P. O. B. 17
8127 Forch
Switzerland
Phone +41 43 366 10 70
Fax +41 43 366 10 79
E-Mail: dignitas@dignitas.ch
Internet: www.dignitas.ch

Sender: P. O. B. 17, 8127 Forch Switzerland

Assisted dying public consultation
Government of Jersey
Ground floor, 19-21 Broad Street
St Helier
JE2 3RR

Forch, 11 January 2023

Assisted Dying in Jersey Consultation

Responses to the questions in the consultation report of October 2022
Submission by DIGNITAS – To live with dignity – To die with dignity
Forch, Switzerland

for and on behalf of the 4 Island of Jersey and 1,433 UK members
of DIGNITAS – To live with dignity – To die with dignity
submitted in electronic format to assisteddying@gov.je

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1) Introduction

This submission answers the 33 questions of and comments on the consultation report "Assisted Dying in Jersey"[1]. In this, it also provides information for the discussion on introducing assisted dying legislation in Jersey. 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 that 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 proposed assisted dying service in Jersey is an important step forward to resolve several problems of the present legal situation in Jersey which, in regard of assisted dying, is now inadequate and incoherent, as it (still) is all over the UK[5], despite recent developments which give rise to hope for a change. Therefore, DIGNITAS is fully supportive of the proposed assisted dying service in Jersey despite raising criticism in some points as explained hereafter.

DIGNITAS is happy to give further evidence, personal, oral and written, if anyone involved in the consultation would wish so, as DIGNITAS already did in other consultation processes. They are also welcome to visit DIGNITAS.

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 may be questioned whether they would be in line with the basic human rights and liberties

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1 https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf
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-dansketnomedicalsociety-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

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 law for Jersey[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 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-

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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

> 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 against 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 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

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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).

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 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,

[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

> 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 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.

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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

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) Answers to the questions in the consultation document

Q. 1 Do you give permission for your comments to be quoted?

A. Yes, attributed.

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

A. Yes.

Q. 3 If yes, do you think assisted dying …

A. … should be permitted? Yes.

Q. 4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

A. Yes.

In fact, the eligibility criteria should be changed in doing away with the criterion 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 or 12 months or any other number of months or days. Quite rightly, the consultation report acknowledges that "any assessment of 'time remaining' cannot be exact…" (para 197). 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: one medical professional may hold the opinion that the patient is going to die in 6 months, but another may estimate this to be 6 months plus one day. Depending on the opinions of the coordinating doctor, independent assessment doctor or second opinion doctor patients meets in the process, they may be judged differently. What is the purpose of a limited life expectancy criterion in relation to assisted dying law-making anyway? Some claim it 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 professionally-medically assisted dying practice (PSAS) of over 35 years) and Germany, do not have such restrictive criterion.

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[20] As to Jersey, see e.g.: http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight.pdf and http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight-2.pdf

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

Furthermore, to only allow access to assisted dying for individuals who face a terminal and/or neurodegenerative 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[22].

In fact, prohibiting access to assisted dying on the grounds of the individual being part of a certain group, especially a minority group, constitutes a discrimination against such an individual and group. This applies to individuals having a disability[23]. Those denied access to and help in assisted dying are left to illegal and/or risky approaches and methods, for example, unguided DIY-suicide of which the majority fail with dire consequences for the individual, their loved ones and society in general[24]. Not permitting access can violate the human right to (the protection of) life and/or constitute an inhumane or degrading treatment, besides the right to respect for private and family life. All are aspects of the ECHR.

Furthermore, individuals with severe psychiatric ailments are discriminated against – whilst in fact the very claimant 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[25]. A psychiatric illness may impact a person's capacity to make decisions, 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 decision-making capacity (in relation to assisted dying) unless the person is shown not to have that capacity, as stated in the consultation report para 21. 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 risking these people potentially not talking to doctors, therapists and their loved ones but "taking matters in their own hands"[26].

Making use of any form of assisted dying – whether by PSAS or voluntary euthanasia or discontinuing treatment ("passive euthanasia"; e.g. based on a legally effective advance directive) – is a personal choice in the frame of every individual's right to self-determination; no matter whether (or not) such individual is in fact or assumed to be a member of a certain group defined by medical diagnosis or life expectancy.

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[22] 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

[23] Cf. the findings of Prof. Ben Colburn, University of Glasgow, and further references in the section "Disability" in the Overview of the Assisted Dying Consultation of the Isle of Man: https://consult.gov.im/private-members/assisted-dying

[24] See also 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

[25] Case of HAAS v. Switzerland, application no. 31322/07, https://hudoc.echr.coe.int/eng?i=001-102940 ; see also subheading 2) "Assisted Dying: a matter of human right, freedom and choice" in this submission.

[26] See 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

DIGNITAS suggests that the Jersey Assisted Dying legislation adopts eligibility criteria that do not give precedence to what some doctors judge about suffering of their patient, but rather to focus on the personal experience / point of view of the individual/patient.

Besides, permitting access to assisted dying for only those with a limited life expectancy appears illogical in the light of the fact that life itself is a "diagnosis" that is expected to cause death, whether or not a medical practitioner finds a condition that is neurodegenerative, progressive, terminal and estimates a certain life expectancy.

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

A. No.

All discrimination related to the place of residency should be avoided. Even more so as this eligibility criterion discriminates against Jersey-born individuals who have been living elsewhere and towards the end of their life return back home and suddenly may face a health situation that makes them wish to have access to assisted dying. The issue of "death tourism", as the consultation report calls it, should not be solved with setting up discriminating criteria, but with engaging in the decriminalisation of assisted dying in legislations around Jersey, so that such people would not need to consider at all turning to Jersey (and elsewhere). In this context it is also to be noted that the residency criterion of the US State of Oregon was challenged to be unconstitutional in the GIDEONSE v. BROWN, et al. court case, which on 18 March 2022 led to a settlement in which the Oregon Health Authority, Oregon Medical Board, and the Multnomah County District Attorney have all agreed to "not apply or otherwise enforce the residency requirement" in the Oregon Death with Dignity Act, and the Oregon Health Authority agreed "to submit a legislative concept that would repeal the residency requirement"[27].

Q. 6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

A. No.

This, even though it is to be expected that requests for assisted dying in Jersey will come forward mainly from Islanders aged over 18. To compare: in Switzerland, according to the Federal Office of Statistics analysing the years 2010-14, most assisted dying cases (PSAS) took place in the age group 75-84, and overall 94% of the persons concerned were over 55 years old[28]. Yet, there may be cases of younger than 18-year-old individuals with an illness which impairs their quality of life grievously to the point of them possibly wishing to have the option of assisted dying. The assisted dying laws of Belgium and Netherlands adhere to this and allow for under-18 to access assisted dying under specific circumstances[29]. Jersey should take this as an example. A 17-year-old young Jersey Islander may well have capacity to understand the consequences of a diagnosis of a severe illness, may it be terminal cancer or neurodegenerative ailment or any other, and what assisted dying implies. Furthermore, if a 17-year-old is permitted to set up and/or have respected an advance directive to refuse

[27] https://compassionandchoices.org/docs/default-source/legal/rec-doc-20-1-exhibit-wm.pdf?sfvrsn=6041423c_1 and https://compassionandchoices.org/legal-advocacy/recent-cases/gideonse-v-brown-et-al
[28] https://www.bfs.admin.ch/bfs/en/home/statistics/catalogues-databases/publications.assetdetail.3902308.html
[29] https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

treatment, which will hasten death if applied (passive euthanasia), it does not make sense to bar such young person from assisted dying which leads to the same result[30].

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?

A. Yes, it should be free.

This ensures that nobody is barred from access to assisted dying and such discriminated against due to their personal financial situation. Costs will occur of course, and if the service is for free this will be carried by the community. It could be considered to apply two approaches of DIGNITAS: a) fixed fees for the assessment and for carrying out PSAS which are reduced or waived on reasoned request for people who live under modest financial circumstances[31] and b) setting up a fund which anyone can donate to, from where monies are used to cover costs related to the service of assisted dying.

Q. 8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

A. Yes, they should have the right to refuse.

Assisted dying is about the right and freedom to choose; this concept of free choice should apply for the individual who wishes to make use of assisted dying just as much as for those directly co-decisive: medical professionals.

Q. 9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

A. No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises.

Assisted dying should always be possible at one's home, one's place of living. A care home may well be the new home, the new place of residency of a person, because due to health reasons they cannot live in their flat or house anymore. It would be undignified and a possible health risk to impose on such person to leave their (new) home, their (new) place residency in the care home just because they wish to make use of assisted dying.

Q. 10 Do you agree that the assisted dying register should be public?

A. Yes.

Q. 11 Do you agree that the nine proposed steps are all necessary?

A. No.

Whilst DIGNITAS acknowledges that involving two separate doctors and a tribunal in the process of assessing and possibly supporting an individual's request for assisted dying may be seen as a safeguard, it adds an unnecessary hurdle that consumes time which a rapidly

[30] Cf. judgment by the Austrian Constitutional Court of 11 December 2020 mentioned in subheading 2).
[31] Cf. article 9, para 6 of the statutes / articles of association of DIGNITAS.

declining individual may have little left of, and it prolongs the suffering.

Furthermore, the criterion of (incurable medical condition that is giving rise to) "unbearable suffering that cannot be alleviated" should be done away with. An incurable medical condition is itself sufficient grounds to permit access to assisted dying. This approach resolves the issue of complexity around objectivity and subjectivity as discussed in the consultation report (para 197 ff) and makes establishing a separate route and a tribunal unnecessary.

In the Swiss legal system of PSAS, one doctor is seen as sufficient[32]. This doctor may choose to reach out to one or several colleagues if, for example, the individual's situation and request for assisted dying appears complex and the doctor wishes for support and second opinion(s). Furthermore, there is no eligibility criteria of a limited life expectancy. This has proved to work well for over 35 years, and DIGNITAS suggests this approach.

In para 195, the consultation report states "Whilst the primary purpose of an assisted death is to end life…" By its experience, DIGNITAS finds this a wrong understanding of assisted dying and inappropriate, even stigmatising. People making use of assisted dying do not primarily wish to end their life. No one wishes to die. But, people wish to not continue suffering. If their suffering could be alleviated, if their medical condition could be resolved, they would continue living. In fact, assisted dying is about alleviating suffering and for this to provide a legal and safe framework which an individual can choose to make use of. Furthermore, assisted dying is about improving quality of life, protecting life and safeguarding public health, as it can make unnecessary that people travel abroad to DIGNITAS or take to risky unguided DIY suicide attempts.

In the analysis and discussion following the consultation, the question should be discussed whether *at all* doctors should be involved as "gatekeepers" for assisted dying. In the light of the human rights and constitutional court judgments mentioned in subheading 2 of this submission, it can be noted that the prerequisite of a medical condition, even more so one that is diagnosed as being progressive and causing death as foreseen in the proposed Bill, violates the very human right to decide on the time and manner of one's own end in life (and for this to reach out to voluntary help from others). A different assessment procedure should be discussed, in which doctors 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. Rather, they should put centre stage what the individual considers to be quality of life. The role of doctors would then be to focus 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

[32] Cf. http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dansketnomedicalsociety-31082022.pdf pages 11, 13 and 31.

"surprise effect" and impact for these loved ones.

This approach would also alleviate any pressure that doctors may feel about making predictions about "reasonably expected to die within six months" (and twelve months with neurodegenerative conditions), and about whether or not a condition is "expected to result in unbearable suffering".

Q. 12 Do you think there are any further steps / actions that should be included?

A. No.

Q. 13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

A. No.

Assisted dying in Jersey should adhere to the approach of Canada, Belgium, the Netherlands, New Zealand, Switzerland and Germany (the latter two were forgotten to be listed on page 33 of the consultation report), which have no such minimum timeframe in law. For the very reason stated in the consultation report, which matches DIGNITAS' 24 years' experience of having conducted over 3,400 PSAS[33]: by the time a person makes a formal first request, they have already carefully considered their decision

Any imposed minimum timeframe for a "period of reflection" – 14 days, 90 days, etc – appears arbitrary and paternalistic, and leads to possibly prolonging the suffering. The assessment procedure as outlined in the consultation report already takes time. In the Swiss legal system of PSAS, as mentioned, there is no such mandatory waiting period and it does not appear to have posed a problem in over 35 years of this being practice.

Q. 14 Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

A. No.

See Q. / A. 13

Q. 15 Do you agree that the law <u>should not</u> prohibit professionals for raising the subject of assisted dying?

A. Yes – agree.

This is in line with the concept of the right and freedom of choice. See also Q. / A. 8.

Q. 16 Do you agree that the law <u>should not</u> place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

A. Yes – agree.

See Q. / A. 15 and 8. However, all health care professionals should be obliged 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.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

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[33] http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2021.pdf

A. No.

This is an unnecessary criterion which limits access to assisted dying for people who suffer from slowly progressing illnesses and may not be seen as eligibly in the now limited to two rounds of assessments but possibly be found eligible in a third round in due course.

Q. 18 Should the law allow for confirmation of consent to proceed?

A. Yes.

This is an element of safety ensuring that the person who wishes to have assisted dying reaches their goal.

Q. 19 Should the law allow for the option of a waiver of final consent?

A. Yes– the law should allow for a waiver of final consent.

This provides an important element of emotional relief for a severely suffering person, especially those with a diagnosis that is likely to rob them of their capacity of judgment e.g. a brain tumour or dementia.

Q. 20 Do you agree with the two different approval routes as proposed?

A. No.

See Q. / A. 11

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

A. See Q. / A. 11

Q. 22 Do you agree that the Law should provide for appeals to the Royal Court?

A. No.

As the consultation report points out in para 235, most jurisdictions do not provide for an appeal process within their assisted dying legislation, so it is not a necessity. The argument of making such provision in Jersey law "to help support public confidence" appears hypothetical in the light of the fact that a polls show a robust majority of the Jersey public in favour of assisted dying. Regarding para 250 "The decision of the Royal Court will be final. There will be no further right of appeal" overlooks that such provision may be in conflict with the ECHR.

Q. 23 Do you agree with proposed grounds for appeal?

A. See Q. / A. 22.

Q. 24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

A. No – do not agree, there should be no minimum time period for appeals.

Any time period, may it be 48 hours or longer or shorter, results in prolonging the suffering of the individual wishing to make use of assisted dying.

Q. 25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

A. See Q. / A. 22.

Q. 26 Do you agree that there should be no expiry date for the approval of an assisted death?

A. Yes – agree, there should be no expiry date.

This, for the reason stated in the consultation report. It matches the over 35 years legal practice of assisted dying / PSAS in Switzerland from which it is known that an "emergency exit door" (or "provisional green light" as it is called in the procedure at DIGNITAS) provides important emotional relief for suffering individuals[34].

Q. 27 Do you agree that there should be an Administering Practitioner with the person or nearby?

A. Yes.

Q. 28 Do you agree that a loved one should be able to support the person to self-administer the substance?

A. Yes.

This is an element of additional support and care. But it should be observed that this loved one is instructed by professionals about what to do, how, and to which extent.

Q. 29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

A. Yes.

Q. 30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

A. Don't know.

The people of Jersey will know best which authority, if any, makes sense to install.

Q. 31 Do you agree that post-death administrative review of each assisted death is required?

A. Yes.

To compare with Swiss legislation: assisted dying is considered an "unusual death" which entails investigation to ensure compliance with the law of the procedures leading to the death. This review may also be understood as a duty of the state to protect life, in the sense of ensuring that no one will lose their life due to illegal actions by others. Clearance of the assisted dying case by the administrative review will also emotionally relieve everyone involved, e.g. medical professionals and loved ones, as they such will be assured of having acted correctly.

Q. 32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service?

A. Don't know.

See Q. / A. 30

[34] Cf. "Aims – Philosophy – Activities of DIGNITAS", pages 3 and 24, http://www.dignitas.ch/images/stories/pdf/broschuere-verein-e.pdf

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)

A. Yes – agree, it should not be considered an essential service.

The law should be changed as it is outlined in para 331 of the consultation report.

Additional comments on the consultation report

Re page 12 "A number of studies have been undertaken to try to understand whether assisted dying results in increased rates of suicide…"

The consultation report does not mention the suicide rate of Switzerland, a country with over 35 years standing practice of assisted dying / PSAS and arguably one of the most liberal of such schemes: the number of DIY-suicides has declined for many years (and levelled off from the year 2007 onwards)[35].

Re para 319 "The Jersey Assisted Dying service: […] must be safe, and protect and safeguard people who may be vulnerable to coercion and control"

It should be noted that the argument of protecting vulnerable people 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. Such paternalism very much applies to psychiatry, which has a long-standing view that a desire to die is a manifestation of mental illness, whilst in fact patients who secure and utilise a lethal prescription are generally exercising an autonomous choice unencumbered by clinical depression or other forms of incapacitating mental illness[36].

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, as pointed out earlier in this submission, practical and effective and not merely theoretical or even illusionary[37]. Only wide eligibility criteria will resolve the undesirable negative consequence that people travel to DIGNITAS or choose unguided risky DIY-suicides.

Re Appendix 2 jurisdictions where assisted dying is permitted (page 102 of the consultation report): the list lacks three countries (though, two of them, Switzerland and Germany, are mentioned in the consultation report):

Country	Date legislation came into effect	For those with terminal illness only?
Switzerland	1942 (though, suicide and assistance were decriminalised already earlier)	No
Germany	2020 (and earlier up until 2015)	No
Italy[38]	2019 (court judgment)	specific situation

[35] See: http://www.dignitas.ch/images/stories/pdf/statistik-suizid-ftb-bevoelkerung-lebenserwartung-ch-e.pdf

[36] Cambridge Quarterly of Healthcare Ethics 2014, http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9333247&fileId=S0963180114000085

[37] 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).

[38] By judgment 242/2019 of 25 September 2019, the Constitutional Court of Italy – dealing with the case of criminal prosecution against MARCO CAPPATO for assisting in the suicide (at DIGNITAS) of Fabiano Antoniani, a man

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 consultation report is submitted by e-mail. DIGNITAS confirms to have read and understood the Privacy Notice set out in the consultation document.

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

Ludwig A. Minelli Silvan Luley

paraplegic, blind and on life-support after a car accident in 2014 – found article 580 of the Italian Criminal Code (prohibiting to help or convince someone to commit suicide) unconstitutional insofar as it did not make an exception for assisting in the suicide of a person fully capable of making free and conscious decisions with a condition such as Mr. Antoniani, that is, an irreversible pathology causing physical or psychological suffering which the person considers intolerable. https://www.cortecostituzionale.it/actionSchedaPronuncia.do?anno=2019&numero=242