

Written evidence submitted by Humanists UK (ADY0298)

At Humanists UK, we want a tolerant world where rational thinking and kindness prevail. We work to support lasting change for a better society, championing ideas for the one life we have. Our work helps people be happier and more fulfilled, and by bringing non-religious people together we help them develop their own views and an understanding of the world around them. Founded in 1896, we are trusted to promote humanism by 100,000 members and supporters and 115 members of the All-Party Parliamentary Humanist Group.

We support assisted dying for those of sound mind who are terminally ill and incurably suffering, provided there are robust safeguards. We gave oral evidence to Jersey's citizens' jury in 2021 and to the UK Parliament's last assisted dying inquiry in 2005. We intervened in support of the claimants in *Nicklinson* and all subsequent assisted dying cases in England and Wales, each time being the only organisation to have done so. Our Chief Executive was a member of the Department of Health and Social Care's Moral and Ethical Advisory Group during the pandemic, and our Wales Coordinator was a member of the Welsh Government's Moral and Ethical Advisory Group. We are directly involved with hospitals and hospices through the provision of non-religious pastoral carers, a dozen of whom are now employed by NHS Trusts. Around 40% of Trusts have a staff member or volunteer, and two employ a humanist as their Head of Chaplaincy and Pastoral Care.

SUMMARY

- Current legislation is not fit for purpose as many UK citizens of sound mind continue to suffer unnecessarily intolerable pain when they have a clearly articulated and settled wish for an assisted death.
- Public support for assisted dying is overwhelming. The public supports individual choice over those religious beliefs hostile to any form of assisted death.
- Decades of international evidence show that assisted dying legislation can be safe. Drawing on this, we can make sure the right safeguards are put in place for people in the UK to access this service in their own country.

THE ISSUE WITH CURRENT LEGISLATION

The current ban on assisted dying is causing people to die painful, drawn-out and undignified deaths. We believe that any changes to legislation must be led by the voices and experiences of dying people and their loved ones.

Tony Nicklinson suffered from locked-in syndrome and was paralysed from the neck down and unable to speak. He could only communicate via blinking, and described his life as a 'living nightmare'. Tony took his right-to-die case to the High Court, and during proceedings said:

'I can't tell you how significant it would be in my life, or how much peace of mind I would have, just knowing that I can determine my own life instead of the state telling me what to do – staying alive regardless of my wishes or how much suffering I have to tolerate until I die of natural causes.'¹

Tony Nicklinson died after contracting pneumonia and refusing food and treatment, only a week after his case was rejected by the High Court.

¹ Witness statement of Tony Nicklinson in *R (on the application of Nicklinson and another) (Appellants) v Ministry of Justice (Respondent)*

Paul Lamb subsequently stepped in to continue Tony's case after his death, alongside Tony's widow Jane. Paul said:

'I am paralysed from the neck down and live in a state of constant pain. In the future my suffering will inevitably become too much to bear. When that happens, I want to be able to control and choose the circumstances of my death. As the law stands, my only option would be to die through the inhumane process of dehydration and starvation. This situation cannot be allowed to continue.'²

Paul died in 2021.

The current legislation on assisted dying does not only affect the dying individual, but their **loved ones, friends and family**. Lauren Nicklinson, when talking about her father's experience, said:

'It was painful for him but it was painful for us to watch.'³

Omid T suffered from multiple system atrophy (MSA) and died in 2018 while awaiting judgment from the High Court on his legal case that sought to change the law on assisted dying. In a documentary on his campaigning, he said:

'I have good days and bad days, but these days are the worst days of my life. I don't want to see my face in the mirror.'⁴

Humanists UK intervened in support of Jane Nicklinson and Paul Lamb's landmark legal case. We also supported our members Noel Conway, Omid T, Phil Newby, and Paul's subsequent attempts to change the law. However, pain and suffering are not limited to people who have taken their cases to the courts.

Many people who face situations like theirs take their own lives before the decision is taken away from them. A study by the Office of National Statistics found that a diagnosis of serious health conditions more than doubles the suicide rate. One year after a diagnosis of degenerative neurological conditions like Huntingtons' Disease, the suicide rate for patients was 107.7 deaths per 100,000 people.⁵

Assisted deaths are already happening in the UK, but they are in the form of mercy killings, suicide pacts and DIY suicides. These events are often highly traumatic. David Ridley, Wiltshire and Swindon coroner, said that suicide pacts are increasingly common in the absence of assisted dying legislation.⁶

These experiences are highly contrasted with the experiences of people living in jurisdictions where assisted dying is legal as well as people who travel to Switzerland for an assisted death.

Dawn Voice-Cooper died at Lifecircle, an assisted dying centre in Basel, in 2021. She died listening to her favourite song, Nick Drake's *Day is Done*, with her friends holding her hands. Before she died Dawn said:

² Humanists UK. 'Paul Lamb to bring new legal case for the right to die'. 2019 <https://humanists.uk/2019/05/07/paul-lamb-to-bring-new-legal-case-for-the-right-to-die/>

³ Sky News, 'Lauren Nicklinson Interview'. May 2021 <https://www.youtube.com/watch?v=sKdOM2vQWQs>

⁴ My Death, My Decision. 'Why Omid T wanted to end his life'. 25 May 2017 <https://www.youtube.com/watch?v=uRuT2tylY0g>

⁵ ONS. 'Suicides among people diagnosed with severe health conditions, England: 2017 to 2020'. 20 Apr 2022 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020>

⁶ BBC News. "'Suicide pacts' increasingly common in the absence of assisted dying' 13 May 2022 <https://www.bbc.co.uk/news/uk-england-wiltshire-61434964>

‘I would just like people to know it is a dignified choice. It gives people dignity. It gives people peace that they can do it and they have this offer. It gives you autonomy. And it enables people whose quality of life is low and can’t get better to take control of themselves and their lives.’⁷

Research by the Assisted Dying Coalition found that one Briton a week travels to Switzerland for an assisted death.⁸ Since 2002, 498 UK citizens have travelled to Dignitas, one of the three assisted dying centres in Switzerland.⁹

Sharon Johnston, a tetraplegic woman from Cardigan died at Dignitas in 2019. Her last words were:

‘This is a lovely feeling’.

Despite Sharon appearing in the BBC documentary *When Would You Want to Die?* where she openly discussed her wish for an assisted death, Sue Lawford was arrested for accompanying her abroad. Sue was arrested at 5 am, her home searched, her electronic devices seized and was under investigation for over six months.¹⁰

Many friends and loved ones face the cruel and impossible decision: stay and watch their loved one suffer, or help them travel abroad and risk prosecution and up to 14 years in prison. While prosecutions remain low,¹¹ the pressure it puts on people who are acting out of compassion is unnecessary and cruel. It also means that people often have to travel to Switzerland long before they would otherwise choose to die, as they fear losing the ability to if they wait.

4. WHAT, IF ANY, ARE THE PHYSICAL AND MENTAL HEALTH CRITERIA WHICH WOULD MAKE AN INDIVIDUAL ELIGIBLE TO ACCESS ASSISTED DYING/ASSISTED SUICIDE SERVICES?

We believe that **adults** of sound mind who are incurably, intolerably suffering from a physical condition and have a clear and settled wish to die should be eligible for an assisted death.

Sound mind is an already defined term that exists under the Mental Capacity Act.¹² If an assessing professional had any doubt about the mental capacity of the individual, the process would stop until a psychiatric evaluation had been carried out. People with mental illnesses would **not** be eligible under this criteria. If a person were to lose their mental capacity the process should not be able to continue.

Incurably suffering is defined as an illness where there is no cure in the foreseeable future. The healthcare professional who carries out the assessment must be satisfied that all options and changes to circumstances that could alleviate the suffering have been exhausted. It must be the disease itself that causes the individual’s suffering and not their social situation.

Intolerably suffering means suffering from a severe illness or ailment that the individual themselves evaluates to be intolerable. Healthcare practitioners regularly make evaluations of patients’ pain in many circumstances.

⁷ *The Mirror*. ‘Final moments of mum who drank champagne before ending life at assisted dying clinic’. 2 Nov 2021 <https://www.mirror.co.uk/news/uk-news/final-moments-mum-who-drank-25352801>

⁸ Assisted Dying Coalition. ‘Number of UK citizens going to Switzerland to seek an assisted death’. 1 Feb 2019

⁹ DIGNITAS. ‘Members of DIGNITAS by country of residency’. 31 December 2021 http://www.dignitas.ch/index.php?option=com_content&view=article&id=32&Itemid=72&lang=en

¹⁰ Humanists UK. ‘Humanist subjected to six-month investigation over assisted death’. 15 Nov 2022 <https://humanists.uk/2022/11/15/humanist-subjected-to-six-month-investigation-over-assisted-death/>

¹¹ From 1 April 2009 up to 31 March 2022, there have been 174 cases referred to the CPS by the police that have been recorded as assisted suicide. Of these 174 cases, 115 were not proceeded with by the CPS and 33 cases were withdrawn by the police. CPS. Assisted Suicide. 2022 <https://www.cps.gov.uk/publication/assisted-suicide>

¹² Mental Capacity Act 2005. <https://www.legislation.gov.uk/ukpga/2005/9/contents>

Why include the incurably, intolerably suffering?

The voices and experiences of our members and the people we have supported have shaped our opinion of the law. No one should be forced to live in pain, misery, or indignity.

Legislation that is made solely for the terminally ill can be discriminatory. Someone who is incurably, intolerably suffering will be likely to be in pain for a longer period of time than someone who has six months to live. They may lose mental capacity before a doctor would diagnose them as having fewer than six months to live.

In 2021 the British Medical Association survey found that a majority of doctors (59%) would prefer eligibility criteria inclusive of those with a 'physical condition causing intolerable suffering which cannot be relieved'.¹³

5. WHAT PROTECTIONS COULD BE PUT IN PLACE TO PROTECT PEOPLE FROM COERCION AND HOW EFFECTIVE WOULD THESE BE?

A clearly defined process with safeguards will prevent a law enabling assisted dying from being misused. Many jurisdictions have special services to help patients navigate the assisted dying process. Examples of processes used successfully in other countries include the following:

Written consent must be made by the individual and signed by an independent witness who will not gain anything from the individual's death.

Two independent healthcare practitioners must sign off that the individual meets the criteria on suffering, has the mental capacity to consent to end their life, and that all other options have been exhausted.

A waiting period between the first and the final assessment of two weeks. This can be waived in extreme cases of pain and suffering, or if death is imminent. We know from international evidence that the rates at which individuals change their minds are incredibly low.¹⁴

Regulation by a special body created to provide oversight of the service. This body should be able to provide information and guidance to applicants as well.

An implementation period after the passage of assisted dying legislation in order for doctors to be trained, safeguards to be put in place, and services to be set up.

A matter of healthcare where courts, lawyers, and tribunals should not be required for every single case, as they add little expertise to the process. Medical professionals are trusted to help patients make decisions about very serious treatments, such as aggressive cancer treatments and major surgeries, without judicial input. Only extreme or controversial cases should be subjected to external reviews.

Protect autonomy for assisted dying decisions. Guidance and legislation can ensure that informed decisions are made without coercion. Family members should not be able to delay, disrupt, or be a barrier to an individual's choices.

8. WHAT SHOULD THE GOVERNMENT'S ROLE BE IN RELATION TO THE DEBATE?

The Government should listen to those who want an assisted death, their loved ones, and the public at large. It is evident that a strong majority of UK adults support assisted dying. Data from the British Social Attitudes surveys shows that support for assisted dying has been stable for over 30 years.¹⁵

¹³ Humanists UK. 'BMA drops opposition to assisted dying'. 2021. <https://humanists.uk/2021/09/14/bma-drops-opposition-to-assisted-dying/>

¹⁴ In 2021 in Canada less than 2% of people who were approved decided not to go ahead in the end.

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>

The data is robust, bountiful, reliable, and from reputable sources, such as Populus¹⁶ and YouGov.¹⁷ While some polls have been commissioned by campaigning groups, many are independent. Opinion-gathering exercises have been carried out by devolved governments¹⁸ and crown dependencies,¹⁹ all of which have shown extensive support.

The creation of a Citizens' Jury would provide a robust and transparent way to assess public thinking on this issue. Jersey's Assisted Dying Citizens' Jury looked at the issue in considerable depth, and the process has been widely respected.²⁰ France is currently hosting a Citizens' Assembly on this same issue.²¹

Freedom of religion or belief

England and Wales are diverse countries where no single religion has a majority, and legislation should reflect that.²² Individual determination is the only way to ensure freedom of religion or belief (FoRB). Humanists do not subscribe to the same beliefs about the afterlife and the inherent sanctity of life as many religions do. Rather, humanists believe that meaning in life is something that we all create for ourselves, rather than something that is externally defined for us. That means maximising individuals' freedom of choice as to how to live their lives, provided they do no harm to others; and doing everything we can to maintain people's dignity. For some people, their pain and suffering mean that the most meaningful thing for them is to bring their lives to an end. For us, our FoRB means our having freedom of choice and this is being denied by the lack of assisted dying legislation.

FoRB is a human right that has been guaranteed under international law within the International Covenant on Civil and Political Rights (ICCPR) since 1966. The UK Government is committed to defending FoRB for all and promoting respect between different religious and non-religious communities.²³

Autonomy and freedom of choice

People deserve the right to make decisions about their own lives. It is already understood that we have the right to make decisions about our own bodies, our own healthcare, and to some extent our own deaths. You have the right to refuse treatment, nutrition and hydration and there are no additional safeguards for making these decisions.²⁴

A choice for people with disabilities

Current legislation discriminates against people with severe disabilities. Paul Bowen KC, the lawyer for Tony Nicklinson, said in the case: 'The claimant, who has made a voluntary, clear, settled, and informed wish to end his own life with dignity, is too disabled to do so.'²⁵ While suicide and attempting suicide are not illegal in the UK, some people with severe disabilities are physically unable to die by suicide without assistance.

¹⁵ National Centre for Social Research. *British Social Attitudes: the 34th Report*. 2017 https://www.bsa.natcen.ac.uk/media/39196/bsa34_full-report_fin.pdf

¹⁶ Populus. 'Dignity in Dying Survey'. March 2019 https://www.bsa.natcen.ac.uk/media/39196/bsa34_full-report_fin.pdf

¹⁷ YouGov. 'Doctor-assisted suicide'. June 2021 <https://docs.cdn.yougov.com/9zj99qnof/YouGov%20-%20Doctor-assisted%20suicide.pdf>

¹⁸ Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill. *Summary of Consultation Responses*. Sep 2021 <https://www.assisteddying.scot/wp-content/uploads/2022/09/Assisted-dying-consultation-summary-FINAL-DRAFT.pdf>

¹⁹ Jersey States Assembly, *Assisted dying consultation report*, 17 Oct 2022

²⁰ Ibid.

²¹ Humanists UK, 'France announces launch of assisted dying citizens assembly', 9 Sep 2022 <https://humanists.uk/2022/09/09/france-announces-launch-of-assisted-dying-citizens-assembly>

²² The results of the 2021 Census in England and Wales showed 37% of the population ticked 'No religion', and 46% ticked 'Christian'. In Wales, more people ticked 'No religion' than 'Christian'.

ONS. 'Ethnic group, national identity, language, and religion: Census 2021 in England and Wales'. 29 Nov 2022 <https://www.ons.gov.uk/releases/ethnicgroupnationalidentitylanguageandreligioncensus2021inenglandandwales>

²³ FCDO. 'Freedom of religion or belief: understanding this human right'. 12 May 2022 <https://www.gov.uk/guidance/freedom-of-religion-or-belief-understanding-this-human-right>

²⁴ BMA, *Consent and Refusal by Adults with Decision Making Capacity*, Sep 2019 <https://www.bma.org.uk/media/2481/bma-consent-toolkit-september-2019.pdf>

²⁵ Nicklinson

People with disabilities support assisted dying. 88% of people living with a disability support a change in the law.²⁶ And an independent study of 140 UK disability rights organisations found that 96% did not oppose reform.²⁷

Research by Policy Scotland found that ten studies have explored international evidence on the impact of assisted dying on people with disabilities. None have found evidence of harm, disproportionate impact, or an incremental reduction in protection.²⁸

1. TO WHAT EXTENT DO PEOPLE IN ENGLAND AND WALES HAVE ACCESS TO GOOD PALLIATIVE CARE?

International evidence shows assisted dying does not impact access to palliative care. A report by Palliative Care Australia concluded that there is 'no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced'.²⁹

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.³⁰ There is no evidence to suggest that a lack of palliative care is related to levels of assisted death.

The UK has consistently ranked as having the best palliative care in the world.³¹ In the 2021 ranking of 81 countries by the *Journal of Pain and Symptom Management*, many jurisdictions with assisted dying legislation ranked highly. Australia was 4th place, New Zealand 12th, and Switzerland 13th.³²

2. WHAT CAN BE LEARNT FROM THE EVIDENCE IN COUNTRIES WHERE ASSISTED DYING/ASSISTED SUICIDE IS LEGAL?

There is considerable evidence from abroad showing that assisted dying can be implemented safely and humanely. Internationally, 370 million people have access to some form of assisted dying legislation.

Assisted dying for the incurably, intolerably suffering is now the most prominent and viable international model. **Austria, Belgium, Luxembourg, The Netherlands, Colombia, Canada, Switzerland, and Spain have legalised assisted dying for both the terminally ill and incurably suffering.** Jersey is likely to follow suit.³³ Legislation for just the terminally ill is found in 11 US jurisdictions, New Zealand, and all Australian states.

Switzerland has allowed assisted dying in some form for 80 years.³⁴ Oregon legalised assisted dying in 1997 for the terminally ill. The Netherlands legislated in 2001 and Belgium in 2002. In all of these jurisdictions, the concerns some parliamentarians in the UK have expressed about the law have not materialised. There is no

²⁶ Populus. 'Dignity in Dying Poll'. 2015.

²⁷ 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* 2021

²⁸ University of Glasgow. 'Disability and Assisted Dying Laws Policy Briefing'. 2021 <https://policyscotland.gla.ac.uk/wp-content/uploads/2021/09/PolicyBriefingDisabilityAndAssistedDyingLaws.pdf>

²⁹ 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

³⁰ 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>

³¹ *The Economist*. 'The 2015 Quality of Death Index'. 2015 https://www.coordinatemycare.co.uk/wp-content/uploads/2019/04/quality-of-death-index-country-profiles_oct-7-2015.pdf

³² *JPSM*, 'Cross Country Comparison of Expert Assessments of the Quality of Death and Dying', 2021 [https://www.jpsmjournal.com/article/S0885-3924\(21\)00673-4/fulltext](https://www.jpsmjournal.com/article/S0885-3924(21)00673-4/fulltext)

³³ Jersey States Assembly. 'Assisted dying consultation report'. 17 Oct 2022 <https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf>

³⁴ Since 1937, Switzerland has allowed assisted suicide as long as the motives are not selfish. Swiss Penal Code, 'Art. 115'. 1937.

evidence of coercion, palliative care remains strong, doctors actively partake in the system, and society has not been negatively impacted.

3. WHAT ARE THE PROFESSIONAL AND ETHICAL CONSIDERATIONS INVOLVED IN ALLOWING PHYSICIANS TO ASSIST SOMEONE TO END THEIR LIFE?

Internationally, doctors, healthcare professionals, and healthcare systems work with safe and legitimate assisted dying legislation. We are not aware of any legislation where doctors cannot conscientiously object to the assisted dying process. The General Medical Council (GMC) already has guidance on 'Personal beliefs and medical practice' for doctors who wish to conscientiously object.³⁵

There has been a significant shift in professional medical opinion in the UK in the past decade. The British Medical Association (BMA) moved to a neutral position on assisted dying in 2021.³⁶ This reflects the position of similar medical bodies.³⁷

We believe that the process should be free at the point of access and a part of the NHS. 36% of doctors surveyed by the BMA said they would be prepared to actively participate,³⁸ sufficient to create a reliable, and evenly distributed service.

As with all medical procedures, there should be consequences for doctors who are found to have not followed guidance. This should include being struck off the medical register and in serious cases criminal charges.

³⁵ GMC. 'Personal beliefs and medical practice'. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice>

³⁶ Humanists UK. 'BMA drops opposition to assisted dying'. 2021 <https://humanists.uk/2021/09/14/bma-drops-opposition-to-assisted-dying/>

³⁷ The Royal College of Physicians, the Royal Society of Medicine, the Royal College of Nursing, the Royal College of Psychiatrists, and several others have moved to a neutral position on assisted dying.

Humanists UK. 'Royal College of Physicians moves from hostile to neutral position on assisted dying'. 2019. <https://humanists.uk/2019/03/21/royal-college-of-physicians-moves-from-hostile-to-neutral-position-on-assisted-dying/>

³⁸ BMA. *BMA Survey on Physician-Assisted Dying*. 2020 <https://www.bma.org.uk/media/3367/bma-physician-assisted-dying-survey-report-oct-2020.pdf>