amendment 23 (Campbell)

requires, in the case of an applicant under the age of 25, that their next of kin be notified of the outcome any application they have made to the Panel.

TERMINALLY ILL ADULTS (END OF LIFE) BILL

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# Key issues ahead of Report Stage Day 2

# 1. Ministers will be able to fundamentally change the NHS through secondary legislation (amendment 12)

Only 26% of the public believe that the NHS is currently in a fit state to provide people with the option of assisted dying. Yet, by 2029 the NHS will be radically reconfigured to include the state ending lives with lethal drugs, with MPs having very little say. We are still in the dark about what this will look like, how the NHS will change, and what people will experience at the point of access. Many safeguards governing integration into the NHS and the behaviours of doctors will rely entirely on non-binding codes of practice. Fundamental reconfiguration of the NHS and its principles shouldn't be done with Parliament cut out.

# 2. The Bill signs off a cost-cutting, for-profit service, with no requirements for transparency by private contractors (amendment 15)

The NHS will save £13k for every person who ends their life four months early. It creates perverse incentives within the NHS to encourage greater and earlier use of 'the service'. The risks are intensified as the Bill permits any doctor to propose ending the patient's life. Outsourcing 'the service' to "independent contractors" and for-profit private firms is openly being explored by Ministers. Promises to cap profits haven't materialised, and transparency requirements for future providers are nowhere to be seen.

# 3. The system has extraordinarily feeble oversight, with Parliament sidelined (NC19, NS2, amendments 88, 103, 104)

Ministers are given sweeping powers under the Bill, with MPs sidelined. At best, MPs will have 90 minutes to debate and rubber-stamp decisions on statutory instruments on how to change the NHS or how to end patients' lives. Many decisions won't even be debated, giving Ministers carte blanche. Independent oversight of the system by the Chief Medical Officer has been removed. Instead, the 'Voluntary Assisted Dying Commissioner' assesses the system and marks their appointees' homework. How will policy or system failures ever be caught? *Amendments 103 and 104 (Paul Kohler), and NC19, NS2 and 88 (Sarah Olney) strengthen procedure on regulations, and address monitoring, consultation and reviews.* 

# The Bill requires MPs to be relaxed about unregulated drugs and bad deaths (amendment 99)

'Dignified death' is promised, but this is in no way secured by the Bill as drafted. As a bare minimum, it would be reasonable to expect strict regulation of lethal drugs, but the Bill bypasses the UK's established drug approval process. There is no minimum standard threshold, nor emphasis on avoiding unintended suffering or inflicting pain. Patients have no right to be informed of the risk of complications. There is no requirement to report when they do happen. Amendment 99 (Caroline Johnson) requires a report on drug effects (time to death, complications, side effects) before Parliament approves regulations.

# 5. This Bill has no "off switch" and no guarantee of future choice (amendment 42)

The four-year rollout plan is reckless and locks the country into the launch of 'the service' in 2029 - irrespective of what has been left undone, the state of the NHS, palliative care shortages or unforeseen crises. The Bill focuses on only one end-of-life option and gives no guarantee terminally ill people will be given a meaningful choice. It is a pathway leading in one direction. Amendment 42 (Adam Jogee) replaces auto commencement in England with a Secretary of State commencement order.

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## A blank cheque to fundamentally change the NHS: MPs have no clarity on what the service will look like and how the NHS will be reconfigured (amendment 12)

#### THE ISSUE

#### Ministers will be able to fundamentally change the NHS through secondary legislation.

Only 26% of the public believe that the NHS is currently in a fit state to provide people with the option of assisted dying. Yet, by 2029 the NHS will be radically reconfigured to include the state ending lives with lethal drugs, with MPs having very little say. We are still in the dark about what this will look like, how the NHS will change, and what people will experience at the point of access. Many safeguards governing integration into the NHS and the behaviours of doctors will rely entirely on non-binding codes of practice. Fundamental reconfiguration of the NHS and its principles shouldn't be done with Parliament cut out.

#### WHY IT MATTERS

Six months after Second Reading and MPs still do not know anything about the service on which they

How will it be delivered? Will it be integrated within NHS pathways? Will it be a separate service? Will there be a presumption that all doctors - unless they explicitly opt out - will raise it with every terminally ill patient? Will there be a 'public health campaign' promoting its launch? Will it be casually promoted through information leaflets and posters in surgeries and hospitals? All MPs know is that the Bill requires the founding principles of the National Health Service - preserved since 1946 - to be amended by regulations so that the NHS is no longer focused solely on improving the mental and physical health of the public but will also end lives through the administration of lethal drugs.

- MPs are being asked to sign a blank cheque and give ministers unfettered powers to design a service, including the provision of the service by private sector providers on a for-profit basis. Any future government can use these powers, too, completely reconfiguring the service again and again, and the only say that MPs will have - at best - is a 90-minute debate and a yes/no vote. MPs will not even have the guarantee of an impact assessment when proposals are brought forward - the Committee rejected making that a requirement.
- The service is not guaranteed to be free at the point of use, despite the sponsor implying this. Minister for Health informed the Committee that it "must be free of charge, unless charging is expressly provided for". The Bill provides a Henry VIII power to amend the NHS Act 2006, without limit, which could include the specification of charges. Why was this clause written in this way?

#### THE AMENDMENT

| Amendn<br>No. | nent Sponsor              | Category       | Short Explanation                                                                                                                                                                                                            |
|---------------|---------------------------|----------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 12            | Dame Siobhain<br>McDonagh | Implementation | Prevents regulations from amending section 1 of<br>the National Health Service Act 2006, requiring<br>changes via an Act of Parliament. If the NHS's<br>purpose must change, this should be done on the<br>face of the Bill. |

## MPs are asked to sign off on a cost-cutting, for-profit service, where any doctor can suggest ending the patient's life

#### THE ISSUE

MPs are signing off on a cost-cutting, for-profit service with few safeguards. For every patient that ends their life four months early, the NHS will save £13k in 'unutilised healthcare'. The final month is estimated as particularly costly for the NHS, accounting for 34% of the healthcare costs in the final six months. On a per-person basis, this creates powerful incentives within the NHS to encourage greater and earlier 'use' of the service. That's before other cost savings for the government. The risks are intensified as the Bill permits any doctor to propose ending the patient's life, while outsourcing 'the service' to "independent contractors" and for-profit private firms provides moral distance. This option is openly being explored by Ministers, while promises to cap profits haven't materialised, and transparency requirements for future providers are nowhere to be seen.

#### WHY IT MATTERS

The Bill allows for a system where any NHS doctor can raise assisted dying with a patient, and then subsequently hand them off to private contractors for assessment - and, if approved - for help ending

That referral lessens responsibility and has the appearance of the NHS 'washing their hands' of the patient, while the private for-profit service will be incentivised to progress the patient, as the final act - ending the patient's life - will attract the largest fee.

The lead Minister, Stephen Kinnock, has said he - and the Department - are 'comfortable' with the use of independent contractors.

The sponsor promised to clarify by amendment how the service will be delivered but this has not happened.

- 'Reasonable remuneration' is explicitly discounted in the Bill as a conflict of interest for doctors. But the term is undefined, and there are no limits on the profits a contractor can make from the service. Leadbeater told the Sunday Times she was considering tabling an amendment to cap and define "a reasonable profit" but for reasons that were never explained, she decided not to.
- There is no limit on commercial relationships existing between providers. cross-referral between two private practices to complete the different doctor assessments is permitted, increasing the risk that, rather than coming to each assessment with a fresh pair of eyes, there will be an established mutually beneficial relationship between the co-ordinating doctor and the independent doctor, and a conveyor belt to progression.
- Transparency over what is being charged, who is profiting from the service, the volume of cases processed, and 'market share' will help to maintain public trust.

#### RELEVANT AMENDMENT

| Amendment No. | Sponsor         | Category                                   | Short Explanation                                                                                                          |
|---------------|-----------------|--------------------------------------------|----------------------------------------------------------------------------------------------------------------------------|
| 15            | Blair McDougall | Monitoring,<br>consultation and<br>reviews | Requires private providers of assisted dying services to publish annual statements on service numbers, costs, and revenue. |

# 3.

# MPs are being asked to sign off on a system with feeble oversight, where Parliament is sidelined. They will have little further say

#### THE ISSUE

The system has extraordinarily feeble oversight, with Parliament sidelined.

Ministers are given sweeping powers under the Bill, with MPs sidelined. At best, MPs will have 90 minutes to debate and rubber-stamp decisions on statutory instruments on how to change the NHS or how to end patients' lives. Many decisions won't even be debated, giving Ministers carte blanche. Independent oversight of the system by the Chief Medical Officer has been removed. Instead, the 'Voluntary Assisted Dying Commissioner' assesses the system and marks their appointees' homework. How will policy or system failures ever be caught?

#### **WHY IT MATTERS**

- · It's irresponsible that the policy has not been worked through.
  - Whenever a difficult issue emerges, the solution has been to take another power for the detail to be resolved later, or to rely on training, non-binding guidance and codes of practice which doctors only must have 'regard to'. As Jill Rutter, Senior Fellow at the Institute for Government, commented in March, "the government has been quite irresponsible if it really wants this change to pass by trying to do it through the private members' legislation... Commons scrutiny is being left to solve a whole range of problems it isn't equipped to deal with..."
- There are now 55 clauses and 38 regulation-making powers, including five Henry VIII clauses allowing Ministers of any stripe to change any Act of Parliament.
  - These are not minor details to be resolved. They include how to reconfigure the National Health Service's founding principles to include ending patients' lives, the involvement of the private sector to provide a forprofit service, the entire regulatory regime for such services and the approved substances, and the standards doctors must reach to end patients' lives. **No other assisted dying legislation in the world uses powers as this one does.**
- When these powers are used, MPs will be almost entirely excluded from the policy process and will have little to no ability to object.
  - Most statutory instruments will be debated if at all in a small committee. If a debate on the floor of the House is arranged, MPs will have only 90 minutes to say why they object, and the vote will still go ahead on a 'yes/no' basis. No amendments are permitted. It's been half a century since a statutory instrument was rejected.
- Nor can MPs rely on independent oversight once the system is up and running.
   Oversight by the Chief Medical Officer was removed in Committee.
  - That responsibility now rests with the Voluntary Assisted Dying Commissioner, who is also responsible for appointing the panels that will approve requests. They will be marking their own and their appointees' homework.
- Unless instructed otherwise, the Commissioner will also determine what is in the annual report
  provided to Parliament because the Bill is entirely silent on what it needs to guard against, and the
  data that needs to be collected to provide that insight and ensure trust in the system.
   We are at risk of repeating the problems in other jurisdictions where data collection has been poor and
  inconsistent, a problem noted by the Health and Social Care Committee. Without adequate data, patterns
  cannot be spotted, guestions asked, and action taken.

#### · Examples of patchy oversight are common.

- In Belgium, of over 50,000 assisted deaths, only about half have been properly reported.
- In Oregon, information on complications following ingestion of lethal substances is missing in around 70% of cases.
- Inexplicably, in 2019, Washington stopped reporting data relating to complications (despite multiple complications being reported between 2009-2018).
- o Only one jurisdiction reports on disabilities.
- Only some jurisdictions record that a refusal happens, sometimes with a basic category (e.g., ineligibility), but not why.
- In Victoria, Australia, the former Attorney General observed a system "designed for the regulator to find out nothing, investigate nothing and report nothing that could suggest that assisted dying has been anything other than an unblemished success". This Bill has not dealt with those concerns.

#### RELEVANT AMENDMENTS

| Amendment No. | Sponsor        | Category                                   | Short Explanation                                                                                                                                                 |
|---------------|----------------|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 103           | Mr Paul Kohler | Regulations                                | Requires all statutory instruments (except commencement orders) to use the draft affirmative procedure.                                                           |
| 104           | Mr Paul Kohler | Regulations                                | Allows the Secretary of State to use the made affirmative procedure in emergencies, linked to Amendment 103.                                                      |
| NC19          | Sarah Olney    | Monitoring,<br>consultation and<br>reviews | Requires the Commissioner to collect and publish statistics on assisted dying as specified in a schedule (NS2), with a power for the Secretary of State to amend. |
| NS2           | Sarah Olney    | Monitoring,<br>consultation and<br>reviews | Introduces a schedule requiring the Commissioner to collect detailed statistics on assisted dying, including demographics, health support, and process details.   |
| 88            | Sarah Olney    | Regulations                                | Makes regulations under NS2 (statistics collection) subject to the affirmative procedure, ensuring they are debated and voted on.                                 |

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# 4. T

### MPs risk failing in a duty of care as they are asked to turn a blind eye to unregulated drugs, complications and bad deaths

#### THE ISSUE

The Bill requires MPs to be relaxed about unregulated drugs and bad deaths (amendment 99).

A 'dignified death' is promised, but this is in no way secured by the Bill as drafted. As a bare minimum, it would be reasonable to expect strict regulation of lethal drugs, but the Bill bypasses the UK's established drug approval process. There is no minimum standard threshold, nor emphasis on avoiding unintended suffering or inflicting pain. Patients have no right to be informed of the risk of complications. There is no requirement to report when they do happen.

#### **WHY IT MATTERS**

- There is no requirement in the Bill for the drugs to meet any minimum standard, nor any emphasis on avoiding unintended suffering from taking these drugs.
  - The Bill remains silent on how to ensure the safe regulation of approved substances everything is to be resolved through another Henry VIII power. The Committee also rejected multiple amendments requiring patients to be informed of the risk of complications and adverse reactions. This places even more responsibility on MPs to ensure that they understand the effects of the drugs that they will sign off to end patients' lives, including the risk of prolonged death, which assisted dying practitioners have acknowledged increases for younger patients.
- The Government confirmed in its Impact Assessment that "the safety and efficacy of those substances used for assisted dying is currently difficult to assess.
  - This is partially because clinician reporting is often very low in those jurisdictions where assisted dying is legal, or clinicians are not generally present when the person is ingesting the prescribed substance(s). Despite this, some evidence about complications is available from Oregon and Western Australia, where complications such as difficulties ingesting or regurgitating, seizures, and intravenous line complications are reported".
- The Government has confirmed "there is evidence from international jurisdictions, such as Oregon and Canada, that certain medications can lead to prolonged deaths and unpleasant side effects which should be considered."
  - Despite this, the Bill does not require complications to be reported to a regulator, or any data to be collated.
- Complications are not exceptional occurrences.
  - Canadian studies indicate that around five per cent of oral-assisted deaths result in a prolonged and often distressing process. In some instances, medical intervention is required. Adverse effects such as burning sensations, vomiting, and failure to achieve the intended outcome in a timely manner are all too common. Evidence also suggests that younger adults particularly those aged between 18 and 24 are more likely to experience extended and unpredictable deaths.
- · A prolonged death is not unusual.
  - In Oregon in 2023, time to death ranged from 3 minutes to 137 hours, more than five and a half days, and the time to unconsciousness ranged from 1 minute to 488 minutes. These figures demonstrate a wide and unpredictable variation in outcomes.

- MPs owe a duty of care to those who will choose assisted dying, but this Bill does not contain a comprehensive framework for ensuring informed consent.
  - There is no requirement to disclose side effects. No standardised documentation. No obligation to detail the known risks. That would not be deemed acceptable in any other field of medical practice.
- Amendment 99 will help ensure the safety and efficacy of substances used in assisted dying, the collation and provision of scientific evidence, and parliamentary oversight to protect patients from potential risks, such as pain or adverse reactions.

#### RELEVANT AMENDMENT

| Amendment No. | Sponsor                | Category                        | Short Explanation                                                                                                      |
|---------------|------------------------|---------------------------------|------------------------------------------------------------------------------------------------------------------------|
| 99            | Dr Caroline<br>Johnson | Approved substances and devices | Requires a report on drug effects (time to death, complications, side effects) before Parliament approves regulations. |

#### If MPs pass the Bill, there is no 'off switch'

5.

#### THE ISSUE

The Bill automatically commences in four years, no matter what. The 'service' will have to start no matter what the circumstances at the time: no matter what problems there are with the NHS, or how underfunded palliative care is, or what circumstances the country finds itself in. It means that important decisions and safeguards may be rushed, resulting in a process that is at best unfinished and at worst unsafe. This approach is not taken in other legislation.

#### **WHY IT MATTERS**

- It reflects lack of trust in Government, but it also creates a cliff-edge for Parliament.
   if MPs are concerned and threaten to reject regulations and ask the Government to think again, they will be told that there is no time to fix the problem, and they will have to accept what is in front of them.
- The Bill focuses on only one end-of-life option and gives no guarantee terminally ill people will be given a meaningful choice when the service commences.
  - MPs will have no ability to intervene if the Government in 2029, or any future Government, fails to fund other end-of-life options.
- MPs will have given up all leverage, having failed to write on to the face of the bill the need for a choice of options.
- The only guarantee in statute will be the provision of an assisted dying service, making a mockery of it being a 'free choice'.

#### RELEVANT AMENDMENTS

| Amendment No. | Sponsor    | Category     | Short Explanation                                                                        |
|---------------|------------|--------------|------------------------------------------------------------------------------------------|
| 42            | Adam Jogee | Commencement | Replaces automatic commencement in England with a Secretary of State commencement order. |

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# What else is being debated on Day 2?

Group 2: Approved substances and devices, Advertising, Inquests, investigations and death certification, Guidance and codes of practice, Welsh language, Monitoring, consultation and reviews, The Assisted Dying Commissioner, Implementation, Regulations, Extent, Commencement

Below is a list of amendments in order of the Speaker's provisional grouping and selection

| Amendment No. | Sponsor                | Category                                   | Short Explanation                                                                                                                                                                                                                                     |
|---------------|------------------------|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NC13          | Kim<br>Leadbeater      | Approved substances and devices            | Mandates regulations on approved substances and devices for self-administration, including supply, storage, and enforcement provisions. Henry VIII power                                                                                              |
| NC14          | Kim<br>Leadbeater      | Prohibition on<br>Advertising              | Mandates regulations prohibiting advertisements to promote services relating to voluntary assisted dying, but the Secretary of State can make exceptions without limit, including "provision of certain information to users or providers of services |
| NC15          | Kim<br>Leadbeater      | Investigations and death certification     | Amends the Coroners and Justice Act 2009 to exclude assisted deaths from unnatural death investigations, defines assisted death on certificates, and lists offences as homicide offences for purposes of that Act.                                    |
| NC20          | Kim<br>Leadbeater      | Guidance and codes of practice             | Requires the Secretary of State to issue guidance on the Act's operation, with consultations and provisions for Welsh devolved matters.                                                                                                               |
| NC21          | Kim<br>Leadbeater      | Welsh language                             | Ensures Welsh language provisions for assisted dying services in Wales, including communications and documentation.                                                                                                                                   |
| NC4           | Andrew Pakes           | Monitoring,<br>consultation and<br>reviews | Assigns monitoring, investigation, and annual reporting on the Act's operation to the Chief Medical Officer, including data on protected characteristics.                                                                                             |
| NC5           | Valerie Vaz            | Monitoring,<br>consultation and<br>reviews | Requires a report within six months on the Act's implications for civil procedure rules and probate proceedings.                                                                                                                                      |
| NC6           | Valerie Vaz            | Monitoring,<br>consultation and<br>reviews | Mandates the Commissioner to appoint a consultation board to report annually on the Act's impact on communities, including Black, Asian, and Minority Ethnic groups.                                                                                  |
| NC19          | Sarah Olney            | Monitoring,<br>consultation and<br>reviews | Requires the Commissioner to collect and publish statistics on assisted dying as specified in a schedule (NS2), with a power for the Secretary of State to amend.                                                                                     |
| 13            | Patricia<br>Ferguson   | The Assisted Dying Commissioner            | Requires Health and Social Care Select Committee consent for appointing the Commissioner.                                                                                                                                                             |
| 96            | Dr Caroline<br>Johnson | Approved substances and devices            | Requires scientific consensus that approved drugs are effective and pain-free for assisted dying.                                                                                                                                                     |
| 97            | Dr Caroline<br>Johnson | Approved substances and devices            | Requires drugs to be licensed by the MHRA for assisted dying purposes.                                                                                                                                                                                |
| 98            | Dr Caroline<br>Johnson | Approved substances and devices            | Allows the Secretary of State to not approve drugs if none are deemed appropriate.                                                                                                                                                                    |

| Amendment<br>No. | Sponsor                      | Category                                   | Short Explanation                                                                                                                         |
|------------------|------------------------------|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------|
| 27               | Rachael<br>Maskell           | Approved substances and devices            | Requires lethal drugs to be licensed by the MHRA and recommended by NICE or the All Wales Medicines Strategy Group.                       |
| 99               | Dr Caroline<br>Johnson       | Approved substances and devices            | Requires a report on drug effects (time to death, complications, side effects) before Parliament approves regulations.                    |
| 69               | Kim<br>Leadbeater            | Approved substances and devices            | Replaces Clause 25 subsection (3) to reference NC13 (regulation of approved substances and devices).                                      |
| 53               | Kim<br>Leadbeater            | Approved substances and devices            | Removes Clause 34, consequential to NC13 (regulation of approved substances).                                                             |
| 54               | Kim<br>Leadbeater            | Regulations                                | Removes Clause 35, consequential to NC15.                                                                                                 |
| 19               | Dr Ben<br>Spencer            | Guidance and codes of practice             | Requires the code of practice to address how the Act relates to suicide prevention, human rights, mental health, and liberty safeguards.  |
| 70               | Kim<br>Leadbeater            | Guidance and codes of practice             | Adds a requirement for the code of practice to cover effective communication, including interpreter use.                                  |
| 71               | Kim<br>Leadbeater            | Guidance and codes of practice             | Removes Clause 36 subsection (3), consequential to Amendment 70.                                                                          |
| 20               | Dr Ben<br>Spencer            | Guidance and codes of practice             | Makes code provisions or non-compliance relevant in court proceedings, requiring courts to consider them.                                 |
| 89               | Kim<br>Leadbeater            | Guidance and codes of practice             | Removes Clause 37, consequential to NC20 (guidance issuance).                                                                             |
| 34               | Valerie Vaz                  | Guidance and codes of practice             | Adds consultation with Black, Asian, and Minority Ethnic communities and hospice workers to Clause 37 guidance requirements.              |
| 12               | Dame<br>Siobhain<br>McDonagh | Implementation                             | Prevents regulations from amending section 1 of the National Health Service Act 2006, requiring changes via an Act of Parliament.         |
| 15               | Blair<br>McDougall           | Monitoring,<br>consultation and<br>reviews | Requires private providers of assisted dying services to publish annual statements on service numbers, costs, and revenue.                |
| 92               | Kim<br>Leadbeater            | Welsh language                             | Removes redundant wording in Clause 39 to clarify Welsh Ministers' powers.                                                                |
| 93               | Kim<br>Leadbeater            | Welsh language                             | Clarifies that Clause 39 includes provisions for arranging voluntary assisted dying services.                                             |
| 29               | Andrew Pakes                 | Monitoring,<br>consultation and<br>reviews | Requires notifications to the Commissioner to be forwarded to the Chief Medical Officer, who may exercise Commissioner powers.            |
| 21               | Munira<br>Wilson             | Monitoring,<br>consultation and<br>reviews | Requires the first report on the Act to assess the state of palliative and end-of-life care services, including availability and quality. |
| 28               | Andrew Pakes                 | Monitoring,<br>consultation and<br>reviews | Removes Clause 45, linked to NC4 (Chief Medical Officer monitoring duties).                                                               |

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Amendment Sponsor

Leadbeater

Leadbeater

Commencement

Kim

95

Category

in Wales, with power only over whether to commence

Removes Clause 54 subsection (6), consequential to

specific clauses (VAD services in Wales)

Amendment 94.

Short Explanation

| Amendment No. | Sponsor                | Category                                   | Short Explanation                                                                                                                                               |
|---------------|------------------------|--------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------|
| NS2           | Sarah Olney            | Monitoring,<br>consultation and<br>reviews | Introduces a schedule requiring the Commissioner to collect detailed statistics on assisted dying, including demographics, health support, and process details. |
| 82            | John Glen              | The Assisted Dying Commissioner            | Requires panel members to be appointed by the Judicial Appointments Commission.                                                                                 |
| 83            | John Glen              | The Assisted Dying Commissioner            | Limits legal panel members to High Court judges or those under the mandatory retirement age.                                                                    |
| 41            | Liz Saville<br>Roberts | Welsh language                             | Requires panel members in Wales to have fluent Welsh proficiency if services are provided in Welsh.                                                             |
| 84            | John Glen              | The Assisted Dying Commissioner            | Ensures only High Court judges, not deputy judges, can chair panels.                                                                                            |
| 85            | John Glen              | The Assisted<br>Dying Commissioner         | Makes all High Court judges automatically eligible for panels and requires non-legal members to take the judicial oath.                                         |
| 86            | John Glen              | The Assisted Dying Commissioner            | Grants panels the same powers, privileges, and authority as the High Court.                                                                                     |

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