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To die with dignity

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Assisted dying Isle of Man public consultation

Responses to the questions in the consultation / survey
Submission by DIGNITAS – To live with dignity – To die with dignity
Forch, Switzerland

for and on behalf of the 7 Isle of Man and 1,433 UK members
of DIGNITAS – To live with dignity – To die with dignity
submitted in electronic format to privatemembersbill@tynwald.org.im

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1) Introduction

This submission answers the 28 questions of and comments on the consultation / survey regarding Assisted Dying on the Isle of Man[1]. In this, it also provides information for the discussion on introducing assisted dying legislation on the Isle of Man. 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 proposed assisted dying Bill for the Isle of Man is an important step forward to resolve several problems of the present legal situation 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 Bill despite raising criticism in some points as explained hereafter.

DIGNITAS is happy to give further evidence, personal, oral and written, if members of Tynwald and/or others involved in the consultation would wish so, as DIGNITAS already did in earlier 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

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1 https://consult.gov.im/private-members/assisted-dying
2 See subheading 4 of 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 the Isle of Man[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 or her own 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 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].

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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).

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 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

[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

> 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, 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

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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

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.

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 of the consultation / survey

Questions (Q.) 1 – 6 regarding name, address, etc.

Answer (A.): See page 1 of this submission.

Q. 7 May we publish your response?

A. Yes, in full.

Q. 8 In principal, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

A. Agree.

Assisted dying should be permitted not only for the terminally ill, but for everyone who "is capable of freely reaching a decision on this question and acting in consequence" as found by the ECtHR[22]. It is an individual's human right and freedom to decide on the time and manner of their own end in life, as outlined in subheading 2 of this submission. Several polls have shown that a majority of the people in the UK and the Isles wish for assisted dying to be legalised, which is also the case for the Isle of Man according to an Island Global Research opinion survey carried out in May 2021 mentioned in the overview on this public consultation. Permitting assisted dying is to protect lives: premature deaths can be avoided because individuals would not, or at least less likely, (need to) travel abroad to DIGNITAS or to take to risky do-it-yourself (DIY) suicide attempts to end their suffering. And, permitting assisted dying is to improve health, in the words of Julian Gardner, Chairperson of the Voluntary Assisted Dying Review Board of the state of Victoria, Australia[23]: "Having some control of the dying process may lift psychological and general health. For many people, having access to medication gives them the option to exercise their autonomy and die on their own terms. Some of those people choose not to have the medicine dispensed and some have the medication and choose not to take it. We know from feedback they do receive comfort from that[24]."

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[20] As to the Isle of Man, see for example the result of the Island Global Research opinion survey mentioned in the Overview https://consult.gov.im/private-members/assisted-dying/#pasted-question-16699768286-74352-16699768296-65456

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

[22] Judgment in the case of HAAS v. Switzerland, paragraph 51, mentioned in subheading 2 of this submission.

[23] https://www.safercare.vic.gov.au/about/vadrb/members

[24] In the article "Why some people with euthanasia drugs do not take the fatal dose", in "The Age", 8 January 2023.

To only allow access to assisted dying for individuals who face a terminal illness, that is, "diagnosed them as having a progressive disease, which can reasonably be expected to cause their death", is to discriminate against individuals who suffer from other health conditions which severely impair their quality of life. 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. 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[25].

Those denied access to and help in assisted dying are left to illegal and/or risky approaches and methods, for example, unguided do-it-yourself (DIY)-suicide attempts of which the majority fail with dire consequences for the individual, their loved ones and society in general[26]. 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[27]. 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 potentially leading these people to not talk to doctors, therapists and their loved ones but "to take matters in their own hands"[28].

Q. 9 Do you think that there should be a limit on their life expectancy?

A. No.

The eligibility criterion of any life expectancy limit should be done away with. 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 a set time such as 6 or 12 months or any other number of months or days. There may be life expectancy *estimates* based on experience, depending on the

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[25] 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
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

[26] 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

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

[28] 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

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 a set time span, but another may estimate this to be different. Depending on the opinions of the two separate doctors foreseen in the process for assisted dying patients meet 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 (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.

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.

DIGNITAS suggests that the Isle of Man Assisted Dying legislation adopts eligibility criteria that do not give precedence to what some doctors judge about life expectancy 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 diagnoses a terminal illness or other and estimates a certain life expectancy.

Note: the online survey does not provide and allow for ticking "No" with question 9, which may be due to a pre-decision not to look into this aspect (again), but that some limit on an individual's life expectancy as an eligibility criterion is firm, unfortunately.

Q. 10 Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

A. Yes.

However, the criterion of "unbearable suffering that cannot be alleviated by other means" should be done away with. A medical condition which impairs an individual's quality of life is itself sufficient grounds to permit access to assisted dying. Besides, only the individual is capable of determining whether their suffering is "unbearable"; it would be an entirely subjective criterion.

Q. 11 If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

A. Yes.

This provides an important element of relief for a suffering person, especially those with a diagnosis that is likely to rob them of their ability to ingest the medication themselves and orally.

Q. 12 Do you agree that assisted dying should be available only to people over the age of 18 Years?

A. No.

This, even though it is to be expected that requests for assisted dying on the Isle of Man will come forward mainly from individuals 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[29]. 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 the Netherlands adhere to this and allow for under-18 to access assisted dying under specific circumstances[30]. The Isle of Man should take this as an example. A 17-year-old young may well have capacity to understand the consequences of a diagnosis of a severe illness, may it be terminal cancer 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 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[31].

Q. 13 Should they have to be permanent residents of the Isle of Man?

A. No.

All discrimination related to the place of residency should be avoided. The issue of potential "assisted dying tourism", i.e. people from other parts of the UK or even beyond (trying to) access assisted dying on the Isle of Man, should not be solved with setting up discriminating criteria, but with engaging in the decriminalisation of assisted dying in legislations around the Isle of Man, so that such people would not need to consider at all turning to the Isle of Man (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"[32].

Q. 14 If you agree they should be permanent residents please state for how long.

A. See Q. / A. 13

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29 https://www.bfs.admin.ch/bfs/en/home/statistics/catalogues-databases/publications.assetdetail.3902308.html

30 https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

31 Cf. judgment by the Austrian Constitutional Court of 11 December 2020 mentioned in subheading 2 of this submission.

32 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

Q. 15 Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

A. No.

Whilst DIGNITAS acknowledges that involving two separate doctors 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 declining individual may have little left of, and it prolongs the suffering.

In the Swiss legal system of PSAS, one doctor is seen as sufficient[33]. 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). This has proved to work well for over 35 years, and DIGNITAS suggests this approach.

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 "terminal" 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 causes unbearable suffering and whether or not it 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 "surprise effect" and impact for these loved ones.

This approach would also alleviate any pressure that doctors may feel about making predictions about whether a suffering is "unbearable" and «cannot be alleviated by other means" (cf. Q. / A. 10) and/or whether or not the illness "can reasonably be expected to cause death". All these are criteria of opinion, which by nature is subjective. The patient's view should be taken seriously with respect to their own suffering, just as the doctors' word is to be taken with respect as to the diagnosis and treatments and medication possible.

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

Q. 16 Should any health professional be able to conscientiously object to being part of an assisted dying programme?

A. Yes.

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. 17 Do you agree that if either doctor is unsure about the person's capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

A. Yes.

Still though, 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[34].

Q. 18 Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

A. Yes.

Q. 19 Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

A. No.

The person should sign a written declaration of their request, but to have this witnessed and signed by one or more doctors is not necessary. In the assisted dying law proposal for the Isle of Man two doctors will anyway interact with the individual requesting assisted dying and therefore can verify the written request. In the Swiss legal system of PSAS there is no such mandatory witnessing and signing provision, and it does not appear to have posed a problem in 35 years of this being practice.

Q. 20 Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?

A. No.

Assisted dying on the Isle of Man should adhere to the approach of Canada, Belgium, the Netherlands, New Zealand, Switzerland and Germany which have no such waiting period in law[35]. The experience of DIGNITAS derived from having conducted over 3,400 PSAS is that, generally, people who contemplate end-of-life-choices make up their mind as part of their

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[34] This approach 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

[35] Cf. the Assisted Dying in Jersey Consultation Report, page 33, para 76.a. https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf

"personal life philosophy" long before they would face a health situation in which they would get in touch with DIGNITAS to request PSAS.

Any imposed minimum timeframe for a waiting period appears arbitrary and paternalistic, and leads to possibly prolonging the suffering. The assessment procedure as foreseen in the proposed Bill for the Isle of Man already takes time.

Q. 21 Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

A. See Q. / A. 20

Q. 22 Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

A. Yes. But it should be foreseen that if the person cannot do so for health reasons and if there is no relative, someone else should be able to collect it.

Q. 23 Should this be able to be stored securely in the person's home until they decide whether they want to take it or not?

A. Yes.

Q. 24 If they change their mind should the medication be returned to the pharmacy immediately?

A. Yes.

Q. 25 Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

A. Yes.

Q. 26 Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

A. Yes.

Q. 27 Should it be possible to include the provision of assisted dying in a "living will" or advanced directive?

A. Yes.

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. 28 Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

See Q. / A. 15

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 Policy in the Online Survey and that this submission may be published in full.

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

Ludwig A. Minelli Silvan Luley