Written evidence submitted by My Death, My Decision (ADY0282)

About My Death, My Decision

My Death, My Decision is a grassroots, not-for-profit organisation that campaigns for a balanced and compassionate assisted dying law that will allow adults of sound mind who are either terminally ill or suffering intolerably from a physical, incurable condition the option of a peaceful, painless, and dignified death. MDMD is supported by its Clinical Advisory Group, which includes both doctors and other health professionals.

Summary:

- Current legislation is harmful, inconsistently applied and not fit for purpose.
- The inquiry should take into account the experiences of people affected by current legislation.
- England and Wales have an outstanding international reputation for palliative care. Assisted dying legislation would enhance their reputation for end of life care.
- Lessons from international jurisdictions show that assisted dying legislation can be safe and compassionate with effective safeguards.
- Assisted dying legislation promotes open discussions about all end-of-life options, thus strengthening doctor/patient relationships .
- Adults of sound mind who are incurably and unbearably suffering from a physical condition should have the option of an assisted death.
- After decades of laws elsewhere, there is no reliable international evidence of coercion.
- The citizens of England and Wales deserve choice, freedom and autonomy at the end of their lives.
- Many people living with disabilities support assisted dying.
- The overwhelming majority of the UK public has consistently supported assisted dying.
- The government should create a citizens' jury on this vital issue and commit to bringing forward legislation based on its recommendations.

Why legislation is needed

At the heart of the assisted dying debate lie people who are either terminally ill or with incurable conditions, who suffer. Many suffer unnecessarily because our current broken laws preclude help to die. Consequently, we have exported compassion abroad for those who are able to travel and can afford it, with considerable legal uncertainties for those who accompany others. Our laws make no distinction between encouraging suicide and assisting a persistent and settled wish to end life.[1] These two matters should be treated entirely separately.

This inquiry will give parliament the opportunity to listen to the voices of affected people. Their views, as well as the views of their friends, family and loved ones, are central to this debate.

[1] s2(1) Suicide Act 1961 as explained by Sir Stephen Sedley in https://www.lrb.co.uk/the-paper/v43/n20/stephen-sedley/a-decent-death

Sharon Johnston, a tetraplegic, had come to the clear and settled wish that she wanted to end her life. She died on the 5th February 2022 at an assisted dying centre in Switzerland. **Sue Lawford** was arrested and investigated for six months, for the compassionate act of accompanying her. The police's 5am arrest and Sue's 16-hour confinement in a jail cell did not meet the police's guidelines[2] nor did Sue meet the CPS guidelines[3] for prosecution.

Jean Eveleigh suffers from Ehlers-Danlos Syndrome and has come to the clear decision that she would like the option of an assisted death when her condition becomes unbearable. She says the current law discriminates against her as she is not physically capable of ending her own life without assistance.[4] Assisted dying legislation would allow choice and peace of mind to people like Jean.

Phil Newby was diagnosed with motor neurone disease when he was 43. In 2019 he launched a legal case in the High Court. Phil said:

"My end is most likely to be lingering and unpleasant, full of anguish and anxiety and physical suffering. I don't see why I should have to go through that just because I would need some help from someone in ending my own life because I can't do it myself."[5]

Many UK citizens are not alive today to share their experiences with the inquiry, but they took their plea for help to die to the courts, including:

Tony Nicklinson suffered from Locked-In syndrome, meaning he could only move part of his neck and eyes. He called his life a 'living nightmare'[6]. After contracting pneumonia, Tony refused food and treatment and died on his own terms on 22nd August 2012.[7]

Paul Lamb, paralysed following a car accident in 1990, had no function in any of his limbs, only part of his right hand. He needed 24-hour care and wanted to end his life on his terms. In a statement to the High Court in November 2020, Paul said: "I am in pain every single hour of every single day. I have lived with these conditions for a lot of years and have given it my best shot."[8]

These stories clearly show that the law is forcing individuals to live in a state of pain, suffering and indignity. It is morally indefensible to have forced these individuals to suffer.

---

2 Association of Chief Police Officers.'' Guidelines on Dealing with Cases of Encouraging or Assisting Suicide' Para 4.7.9, 2012 https://www.npcc.police.uk/2018%20FOI/Crime/124%2014%20Guidance.pdf

3 CPS, 'Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide' 2014

4 The Mirror, 'Mum, 42, with agonising illness begs MPs for right to die ahead of Commons debate' 3 Jul 2022 https://www.mirror.co.uk/news/uk-news/mum-42-agonising-illness-begs-27388827

5 Sky News, 'Assisted dying: It might be too late for me but I want it for those who come after me', 26 May 2021 https://news.sky.com/story/assisted-dying-it-might-be-too-late-for-me-but-i-want-it-for-those-who-come-after-me-12317078

6 R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent), 2012

7 BBC, 'Right-to-die man Tony Nicklinson dead after refusing food', 22 August 2012 https://www.bbc.co.uk/news/uk-england-19341722

8 BBC, 'Right to die: Paul Lamb takes up Tony Nicklinson fight' 18 April 2013 https://www.bbc.co.uk/news/uk-22191059

1. To what extent do people in England and Wales have access to good palliative care?

1.1. End-of-life care in the United Kingdom is among the best in the world.[9] The National Health Service Act 2006 now[10] includes a duty for each integrated care board to provide palliative care to those for whom it is responsible.

1.2. Palliative care can always be improved but it will never negate the need for assistance in dying. Palliative care cannot ease everyone's suffering. The Office of Health Economics found that even if they received the best possible palliative medicine, at least 6,000 per year would die without any effective pain relief in their final month.[11]

1.3. International evidence shows assisted dying is compatible with good and improving palliative care. Ahead of legislation, Palliative Care Australia conducted research into the relationship between palliative care and assisted dying. They concluded there is:

> 'no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. In jurisdictions where assisted dying is available the palliative care sector has further advanced.'[12]

1.4. The right to choose a medically assisted death is an extension of end-of-life care options, not a replacement for palliative medicine.

2. What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?

2.1. Assisted dying is legal in 27 jurisdictions, with more expected to introduce laws soon.[13] This pattern of increasing acceptance elsewhere reflects the underlying support of a large majority of the public.[14]

2.2. In Switzerland, assisted dying has been legal for over 80 years and ranks as one of the best healthcare systems in the world.[15] Belgium and the Netherlands have had assisted dying legislation for two decades and their healthcare systems consistently rank highly internationally.[16]

---

[9] JPSM, Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021, April 2021 https://www.jpsmjournal.com/article/S0885-3924%2821%2900673-4/fulltext

[10] As amended by the Health and Care Act 2022

[11] Zamora et al, 'Unrelieved Pain in Palliative Care in England' Office of Health Economics (2019). https://www.ohe.org/publications/unrelieved-pain-palliative-care-england

[12] Palliative Care Australia, 'Experience internationally of the legalisation of assisted dying on the palliative care sector', 2019 https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

[13] Scotland and Jersey are expected to introduce assisted dying legislation before 2025. France, Ireland and the Isle of Man are examining assisted dying and expected to introduce legislation.

[14] 65.9% supported change in New Zealand's referendum
The Guardian, 'New Zealand votes to legalise euthanasia in referendum' Oct 2020 https://www.theguardian.com/world/2020/oct/30/new-zealand-votes-to-legalise-euthanasia-but-against-legalising-cannabis-in-referendum
87% supported change in Spain. Metroscopia, 'Muerte digna', 2019 https://perma.cc/Q5LD-6YNX

[15] FREOPP, 'Switzerland: #1 in the 2021 World Index of Healthcare Innovation', 25 Jun 2021 https://freopp.org/switzerland-freopp-world-index-of-healthcare-innovation-60282abb7460

[16] World Population Review, Best Healthcare in the World 2023, Accessed 09 Jan 2023 https://worldpopulationreview.com/country-

2.3. Switzerland, Belgium, the Netherlands and Oregon, with longest-standing laws, are all compassionate jurisdictions that care for their elderly, disabled and vulnerable. Legislation has not led to moral decline or an uncaring attitude towards people living with disabilities or who are seen to be vulnerable which some parliamentarians are wary of.

2.4. Many countries have departed from a life expectancy criterion, most recently Spain, where the law allows an assisted death for those who experience suffering due to an incurable illness or condition. Incurability, not terminality, is the applicable criterion in their law.

2.5. Evidence from Canada is that over 99% of patients prefer the medication for assisted dying to be administered intravenously by a health professional rather than swallowing it themselves.[17]

3. What are the professional and ethical considerations involved in allowing physicians to assist someone to end their life?

3.1. Doctor/patient relationships are only likely to be strengthened by the passage of assisted dying legislation, which promotes open discussions about all end-of-life options.[18]

3.2. In every jurisdiction where assisted dying is legal, medical practitioners have the right of conscientious objection to the assisted dying process. The General Medical Council already has guidance on this, known as Good Medical Practice, which can encompass assisted dying, including the obligation to ensure access to alternative arrangements to meet the patient's wishes.[19] The establishment of some form of assisted dying "care navigator" services, as recommended for Scotland and Jersey, could help in this respect.

3.3. Participating medical practitioners should be fully registered with the GMC but need not be specialists. Referral to an appropriately trained specialist will be required when there is doubt over any issue, including decision-making capacity.

3.4. Participating medical practitioners should be required to undertake specific training and ongoing professional development which will need to be developed by the appropriate professional bodies during the implementation period. This should include the assessment of capacity and the detection of possible coercion. The training developed in Victoria, Queensland and Western Australia provides a helpful model on which to build.[20]

---

rankings/best-healthcare-in-the-world

[17] Health Canada, 'Third annual report on Medical Assistance in Dying in Canada 2021', July 2022 https://www.canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html

[18] Assisted Dying for Terminally Ill Adults (Scotland), 'Medical Advisory Group Report', Nov 2022 https://www.assisteddying.scot/wp-content/uploads/2022/12/Medical-Advisory-Group-Report.pdf

[19] General Medical Council, 'Good Medical Practice', Para 52 "You must explain to patients if you have a conscientious objection to a particular procedure. You must tell them about their right to see another doctor and make sure they have enough information to exercise that right… If it is not practical for a patient to arrange to see another doctor, you must make sure that arrangements are made for another suitably qualified colleague to take over your role." https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf

[20] An example of training developed for Victoria: J Palliat Care, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration', 2021 https://pubmed.ncbi.nlm.nih.gov/32752924/; and see *A cross-sectional study of the first two years of mandatory training for doctors participating in voluntary assisted dying* Willmott, Feeney et al, Cambridge University Press 2022

3.5. A practitioner peer support and self-care network should be established prior to the implementation of assisted dying, such as those in effect in Australia and Canada. Other healthcare practitioners, particularly nurse practitioners, have important potential roles in assisted dying which needs to be recognised in legislation.

3.6. Legislation should incorporate an implementation phase of up to 18 months to enable the necessary professional guidance and training requirements to be developed and support networks and other practical arrangements to be established. Once Parliament has agreed on the basic parameters, a professional working group should be established to address these issues in more detail.

3.7. A survey by the British Medical Association found that 36% of doctors would be prepared to actively participate in the assisted dying process.[21] This would mean that a functional service could be established.

4. What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying/assisted suicide services?

4.1. Any adult of sound mind, who is either terminally ill or incurably, unbearably suffering from a physical condition should have the option of an assisted death.

4.2. An applicant must be:

- an **adult** able to make an informed, independent decision;
- of **sound mind**;
- terminally ill or suffering from a physical condition that is **incurable** by any acceptable means and causes **unbearable** suffering. This would mean a condition that cannot be alleviated to the satisfaction of the individual with any available treatment or prospective cure.

4.3. What constitutes 'unbearable suffering' can only be defined by individual sufferers. Their definitions should be accepted at face value and be more important in guiding management than the nature and prognosis of their illness alone. Individuals should not be forced to tolerate intractable suffering simply because other patients with similar conditions are able or choose to do so.

4.4. It must be the incurable condition that is the primary cause of the unbearable suffering. In Spain, if there are concerns about the motivations of an eligible applicant, they are referred to a specialist panel before approval.[22]

---

[21] BMA, 'BMA Survey on Physician-Assisted Dying'. 2020 https://www.bma.org.uk/media/3367/bma-physician-assisted-dying-survey-report-oct-2020.pdf

[22] Law 3/2021, March 2021.

Legislation shouldn't be limited to terminal illness

4.5. Tony Nicklinson and Paul Lamb were not terminally ill. Tony was undoubtedly suffering unbearably from an incurable condition and Paul sought a law to give him the choice because he knew he was approaching that level of suffering.

4.6. A six-month terminal diagnosis criterion for legislation could lead to situations where people with neuro-degenerative conditions could be blocked from having an assisted death as, by the time a doctor deems they have six months left to live, they may have lost mental capacity and endured many years of avoidable suffering.

4.7. The US state of Oregon's six months criterion came about because of the long-standing hospice care capped contribution under their Medicare system[23]. This healthcare threshold from another jurisdiction is not a relevant reference point in deciding on our own law.

5. What protections could be put in place to protect people from coercion and how effective would these be?

5.1. The requirement for two independent practitioners to assess each patient's eligibility for an assisted death, including that they are mentally competent and acting voluntarily and without coercion, is the cornerstone of successful assisted dying legislation around the world.

5.2. The current blanket ban on assisted dying means there are no safeguards at all for people who are incurably, intolerably suffering and then take their own lives. A study from the Office of National Statistics shows that people are twice as likely to die by suicide after a diagnosis of a serious illness. This suicide rate is increased tenfold for people with neurological diagnoses like Huntington's disease.[24]

5.3. Conversations with doctors, social care workers and family members under a regulated assisted dying regime would achieve better outcomes. This could have been the case for high-profile individuals taking their own lives, like former F1 boss Max Mosley, who killed himself after learning of terminal cancer[25] and Graham Mansfield, who felt driven to kill his terminally ill wife before trying to kill himself in an alleged suicide pact.[26]

5.4. Legislation would introduce regulation and reduce the need for people to take the end of their lives into their own hands. It would empower political and legal institutions to regulate assisted deaths. Regulations in Victoria, Australia, make it a criminal offence to coerce

---

[23] Federal Register I Vol. 48, No. 243 p56008ff https://archives.federalregister.gov/issue_slice/1983/12/16/55981-56024.pdf

[24] ONS, 'Suicides among people diagnosed with severe health conditions', Apr 2022 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithsevere healthconditionsengland/2017to2020

[25] BBC News, 'Former F1 boss Max Mosley shot himself after terminal cancer diagnosis', 29 Mar 2022 https://www.bbc.co.uk/news/uk-england-london-60919994

[26] BBC News, 'Graham Mansfield: Failed suicide pact killer calls for law change', 21 Jul 2022 https://www.bbc.co.uk/news/uk-england-manchester-62257457

someone to request an assisted death or to seek to dissuade someone from making such a request.[27]

5.5. There are other situations in healthcare, notably the refusal of life-saving treatment, where coercion is just as hypothetically possible, and the consequences equally profound, yet we allow these decisions, to respect patient autonomy. An assisted dying law would provide a regulated process.

5.6. Safeguards for people who travel to Switzerland for an assisted death are dictated by the Swiss Penal Code[28]. However, these are completely out of the control of the UK government.

5.7. The fear of coercion often mentioned is not supported by evidence from other jurisdictions. By contrast, the current prohibition is itself a form of coercion - it coerces individuals to die in agony or risk a family member's imprisonment if they flee abroad.

5.8. Participating practitioners would be required to undertake specific training and Continuing Professional Development in the assessment of capacity and detection of possible coercion. This could be developed by professional bodies as part of the implementation of legislation, with much international experience to build on.

5.9. The suggestion in recent Bills of a High Court Order before any assisted death arose from a misconception following the *Nicklinson* case and is not a necessary or practical suggestion, as Professor Penney Lewis has explained.[29] If a prospective approval is required, a system analogous to Spain's Guarantee and Evaluation Committee would be more workable and localised, but should not be needed for most cases.[30]

Most people living with disabilities support assisted dying

5.10. 88% of people living with a disability support a change in the law.[31] Out of 140 UK disability rights organisations, 96% do not oppose reform.[32] Disability Rights UK calls assisted dying "a complex issue on which people hold different, passionately held views." [33]

5.11. A University of Glasgow study in 2021 assessed the hypothesis "that those with disabilities would be negatively affected by an assisted dying law" and concluded that there is no evidence of vulnerable people being subject to abuse in any jurisdiction.[34]

---

[27] Voluntary Assisted Dying Act 2017 No. 61 of 2017 carries a maximum of 5 years imprisonment https://content.legislation.vic.gov.au/sites/default/files/2021-06/17-61aa005%20authorised.pdf "(1) A person must not, by dishonesty or undue influence, induce another person to make a request for access to voluntary assisted dying. "

[28] Swiss Penal Code, Art. 115 StGB

[29] Penney Lewis, International Perspectives on End-of-Life Law Reform, Dec 2021

[30] Bill No. 46-7 on the Organic Law to Regulate Euthanasia https://wfrtds.org/wp-content/uploads/2021/03/Spain-law-EN.pdf

[31] Populus. 'Dignity in Dying Poll'. 2015 https://yonderconsulting.com/poll-archive/dignity-in-dying.pdf

[32] G Box et al, 'Views of disability rights organisations on assisted dying legislation in England, Wales and Scotland: an analysis of position statements' J Med Ethics, 5 Jan 2020

[33] Disability Rights UK, Our position on the proposed Assisted Dying Bill', Sep 2015 https://www.disabilityrightsuk.org/news/2015/september/our-position-proposed-assisted-dying-bill

5.12. Not allowing people with disabilities the right to make decisions about their own end of life removes their autonomy and is discriminatory. Sharon Johnston was denied the right to end her life in Wales, as she had wished; and Jean Eveleigh is being forced to endure pain and distress without the comfort of knowing that the decision about her death will be in her control.

6. What information, advice and guidance would people need in order to be able to make an informed decision about whether to access assisted dying/assisted suicide services?

6.1. There are a number of existing, lawful choices a person can make in relation to their care, including: refusal of life-sustaining treatment, voluntary stopping eating and drinking, deep sedation and DNACPR requests. If new legislation were passed, we would recommend a public education campaign to ensure awareness of end-of-life options and ensure healthcare literacy.

6.2. For an applicant to make an informed decision, assisted dying needs to be seen as one part of a spectrum of end-of-life choices. It must not be treated as something set apart from, or in opposition to, palliative care, for example. A law should not 'gag' health professionals mentioning assisted dying in discussions with patients.

6.3. The assessing health practitioners must be required to establish the reasons and motivations a person has for requesting an assisted death and confirm that they have been referred to appropriate services in respect of counselling, mental health and disability and community support and palliative care, to enable the applicant to make their decision. Provision can be made for referral to a psychiatrist or other specialist if the applicant requests it or there are concerns.

7. What capabilities would a person need to be able to consent to assisted dying /assisted suicide?

7.1. An individual must be mentally capable, as defined by the Mental Capacity Act of 2005. Mental capacity is vital and if an individual were to lose mental capacity throughout any of the processes, they would not be eligible. An applicant with early onset dementia, who still retains mental capacity, would be eligible, but not an applicant with advanced dementia who has lost capacity. Any assessment period must take this into account. People with current, purely psychiatric conditions would not be eligible. Unless there is clear evidence of past or current mental illnesses or any doubt about current mental capacity, a detailed psychiatric assessment should not be necessary.

---

[34] University of Glasgow, 'Disability and Assisted Dying Laws Policy Briefing', 2021 https://policyscotland.gla.ac.uk/wp-content/uploads/2021/09/PolicyBriefingDisabilityAndAssistedDyingLaws.pdf

8. What should the Government's role be in relation to the debate?

8.1. After numerous cases brought by campaigners such as Nicklinson, Lamb and Newby, the courts have made it clear that Parliament must decide on assisted dying.[35] Changes in societal attitude should be expressed through Parliament – but Parliament has so far not wanted to reflect this, despite overwhelming public support.

8.2. Numerous polls commissioned by multiple reputable sources, including Populus, YouGov, NatCen and others, have shown that a clear majority of the public in England and Wales supports assisted dying.[36]

8.3. The government should recognise the importance of personal autonomy. Adults in England and Wales enjoy many freedoms and the right to choice about the end of life should be one of them.

8.4. Jersey's citizens' jury created an effective path to legislation while taking into account public attitudes. The jury, made up of everyday citizens, heard from a wide range of professionals and examined a breadth of evidence. The States Parliament then agreed to implement the parameters for the law as recommended by the jury. A similar citizens' convention has been launched in France.

8.5. We urge the Government to set up a jury to determine the parameters of a law fit for England and Wales, to commit to consulting on a draft Bill that reflects the results of the jury and then allow time for legislation to come to a meaningful vote.

---

[35] e.g. R (Newby) v Secretary of State For Justice [2019] EWHC 3118

[36] Ibid Populus
YouGov, 'Doctor-assisted suicide', Jun 2021 https://docs.cdn.yougov.com/9zj99qnobf/YouGov%20-%20Doctor-assisted%20suicide.pdf
NatCen, 'British Social Attitudes: the 34th Report', 2017 https://www.bsa.natcen.ac.uk/media/39196/bsa34_full-report_fin.pdf