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To die with dignity

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Health and Social Care Committee
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Assisted Dying / Assisted Suicide Inquiry
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SW1A 0AA

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Assisted Dying / Assisted Suicide Inquiry

Responses to the questions in the online inquiry and the additional questions for organisations and campaigning groups

Submission by DIGNITAS – To live with dignity – To die with dignity Forch, Switzerland

for and on behalf of the 1,433 UK members
of DIGNITAS – To live with dignity – To die with dignity
submitted in electronic format, uploaded at
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copy emailed to hsccom@parliament.uk

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1) Introduction

This submission comments on and answers the questions of the Health and Social Care Committee's Assisted Dying / Assisted Suicide Inquiry in the online form and the additional questions for organisations and campaigning groups[1]. In this, it also provides information for the discussion on introducing assisted dying legislation in the UK. It does not claim to, and it cannot cover the issue in all details.

The Swiss non-profit membership association "DIGNITAS – To live with dignity – To die with dignity" (hereafter abbreviated "DIGNITAS" for easier reading and writing) provides this submission based on its work of 24 years which includes know-how and experience from conducting over 3,400 cases of assisted dying (assisted / accompanied suicides, PSAS)[2] in line with Swiss law. The reason for providing this submission is obvious from the aims and further information available on the website of DIGNITAS[3]:

DIGNITAS has, besides other work, focussed on implementing and safeguarding the human right of individuals to decide on time and manner of their own end in life and to have access to professional help to put this into practice in a legal and safe way at their home. DIGNITAS does this so that these individuals (and their loved ones) do not have to carry the burden of going abroad with all the negative consequences thereof. Alongside this, DIGNITAS and the country of Switzerland would not then have to take care of an issue which should be resolved by the states where these individuals travel from.

The aim of DIGNITAS is that the "medical tourism of assisted dying" stops and DIGNITAS becomes obsolete for these people[4]. DIGNITAS will serve as an information provider and "emergency exit" only as long as many countries' governments and legal systems disrespect their citizens' basic human right to self-determination and choice in life and life's end, ban the topic with a taboo, and force them either to turn to lonely risky do-it-yourself suicide attempts or to travel abroad instead.

DIGNITAS finds that the Committee's inquiry is an important step forward to resolve several problems of the present situation which, in regard of assisted dying, is now inadequate and incoherent[5], despite recent developments which give rise to hope for a change.

DIGNITAS is happy to give further evidence, personal, oral and written, if the Health and Social Care Committee would wish so, as DIGNITAS already did in other consultation processes. They are also welcome to visit DIGNITAS, as did earlier UK Committees inquiring about assisted dying.

2) Assisted dying: a human right, freedom and choice

All European states – with the exception of the Vatican, Belarus and Kosovo – have adhered to the European Convention on Human Rights (ECHR)[6]. In specific cases, set legal situations

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1 https://www.smartsurvey.co.uk/s/M66AML/ and https://committees.parliament.uk/call-for-evidence/2744
2 See subheading 4 "terms and abbreviations used in this submission".
3 E.g. "The basic information at a glance and a 'click" on http://www.dignitas.ch/index.php?lang=en
4 See "The goal of DIGNITAS", page 19 herein: http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dans-ketnomedicalsociety-31082022.pdf
5 See the report by The Commission on Assisted Dying https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363
6 The Convention: http://www.echr.coe.int/Documents/Convention_ENG.pdf ; Member States: http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/005/signatures

may be questioned whether they would be in line with the basic human rights and liberties enshrined in the ECHR. The European Court of Human Rights (ECtHR)[7] has developed an important jurisdiction on basic human rights, including the issue of the right to choose a voluntary death. According to its preamble, this international treaty is not only a fixed instrument, "securing the universal and effective recognition and observance of the rights therein declared" but also aiming at "the achievement of greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realisation of human rights and fundamental freedoms"[8]. The ECHR text and case law are relevant in discussing an assisted dying Bill for England and Wales[9], which is why DIGNITAS herewith outlines aspects of a selection of the ECtHR judgments, and further court judgments in relation to a self-determined and self-enacted end of suffering and life.

In the judgment of the ECtHR in the case of DIANE PRETTY v. the United Kingdom dated 29 April 2002[10], at the end of paragraph 61, the Court expressed:

> "Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees."

Furthermore, in paragraph 65 of this judgment, the Court expressed:

> "The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity."

On 3 November 2006, the Swiss Federal Supreme Court recognized that someone's decision to determine the way of ending his/her life is part of the right to self-determination protected by article 8 § 1 of the ECHR, stating:

> "The right to self-determination within the meaning of Article 8 § 1 [of the Convention] includes the right of an individual to decide at what point and in what manner he or she will die, at least where he or she is capable of freely reaching a decision in that respect and of acting accordingly."[11]

In that decision, the Swiss Federal Supreme Court had to deal with the case of a man suffering not from a physical but a psychiatric / mental ailment. It further recognized:

> "It must not be forgotten that a serious, incurable and chronic mental illness may, in the same way as a somatic illness, cause suffering such that, over time, the patient concludes that his or her life is no longer worth living. The most recent ethical, legal and medical opinions indicate that in such cases also the prescription of sodium pentobarbital is not

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7 https://www.echr.coe.int
8 http://www.echr.coe.int/Documents/Convention_ENG.pdf page 5.
9 The ECHR came into force in the UK on 3 September 1953.
10 Application no. 2346/02; Judgment of a Chamber of the Fourth Section http://hudoc.echr.coe.int/eng?i=001-60448
11 BGE 133 I 58, page 67, consideration 6.1 (translated) http://bit.ly/BGE133I58

> necessarily precluded or to be excluded on the ground that it would represent a breach of the doctor's duty of care. […] Where the wish to die is based on an autonomous and all-embracing decision, it is not prohibited to prescribe sodium pentobarbital to a person suffering from a psychiatric illness and, consequently, to assist him or her in suicide. […] The question of whether the conditions have been met in a given case cannot be examined without recourse to specialised medical – and particularly psychiatric – knowledge and is difficult in practice; the respective assessment requires an in-depth psychiatric appraisal…"

Based on this judgment, the applicant made efforts to obtain an appropriate assessment, writing to 170 psychiatrists – yet he failed to succeed. Seeing that the Swiss Federal Supreme Court had obviously set up a condition which in practice could not be fulfilled, he took the issue to the ECtHR.

On 20 January 2011, the ECtHR rendered the judgement HAAS v. Switzerland[12] and stated in paragraph 51:

> "In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention."

In this, the ECtHR adhered to the Swiss Federal Supreme Court and acknowledged that the freedom to choose the time and manner of one's own end in life is a basic human right protected by the ECHR.

In a further case, ULRICH KOCH v. Germany, the applicant's wife, suffering from total quadriplegia after an accident, demanded that she should have been granted authorisation to obtain 15 grams of pentobarbital of sodium, a lethal dose of medication that would have enabled her to end her ordeal by choosing suicide at her home. In its decision of 19 July 2012, the ECtHR declared the applicant's complaint about a violation of his wife's Convention rights inadmissible, however, the Court held that there had been a violation of Article 8 of the Convention in that the [German] domestic courts had refused to examine the merits of the applicant's own rights he claimed[13]. The case had to be dealt with by the German domestic courts again. Finally, the German Federal Administrative Court corrected the lower courts judgments: The general right to personality article 2,1 (right to life) in connection with article 1,1 (protection of human dignity) of the Basic (Constitutional) Law of Germany comprises the right of a severely and incurably ill patient to decide how and at what time his or her life shall end, provided that he or she is in a position to make up his or her own mind in that respect and act accordingly. The Court found, even though it was generally not possible to allow the purchase of a narcotic substance for the purpose of suicide, there had to be exceptions[14].

In the case of GROSS v. Switzerland, the ECtHR further developed its jurisdiction. The case concerned a Swiss woman born in 1931, who, for many years, had expressed the wish to end

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[12] Application no. 31322/07; Judgment of a Chamber of the First Section: http://hudoc.echr.coe.int/eng?i=001-102940
[13] Application no. 479/09, Judgment of the Former Fifth Section: http://hudoc.echr.coe.int/eng?i=001-105112
[14] See the respective press release by DIGNITAS http://www.dignitas.ch/images/stories/pdf/medienmitteilung-08032017.pdf (in English); link to the judgment by the Federal Administrative Court of Germany: http://www.bverwg.de/entscheidungen/entscheidung.php?ent=020317U3C19.15.0 (in German).

her life, as she felt that she was becoming increasingly frail, and she was unwilling to continue suffering the decline of her physical and mental faculties. After a failed suicide attempt followed by inpatient treatment for six months in a psychiatric hospital which did not alter her wish to die, she tried to obtain a prescription for sodium pentobarbital by Swiss medical practitioners. However, they all rejected her wish; one felt prevented by the Swiss code of professional medical conduct as the woman was not suffering from any life-threatening illness, another was afraid of being drawn into lengthy judicial proceedings. Attempts by the applicant to obtain the medication to end her life from the Health Board were also to no avail.

In its judgment of 14 May 2013[15], the ECtHR held in paragraph 66:

> "The Court considers that the uncertainty as to the outcome of her request in a situation concerning a particularly important aspect of her life must have caused the applicant a considerable degree of anguish. The Court concludes that the applicant must have found herself in a state of anguish and uncertainty regarding the extent of her right to end her life which would not have occurred if there had been clear, State-approved guidelines defining the circumstances under which medical practitioners are authorised to issue the requested prescription in cases where an individual has come to a serious decision, in the exercise of his or her free will, to end his or her life, but where death is not imminent as a result of a specific medical condition. The Court acknowledges that there may be difficulties in finding the necessary political consensus on such controversial questions with a profound ethical and moral impact. However, these difficulties are inherent in any democratic process and cannot absolve the authorities from fulfilling their task therein."

In conclusion, the Court held that Swiss law, while providing the possibility of obtaining a lethal dose of sodium pentobarbital on medical prescription, did not provide sufficient guidelines ensuring clarity as to the extent of this right and that there had been a violation of article 8 of the Convention. However, the case was referred to the Grand Chamber of the ECtHR by the Swiss government as, prior to a public hearing on the case, it became known that the applicant had passed away in the meantime. This led to the case not being pursued.

Another important judgment was rendered on 26 February 2020 by the Federal Constitutional Court of Germany[16]: The court declared unconstitutional and void § 217 of the German Criminal Code ("geschäftsmässige Förderung der Selbsttötung"), a statuary provision that had criminalised repeated – and thus professional – advisory work and assistance for a self-determined ending of one's own life[17]. The Court held:

> "As an expression of personal autonomy, the general right of personality (Art. 2(1) in conjunction with Art. 1(1) of the Basic Law) encompasses a right to a self-determined death. The right to a self-determined death includes the freedom to take one's own life. Where an individual decides to end their own life, having reached this decision based on how they personally define quality of life and a meaningful existence, their decision must, in principle, be respected by state and society as an act of personal autonomy and self-determination. The freedom to take one's own life also encompasses the freedom

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15 Application no. 67810/10; Judgment of a Chamber of the Second Section: http://hudoc.echr.coe.int/eng?i=001-119703

16 https://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2020/02/rs20200226_2bvr234715en.html

17 See: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-26022020-e.pdf

> to seek and, if offered, make use of assistance provided by third parties for this purpose. […] The right to a self-determined death, as an expression of personal freedom, is not limited to situations defined by external causes. The right to determine one's own life, which forms part of the innermost domain of an individual's self-determination, is in particular not limited to serious or incurable illness, nor does it apply only in certain stages of life or illness. […] The right to a self-determined death is rooted in the guarantee of human dignity enshrined in Art. 1(1) GG; this implies that the decision to end one's own life, taken on the basis of personal responsibility, does not require any explanation or justification. […] What is decisive is the will of the holder of fundamental rights, which eludes any appraisal on the basis of general values, religious precepts, societal norms for dealing with life and death, or considerations of objective rationality […]."

On 11 December 2020, the Austrian Constitutional Court[18] rendered its judgment on a constitutional complaint against the prohibition of assistance in suicide and voluntary euthanasia. § 78 "participation in self-murder" (sic!) of the Austrian criminal code, which was set up in the Austro-fascist 1930s, said: "Any person who incites another to commit suicide [literally: 'kill himself'], or provides help in this, is liable to a custodial sentence of six months to five years." The Court found the second fact of § 78 ("or provides help in this") unconstitutional, with effect from 1 January 2022. In essence the Court held:

> "A right to free self-determination is to be derived from several constitutional guarantees, in particular the right to private life, the right to life, as well as the principle of equality. This right also extends to the freedom to end one's own life. Where a person decides to end his or her own life, this decision must be respected by the State provided that it is based on the free will of the individual concerned. The right to end one's own life also includes the freedom to seek and, where offered, make use of assistance provided by third parties for that purpose. […] From a fundamental rights perspective there is no difference between a patient that refuses life-prolonging or life-maintaining medical measures within his or her sovereignty over treatment or by exercising his or her right to self-determination within his or her living will, and a person willing to commit assisted suicide as part of his or her right to self-determination in order to die in dignity. In both cases, the decisive aspect is that the decision is taken on the basis of free self-determination."

In this context the so-called ARTICO-jurisdiction based on the ECtHR judgment of 13 May 1980, series A no. 37, no. 6694/74, paragraph 33[19] needs to be remembered:

> "The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective; …"

Dignity and freedom of humans mainly consists of acknowledging the right and freedom of someone who does not lack capacity to decide even on existential questions for him- or herself, without outside interference. Everything else would be paternalism compromising dignity and freedom of choice. In the judgment PRETTY v. the United Kingdom mentioned

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[18] Abstract in English provided by the Court: https://www.vfgh.gv.at/downloads/Bulletin_2020_3_AUT-2020-3-004_G_139_2019.pdf ; respective press release by DIGNITAS: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-11122020-e.pdf

[19] http://hudoc.echr.coe.int/eng?i=001-57424

before, the Court correctly recognized that this issue will present itself increasingly – not only within the Convention's jurisdiction, but internationally – due to demographic developments and progress of medical science.

It also presents itself increasingly because a growing part of the public wishes to have the freedom and right to choose the course of their own life *and* their end in life[20]. Yet sometimes it can be observed that politics and linked administrative authorities take another stand and block or delay assisted dying legislation, despite a majority of the public being in favour of such choice being legalised. The public opinion is relevant from an ECHR perspective: in the judgment OLIARI AND OTHERS v. Italy dated 21 July 2015, the ECtHR observed a reflection of the sentiments of a majority of the (in this case Italian) population as shown through official surveys[21].

3) Responses to the questions in the online survey and to the additional questions for organisations and campaigning groups

Part 1 – questions in the online survey

1. Which of the statements below best reflects your view?

A. We broadly disagree with the law on this issue in England and Wales.

2. Please tell us why you have responded as you have set out above. (No more than 300 words)

A: To quote the Commission on Assisted Dying: "The current legal status of assisted dying [in the UK] is inadequate and incoherent"[22]. It has been out of touch the public opinion for a long time. It ignores the right and freedom of individuals to decide on time and manner of the end of their own life and to reach out to assistance by others for this purpose. It outsources a health care issue abroad, especially to DIGNITAS in Switzerland, instead of Government and Parliament assuming responsibility. It leads to individuals "taking matters into their own hand" by resorting to unguided DIY-suicide attempts of which the majority fails, with negative consequence for the individual, their loved ones, and the public[23]. It leads to discrimination against those who are not able (anymore) to travel to DIGNITAS and use this "assisted dying emergency exit option". It leads to assisted dying happening secretly. As to the latter three aspects, the UK violates articles 2 of the ECHR / the Human Rights Act[24], which states

[20] E.g. https://yonderconsulting.com/largest-ever-poll-on-assisted-dying-conducted-by-populus-finds-increase-in-support-to-84-of-the-public

[21] https://hudoc.echr.coe.int/eng?i=001-156265 paragraph 181 / 144

[22] See the report by The Commission on Assisted Dying https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363

[23] Cf. page 13, subheading 7 "The protection of life and the general problem of suicide" in DIGNITAS' submission to the Joint Committee on End of Life Choices South Australia: http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-submission-end-of-life-choices-south-australia-31072019.pdf ; "Suicides among people diagnosed with severe health conditions, England: 2017 to 2020" https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020

[24] It is interesting, to not say ironic, that the UK Equality and Human Rights Commission states as article 2 example a 20-year-old court judgment (the PRETTY v. United Kingdom case, see subheading 2 of this submission) whilst in the meantime case law has further developed and the freedom and right to decide on time and manner of one's own end in life (and to reach out to assistance by others for this purpose) has been acknowledged https://www.equalityhumanrights.com/en/human-rights-act/article-2-right-life

that "the Government should take appropriate measures to safeguard life". It criminalises those who compassionately support others who wish to make use of assisted dying[25].

Assisted dying is not simply about the right to die. It is about the right to have one's life, human dignity, autonomy, quality of life, health and care respected by being provided with access to legal medical and professional assistance to safely end one's suffering and life in the manner and at the time of one's choice. Already over 80 years ago, the House of Lords debated an assisted dying bill. The UK was the first country worldwide to have a right-to-die, right to end-of-life-choices organisation. There is no reason why the UK should not be able to do what Australia, New Zealand, Canada, Switzerland and other countries have done, which is to implement assisted dying as an option alongside the existing health care measures. The people of the UK and DIGNITAS hope it does not take another 80 years.

3. Which of the following factors are most important to you when considering the issue? Please select up to three.

A. 1) Personal autonomy, 2) Personal dignity, 3) Reducing suffering.

5. Do you think any of the following would be helpful? Tick all that apply

A. - Citizen's assembly
- Referendum

Part 2 – additional questions for organisations and campaigning groups

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

A. The feedbacks DIGNITAS receives from its members and others give the impression of a generally well-working system of palliative care. However, it is indicated that sufficient pain-control treatment is sometimes applied rather late and only when patients and their loves ones put on increased pressure on medical staff. Furthermore, it seems that some palliative care professionals are not familiar with palliative continuous deep sedation and not sufficiently respecting advance directives to refuse treatment. It appears there is some lack of knowledge and education amongst medical professionals about what palliative care treatment really encompasses[26], and on patients' rights. It may have to do with the challenge of not having sufficient staff in health and end-of-life-care – which is, admittedly, not only an issue in the UK.

Q. How can palliative care be improved, and would such improvements negate some of the arguments for assisted dying / assisted suicide?

A. There are two keys to improve palliative care, as generally with public health services: education and funding.

Improvements in palliative care would not negate arguments for assisted dying. Palliative care and assisted dying / assisted suicide are two individual patient choices, which function complimentary. Many members of DIGNITAS who seek access to PSAS, especially those suffering from a terminal illness, make use of palliative care. In its daily advisory work DIGNITAS informs people of the palliative care options. There are palliative care professionals who co-

[25] Cf. the My Death My Decision (MDMD) Parliamentary reception in Westminster Palace, 15 November 2022, i.e. the testimonial by Sue Lawford http://www.dignitas.ch/index.php?option=com_content&view=article&id=26&Itemid=6&lang=en

[26] Cf. the definition and key facts of palliative care by the World Health Organization WHO: https://www.who.int/news-room/fact-sheets/detail/palliative-care

work with DIGNITAS, taking care of DIGNITAS-member, either to support in end-of-life care when patients change their mind not to make use of PSAS or to stabilise the medical condition of the patient, so they are able to make use of PSAS. This always based on the individual's wishes.

Some alleged "experts" claim(ed) that palliative care can soothe all suffering and therefore it is not necessary to introduce assisted dying legislation. Only laypersons make such assertions. Studies show that palliative care cannot alleviate all suffering[27], and despite good palliative care in the UK, there are still people who wish for another option, which is a self-chosen point of end of their suffering and life. Due to the lack of legal PSAS, they are left to resort to do-it-yourself (DIY) suicides[28] or to turn to DIGNITAS if they still can. Both outcomes are undesirable. Since the year 2002, over 500 Britons have chosen PSAS at DIGNITAS.

Overall, it can be referred to the assertions of the Government of the Isle of Man to which DIGNITAS adheres, quote: "Research demonstrates that assisted dying laws contribute to more open conversations and careful evaluation of end-of-life options, as well as more appropriate palliative care training of doctors and nurses, and greater efforts to increase access to hospice care. A report commissioned by Palliative Care Australia which examined assisted dying around the world found "no evidence to suggest that palliative care sectors were adversely impacted by the introduction of legislation. If anything, in jurisdictions where assisted dying is available the palliative care sector has further advanced"[29]. As a European example for the latter, it is to note that Austria introduced its law for physician-supported suicide[30] on the same date, 1 January 2022, as the law to improve funding of hospice and palliative care; from € 6 million to 21 million in 2022, to 36 million in 2023 and 51 million in 2024[31].

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

A. Three core points which are:

- it improves conversations on end-of-life choice matters
- it reduces the risk of deaths by unguided DIY-suicides and suicide attempts
- legalisation is associated with greater trust amongst patients and medical professionals[32].

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

A. Physicians and other medical professionals need to be educated and trained so as to be able to professionally and safely conduct assisted dying. Since assisted dying is about freedom of choice, it is understood that physicians may have the right to conscientious objection from getting involved with assisted dying. However, all health care professionals should be obliged

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27 https://www.ohe.org/publications/unrelieved-pain-palliative-care-england

28 https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020

29 https://consult.gov.im/private-members/assisted-dying

30 "Sterbeverfügungsgesetz"; https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=20011782 , after the Austrian Constitutional Court declared the blanked prohibition of assistance in suicide to be unconstitutional, judgment of 11 December 2020 mentioned in subheading 2.

31 "Hospiz- und Palliativfondsgesetz" https://www.parlament.gv.at/gegenstand/XXVII/I/1290 ;

32 Cf. Government of the Isle of Man, overview for assisted dying survey https://consult.gov.im/private-members/assisted-dying

to answer questions about assisted dying at least on the minimum level of referring those patients asking about it to information sources, including other health care professionals.

It should be remembered that the base for all medical treatment is the individual's choice and autonomy. The patient decides whether or not they accept a certain medical treatment. Medical professionals need to respect the Declaration of Geneva of the World Medical Association which has replaced and is a today version of the Hippocratic Oath[33].

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

A. With (physician-supported) assistance in suicide, the base should be what the ECtHR held in its judgment HAAS v. Switzerland mentioned in subheading 2 of this submission, which is that the individual "…is capable of freely reaching a decision on this question and acting in consequence…" Since it is acknowledged that an individual has the freedom and right to decide on time and manner of their own end in life, eligibility criteria should be such that medical professionals or others do not (need to) pass judgement on whether or not someone has a certain medical diagnosis, whether or not it is progressive and whether or not this is expected to cause death in a certain time estimate. Rather, criteria should put centre stage what the individual considers to be quality of life. The focus would then be on establishing that the individual requesting assisted dying:

- understands the information relevant to the decision relating to access to assisted dying and the effect of the decision; and
- has reached a voluntary decision without coercion or duress; and
- is informed as to palliative, hospice and other care options – this should include information as to the potential negative effects of unguided DIY-suicide attempts; and
- is able to communicate the decision and their views and needs as to the decision in some way, including by speech, gestures or other means, and also able to administer the life-ending medication themselves; and
- has discussed the matter with their loved ones with the aim of avoiding a negative "surprise effect" and impact for these loved ones.

One eligibility criterion often brought up which definitely should not be applied in assisted dying / assisted suicide law-making is that of any life expectancy limit. No one, not even the most expert medical professional, is able to predict the future and to *know* whether a patient is still alive in 6 months or any other number of months or days. There may be life expectancy *estimates* based on experience, depending on the diagnosis; however, there is also the experience of exceptions. In result, the criterion of a certain limited life expectancy is a hypothetical, and it leads to arbitrariness and inequality: someone may hold the opinion that the patient is going to die in 6 months, but someone else may estimate this to be 6 months plus one day. Some claim the criterion of a limited life expectancy to be a "safeguard". The opposite is the case. Patients who do not meet this eligibility criterion, in their despair might try an unguided do-it-yourself (DIY) suicide, or they will turn to DIGNITAS. Both outcomes are undesirable. The limited life expectancy criterion is a copy-paste from the now 20-year-old and outdated Death with Dignity Act of the state of Oregon USA. Most European assisted dying laws, i.e. Belgium, the Netherlands, Luxembourg, Switzerland (with the longest-standing

[33] https://www.wma.net/policies-post/wma-declaration-of-geneva

professionally-medically assisted dying practice (PSAS) of over 35 years) and Germany, do not have such restrictive criterion.

Linked with the limited life expectancy criterion is the one that the individual would have to be diagnosed with a "terminal illness". Again, this should not apply. To only allow access to assisted dying / assisted suicide for individuals who face a terminal illness is to discriminate against individuals who suffer from health conditions that are, by medical opinion, not progressive and/or reasonably expected to cause death. For example, individuals such as the late PAUL LAMB, who was paralysed from the neck downwards after an accident, and who fought in the UK courts to obtain access to assisted dying[34].

Specifically in regard of mental health criteria, two aspects are to be noted:

First, it needs to be remembered that, in principle, people who are of age are assumed to be mentally competent unless there are indications that their mental capacity is limited or no longer present. This is the basis in common law which recognises – as a "long cherished" right – that all adults must be presumed to have capacity until the contrary is proved[35]. Second, the criteria should not exclude and such discriminate against individuals with psychiatric ailments. In fact, the very applicant before the ECtHR, Mr. HAAS, who brought about the judgment acknowledging the human right/freedom to decide on the time and manner of one's own end in life, was suffering from a psychiatric ailment but not a physical and/or terminal disease[36]. A psychiatric illness may impact a person's capacity to make decisions, such as the one to choose assisted dying, but it need not. Sometimes it can be observed, especially amongst opponents of assisted dying working in the fields of psychiatry and psychology, that it is insinuated that individuals requesting assisted dying would up-front not have capacity. This approach not only tries to turn upside down the legal basis that a person is presumed to have capacity, but it labels and stigmatises people who contemplate end-of-life choices – with the negative effects of entrenching the taboo on suicide, on (assisted) dying and on death, and potentially leading these people to not talk to doctors, therapists and their loved ones but "to take matters in their own hands"[37].

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

A. It is often assumed that with assisted dying / assisted suicide coercion to make use of this choice could be a risk. However, the experience of DIGNITAS is such that a different form of coercion takes place, by loved ones of individuals contemplating PSAS and by medical

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[34] The case of Paul Lamb (and Tony Nicklinson) was finally referred to the ECtHR, yet the ECtHR declared LAMB's complaint inadmissible because the rule of exhaustion of domestic remedies had not been observed. https://hudoc.echr.coe.int/eng?i=001-156476

[35] This approach matches the Mental Capacity Act 2005: "person must be assumed to have capacity unless it is established that he lacks capacity." It is also found, for example, in the Assisted Dying in Jersey Consultation Report, page 100: "In line with existing capacity legislation, the person is presumed to have decision-making capacity in relation to assisted dying unless the person is shown not to have that capacity" https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf . Also Swiss law bases on the assumption that everybody is assumed to have capacity of judgment; this, unless there are clear signs that such is not the case, see article 16 of the Swiss Civil Code https://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a16

[36] Case of HAAS v. Switzerland, application no. 31322/07, https://hudoc.echr.coe.int/eng?i=001-102940 ; see also subheading 2 in this submission.

[37] Cf. the TEDx talk "Cracking the taboo on suicide is the best means to prevent suicide attempts and deaths by suicide" http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-tedxzurich-08072021.pdf

professional in that they put pressure on individuals *not* to choose assisted dying in several ways, e.g. by not taking serious the individual's desire for assisted dying, withholding (medical) information, calling the authorities for the individual to be sectioned, etc.

In this context, the argument of protecting vulnerable people needs to be looked at. Such protection can have a stigmatising pretext side to it. Not every individual who may be seen by third parties as vulnerable would personally share this view. One needs to bear in mind that there is a fine line where well-meant protection turns into undesired paternalism. Whilst in principle DIGNITAS agrees with the notion of protection of any individual (not only "vulnerable") who does not wish to get involved with assisted dying, and there is a duty to protect life as enshrined in article 2 ECHR, one needs to aim for an assisted dying law which is practical and effective and not merely theoretical or even illusionary[38]. Only wide, liberal-progressive eligibility criteria will resolve the undesirable negative consequence that people travel to DIGNITAS or choose unguided risky DIY-suicide attempts.

In the Swiss model of PSAS, a practice of over 35 years, and with eligibility criteria which is arguably one of the most liberal-progressive in the world, coercion in the sense of individuals and vulnerable being pushed to make use of PSAS has not been an issue. It may play a role that in this Swiss model, an individual wishing to have PSAS will usually follow a preparation procedure which involves several different professionals, besides the family. Not to be overlooked is the fact that each case of PSAS is to be reported to the authorities for the state prosecution services to investigate.

Q. 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?

A. They would need access to information about all end-of-life choice options, how they can put these in practice, and what are the practical and legal consequences.

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

A. See answer to the earlier question "What, if any, are the physical and mental health criteria which would make an individual eligible to access assisted dying / assisted suicide service".

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

A. It should take seriously and adhere to 1) the long-standing desire of the UK public to have assisted dying legalised and 2) the court judgments outlined in subheading 2 and the move of several countries to legalise assisted dying. It should provide the UK public with comprehensive information from *practical* experience with legal assisted dying / assisted suicide, e.g. from countries such as Switzerland and Canada.

DIGNITAS' many years of experience shows that only a small number of people who enrol as a member make use of the option of PSAS, and even after over 35 years of such practice being in place in Switzerland, only around 1.8% of all deaths take place by this option. This clearly shows that allowing the self-determined ending of suffering and life by a safe means within a carefully-prepared safe arrangement is, for many, an important "emergency exit door": one is glad that it is there – and hopes to never need it. It does not lead to a slippery slope or an

[38] In the sense of the ARTICO-jurisdiction of the ECtHR (case of ARTICO v. Italy, judgment of 13th May 1980, paragraph 33, https://hudoc.echr.coe.int/eng?i=001-57424) mentioned in subheading 2.

erosion of the sanctity of life, such as often claim opponents of self-determination and freedom of choice. Making possible such professionally accompanied self-deliverance *is* protection of life and suicide attempt prevention in action. In the words of the late British conductor Sir Edward Downes, during his consultation with the Swiss medical doctor granting him the definite "green light" for PSAS: *"This is a form of evolution, of humanity."*

4) Terms and abbreviations used in this submission

Assisted dying: an umbrella term including PSAS and/or voluntary euthanasia with the support of and/or carried out by doctors/physicians. In this submission, depending on the context, it is used as defined in the consultation report.

Assisted/accompanied suicide and physician-supported accompanied suicide (abbreviation: **PSAS**): this is what is made possible for members of DIGNITAS in the frame of Swiss law. A person wishing to put an end to their suffering and their life chooses a well-considered, carefully prepared self-administration of a lethal substance provided by a (Swiss) physician usually at their home. The physician has assessed the person's request and medical file, the person is accompanied by professionals all through the process until the end, and next-of-kin and friends are involved.

Voluntary euthanasia: a person wishing to end his/her suffering and life requests and permits a third person to put an end to his/her life, for example by injection of a lethal medication. This is prohibited in Switzerland, yet legal under certain circumstances in some countries such as Belgium, Luxembourg and the Netherlands.

Passive euthanasia: (termination of treatment, "to let die"): ending or not starting life-maintaining and life-prolonging therapies, renouncing treatments, waiving food and drink.

Palliative care: an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (as defined by the World Health Organisation WHO).

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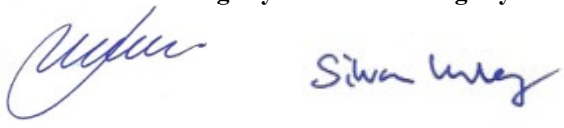
This response to the Assisted dying/assisted suicide inquiry is submitted / uploaded in electronic format. DIGNITAS confirms to have read and understood the Privacy Notice for Parliamentary Functions in the Committee Office Privacy Policy and that the Health and Social Care Committee can publish this submission in full.

Yours sincerely,
DIGNITAS
To live with dignity - To die with dignity



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