Written evidence submitted by The Equality and Human Rights Commission (ADY0317)

1. The Equality and Human Rights Commission is a statutory body established under the Equality Act 2006. It operates independently to eliminate unlawful discrimination, and protect and promote equality and human rights. The Commission has powers to advise the government on the equality and human rights implications of laws and proposed laws, and to publish information or provide advice, including to Parliament, on any matter related to equality and human rights.
2. We welcome the opportunity to respond to this call for views. We recognise that this is a sensitive matter of conscience, and the issue evokes strong emotions from those with deeply-held religious, personal, or philosophical beliefs.
3. This response does not take a position in favour of or opposed to assisted dying or assisted suicide. Instead, we set out the equality and human rights considerations that need to be taken into account if Parliament were to consider legislation on this matter. These include the UK's domestic and international legal obligations as well as broader equality and human rights considerations.

Consultation questions

Question 1: To what extent do people in England and Wales have access to good palliative care? How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying/assisted suicide?

1. High-quality, rights-based palliative care, available to all who need it, should be a prerequisite for the consideration of legislation around assisted dying.[1] Without a viable alternative option to alleviate their suffering, individuals could feel pressured into choosing assisted dying where they may not have done if they had the opportunity to lessen their suffering and spend their final weeks in dignity, for example in a high-quality palliative care setting. Uneven availability and quality of care across the UK could mean that assisted dying exacerbates a 'postcode lottery' for those living with disabilities and/or terminal illnesses.
2. However, palliative care is not the only relevant consideration. Although recent legislative proposals have focused on assisted dying for terminally ill individuals with a very limited life expectancy, jurisdictions such as Canada have legislated for broader eligibility criteria extending to people with a grievous and irremediable medical condition. Furthermore, in the UK case of *R (Nicklinson) v Ministry of Justice (2014),* judges in the Supreme Court[2] suggested that, when Parliament considered the proposed assisted dying legislation at the time, those debates should cover those in the situation of Tony Nicklinson/Paul Lamb (individuals with serious, debilitating or chronic conditions that are not necessarily terminal). It is therefore possible that future proposed legislation could go beyond the scope of the previous Assisted Dying Bill to cover those living with long-term, degenerative and irreversible conditions and disabilities.
3. It is also necessary to consider the availability and quality of services that enable those with disabilities and chronic conditions to live independently with the highest attainable quality of life. These may include housing; access to support services; and infrastructure in areas such as education, employment and transport which enable disabled people's equal participation in society.
4. The Government, having ratified the UN Convention on the Rights of Persons with Disabilities (CRPD), has agreed to reflect it in domestic legislation, policy and guidance. Under the CRPD, disabled people have the right to live independently (Article 19); to equal recognition before the law (Article 12); and to the highest attainable standard of health without discrimination on the basis of disability (Article 25).
5. The human right to the highest attainable standard of physical and mental health (protected by Article 12 of the International Covenant on Economic, Social and Cultural Rights) is also relevant as it places a positive obligation on the state to ensure that everyone, including disabled and terminally ill people, has access to high quality care.

---

1 There are several different terms associated with assisted dying or assisted suicide, and no universally agreed taxonomy. We refer to 'assisted dying' throughout this submission to reflect the terminology of the POST briefing on the subject.

2 Lords Neuberger, Mance and Wilson, together with Lords Clarke and Sumption (in the minority) (paras 118, 197, 233, 292)

6. The EHRC published a report in 2021 making recommendations on how to strengthen the right to independent living in the UK, which the Committee may find a helpful source of further information on this matter.

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

7. In countries that have legalised assisted dying, some National Human Rights Institutions (NHRIs) have taken the position that such legislation can, in principle, be compatible with human rights principles as long as the legislation takes a rights-based approach and the appropriate conditions and safeguards are in place, particularly to protect the rights of disabled people. We concur with this view. We have not conducted a comprehensive review of lessons from other jurisdictions. However, relevant international interventions which could inform consideration of assisted dying in the UK include:

    a. The **New Zealand Human Rights Commission (NZHRC)** highlighted that the omission of disability as a standalone criterion for accessing assisted dying does not automatically protect those with disabilities, as there is not necessarily a clear line between terminal illness and disability. They also urged the New Zealand government to ensure that safeguards against coercion are made, with the understanding that coercion or pressure is not necessarily applied directly by other individuals. It can also be a result of broader feelings and attitudes in their community – that they cannot live with dignity, that they cannot participate in meaningful activities, or that they are a burden on their loved ones.

    b. The NZHRC also noted the importance of enabling doctors who do not want to be part of the euthanasia process to opt-out or conscientiously object. This is vital to ensure proper consideration of medical professionals' Article 9 rights to freedom of thought, conscience and religion.

    c. **UN Special Rapporteurs**[3] in 2021 expressed concern at legislation allowing assisted dying because of disability or old age. They warned that this could institutionalise 'ableism' and violate Article 10 of the CRPD (which protects disabled people's right to life on an equal basis with others) as it would undermine the inherent 'quality of life' or 'worth' of a disabled person.

    d. **Austria** legalised assisted dying in 2022 following a ruling from its federal court that an absolute ban violated "the right to self-determination". This law was enacted alongside measures to protect the rights of citizens, such as additional funding for palliative care, and a requirement that one of the doctors required to sign-off on assisted dying requests is an expert in palliative medicine.

    e. The **Canadian Supreme Court** found that the right to life was engaged when 'the prohibition on physician-assisted dying had the effect of forcing some individuals to

[3] Gerard Quinn, *Special Rapporteur on the rights of persons with disabilities;, Olivier De Schutter, Special Rapporteur on extreme poverty and human rights; and* Claudia Mahler, *Independent Expert on the enjoyment of all human rights by older persons*

take their own lives prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable'.

f. There are previous cases heard by the **European Court of Human Rights** (ECtHR) on this issue. The ECtHR has never decided that assisted dying laws per se violate Convention rights; nor that Convention rights confer a 'right to die.' The Court has repeatedly noted that there is no clear consensus between member states and that it is a matter for individual Parliaments to consider. This is in line with the conclusion of the majority of the UK Supreme Court in *Nicklinson* that the UK Parliament should consider the issue of assisted dying**.** However, the ECtHR has made some specific judgments on this issue:

g. It found that an individual's right to choose the timing and means of their death – provided they are able freely to reach a decision and act on it - falls within the ambit of protection of the right to a private and family life under Article 8(1) of the European Convention on Human Rights (ECHR).

h. In *Pretty v UK (2002)* the ECtHR held that the UK's blanket ban on assisted suicide, although engaging Article 8, was a justified interference as "necessary in a democratic society for the protection of the rights of others" (para 78) and, accordingly, that there was no violation of Article 8 of the Convention.

i. Article 2 requires there to be safeguards to ensure that any person taking their life has capacity, and has taken their decision freely[4].

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

8. There are several fundamental principles which must be considered to ensure any debate on assisted dying is adequately informed by equality and human rights principles.

9. Many of the relevant professional and ethical considerations related to human rights are addressed in our responses above.

10. Under Article 2 of the ECHR (the right to life), the state has a duty to protect vulnerable people, even against actions by which they endanger their own lives. It is also important to consider whether a prohibition on assisted dying is compatible with Article 2, and the UK Supreme Court has noted that Article 2 is relevant to both sides of the argument. The State has a responsibility to protect vulnerable people from coercion into suicide (7(i) above); conversely, a failure to allow a terminally ill person to choose assisted dying could lead them to take their own life while they were still physically capable of doing so, earlier than they may have otherwise chosen to.

11. The right to respect for a private life (Article 8 of the ECHR) has been established by case law as encompassing bodily autonomy and protecting an individual's freedom to make their own decisions about seeking or consenting to medical treatment (so long as they have capacity to

[4] *Haas v Switzerland* (2011) 53 EHRR 1169 para 54, reaffirmed in 2022 in *Lings v Denmark* (application no. 15136/20) para 49

do so), including decisions about the end of their life. This right provides protection against public bodies (such as an NHS Trust or a private hospital exercising public functions) coercing people with capacity into making decisions, or having decisions made for them, which are against their wishes.

12. Article 9 of the ECHR, which protects freedom of thought, conscience and religion, will necessitate thorough consideration of how assisted dying may interact with the beliefs of individuals and their families, and the beliefs of medical professionals. Any legislation will need ensure these beliefs are protected and respected, without infringing on the rights of others.

13. Article 14 of the ECHR protects the enjoyment of human rights by all human beings without discrimination, for example on grounds of age or disability. [5] Individuals also have legal protection from discrimination under the Equality Act 2010.

14. Some cases, such as *Pretty v MoJ (2001),* have argued that the prohibition of assisted dying violates Article 3 of the ECHR (freedom from inhuman or degrading treatment), by failing to prevent significant suffering to a disabled person unable to end their own life. Both the House of Lords and the ECtHR have found that Article 3 does not confer a right to assisted dying as a means to alleviate suffering (similar conclusions have been drawn by senior courts in Canada and New Zealand). However, in some circumstances it may impose on the state a positive obligation to take steps to ameliorate suffering, such as by providing adequate pain relief and palliative care.

15. The UK Government is expected to reflect international UN human rights treaties that it has ratified in domestic legislation, policy and guidance. The UN Convention on the Rights of Persons with Disabilities (CRPD) provides specific and legally binding protections for disabled people, including a requirement that the right to life (Article 10) is enjoyed by disabled people 'on an equal basis with others'.[6] Article 12 (equal recognition before the law) also means that disabled people should have the same legal rights as non-disabled people, in all aspects of life.

16. Finally, the UK Government has an obligation under the Public Sector Equality Duty, section 149 of the Equality 2010, when developing and implementing policy, to have due regard to the need to promote equality of opportunity, eliminate unlawful discrimination, and foster good relations between groups.[7] The effective fulfilment of this obligation requires careful and evidence-based consideration of the impact of any proposals relating to the nine protected characteristics. In the context of an issue with such significant implications and

---

5 The existing UK legal framework also raises an issue of socioeconomic inequality, in that people who can afford to do so can currently travel abroad (for example to Switzerland) to end their lives, an option not open to poorer people.

6 ' *Article 10 - Right to life: States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others'*. The UNCRPD Committee has expressed concern about Canadian federal legislation permitting medical assistance in dying, and hoped that the dialogue would help understand that the legislation would not lead to increased suicide rates among the disabled population due to lack of social and medical support services.

7 *Public Sector Equality Duty,* EHRC, https://www.equalityhumanrights.com/en/advice-and-guidance/public-sector-equality-duty

need for a complex balancing of rights, the duty to foster good relations will require sensitive engagement with a range of stakeholders. The Government should provide leadership, with the EHRC and others, in facilitating respectful discourse, with an awareness of the negative impact that divisive language may have on tensions between groups with different protected characteristics.

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

17. A human rights-based analysis does not necessarily suggest that it would be incompatible with Convention rights to create eligibility criteria that are broader than those relating to terminal illness suggested in the 2021 Assisted Dying Bill and proposed Scottish Assisted Dying Bill. It is possible that narrower criteria could, in some circumstances, be discriminatory. This is because, for some conditions, a person's capacity to consent could deteriorate the closer they get to the end of their life, meaning that they could be prevented from being able to choose the circumstances of their death.
18. Other important considerations include:
    a. Effective safeguards to ensure the person has the mental capacity and circumstances to freely express their wishes and understand the consequences of their choice.
    b. The eligibility criteria for accessing assisted dying alone cannot determine whether any legislative change sufficiently protects equality and human rights. This must be considered in combination with the circumstances in which an individual is making a decision about the end of their life. For example, whether assisting a person with a severe disability to end their life is compatible with their human rights will depend, in part, on contextual factors such as the quality of care or access to services enabling independent living, and the safeguards in place.
    c. Any change in the law should maintain current provisions that enable autonomy – for example, safeguards that cover assisted dying should not take away the current ability to refuse or to withhold life-sustaining treatment. In this regard, proposals should consider the interaction with existing legal provisions for advance directives.
    d. Finally, criteria relating to mental capacity must not be discriminatory. It is imperative that people taking such significant decisions are able to understand fully their circumstances, their options, and the consequences of their decisions. However, sensitive consideration must also be given to the interaction between mental capacity, mental health issues, learning disabilities and conditions such as autism. Refusing assisted dying to someone on the basis of a mental health condition or learning disability, which is unrelated to the reason they are seeking assisted dying, could be discriminatory unless justified in the individual circumstances.

19. As with palliative care provision, individuals must also be able to access high-quality mental health services to ensure that assisted dying does not become a substitute for adequate psychiatric care and support.

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

20. Appropriate safeguards to prevent coercion by medical professionals, family members or any other party are crucial to ensuring any law to allow for assisted dying appropriately protects individuals' rights.

21. Any protections mirroring those in other jurisdictions – such as in New Zealand, where it was proposed that physicians should talk to an individual's family members to establish whether they may be being coerced – would need to respect the patient's right to privacy. An individual would need to consent to the disclosure of their end-of-life decisions to any other parties.

22. It is also necessary to consider coercion beyond the risks posed by individuals. One of the most important protections against people feeling coerced into seeking an end to their life is to ensure social conditions, support, care and services are in place so that people with disabilities or serious or terminal illnesses do not feel that they are a burden to their loved ones or to society. This goes beyond adequate funding and access to health and social services, and must include active efforts to create a society where people are able to live life on equal terms, free from discrimination.

Question 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?

23. Individuals must be made fully aware of their rights, as well as the routes of recourse if they feel their rights have been violated or that they have been discriminated against in the process. They must also be able to access comprehensive information about the options and the services available to them, including social support, counselling and mental health services, funding and clinical care options.

24. Advice and guidance should never imply that any provision of care and/or independent living services is unnecessary, expensive or burdensome.

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

25. Any determination of the capabilities an individual would need, to be able to consent, must not discriminate against particular individuals or groups. Definitions of 'mental capacity' must consider how to accommodate those with mental health disorders, particularly disorders which do not necessarily relate to the person's reason for seeking assisted dying. For example, if a terminally ill cancer patient were to be denied access to assisted dying

because they have a mental health diagnosis unrelated to their terminal illness, this may constitute unlawful discrimination. As set out earlier, if a provision relating to a person's capabilities is discriminatory then it could engage Article 14, taken together with Article 8 and Article 2.

26. Assisted dying in other jurisdictions primarily affects the elderly[8]. As such, discrimination with regard to the protected characteristic of age is an important consideration. Safeguards must be in place to ensure that any determination that a person does not have the mental capacity to consent is not prejudiced by assumptions based on the age of the person, including, for example, assumptions that an elderly patient who can be forgetful or confused therefore has dementia and cannot consent.

27. Finally, when designing this aspect of any assisted dying framework, the Government needs to ensure that it complies with Articles 10 (right to life) and 12 (equal consideration before the law) of the UN CRPD, as referred to above.

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

28. In light of changing public opinions (including organisations such as the British Medical Association adopting a neutral stance), more international comparisons, proposals in Scotland, and the comments made in recent ECtHR and Supreme Court cases, Parliament may choose to reconsider the issue of assisted dying. The EHRC would support a respectful and inclusive national debate on assisted dying/assisted suicide which takes a human rights-centred approach.

29. The Government has a responsibility to consider questions of equality and human rights when making policy or proposing new laws on this issue. It must uphold its obligations under the PSED (mentioned above) ECHR and, in this case, should have particular regard to the UN Convention on the Rights of Disabled Persons. In bringing forward any legislative proposals for assisted dying, it is also imperative that the government acknowledges that this issue is one of conscience, and should be treated as such for Parliamentarians who should not be whipped to vote on the matter.

30. The Government also has a responsibility to facilitate broad consultation prior to any legislative change. This should ensure the particular groups whose rights will be engaged, including disabled people, and those with a religion or belief opposed to assisted dying, are proactively engaged in discussion. Wherever possible, the Government must ensure this discussion is based upon mutual respect and consideration of the rights of others to hold differing opinions.

31. The Government also has an important role in creating the social conditions in which legislation to enable assisted dying would not impinge on individuals' rights. This includes universal access to high-quality palliative care, mental health services, and services that enable independent living. It also includes working actively to eliminate discrimination and to foster a society where everyone is able to enjoy their rights fully and on equal terms.

[8] In Canada in 2021, the median age for accessing Medical Assistance in Dying (MAiD) was in the mid 70's, with 38% over 80

32. Finally, the Government should provide advice and education, working with stakeholder groups, to inform medical professionals and the general public about their rights in relation to any changed legislation on the issue of assisted dying.

Jan 2023