

DIGNITAS

To live with dignity

To die with dignity

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Proposal for an Assisted Dying Bill for England and Wales **Response to the consultation by “DIGNITAS - To live with dignity - To die with dignity”, Forch, Switzerland**

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1) Introduction

“This is a form of evolution, of humanity”

Sir Edward Downes
British conductor and musician (1924 – 2009)¹

¹ As he stated during his consultation with the Swiss physician granting him the “green light” for assisted dying.

In recent years, questions dealing with the subject of self-determination at the end of life, (assisted) suicide and euthanasia have arisen more and more and are now discussed in the public, in parliaments and courts.

Of the many reasons for this development, one is the progress in medical science which leads to a significant prolonging of life expectancy. In fact, even during the congress of the Swiss General Practitioners in 2011² this was an issue when it was emphasised that a sudden death, for example due to a 'simple' heart attack or a stroke is nearly unthinkable today, due to possibilities of modern intensive care.

Obviously, this progress is a blessing for the majority of people. However, it can also lead to a situation in which death as a natural result of an illness can be postponed to a point much further in the future than some patients would want to bear an illness. More and more people wish to add life to their years – not years to their life. Consequently, people who have decided not to carry on living but rather to self-determinedly put an end to their suffering started looking for ways to do so. This development has gone hand in hand with tighter controls on the supply of barbiturates and progress in the composition of pharmaceuticals which led to the situation that those wishing to put an end to their life could not use this particular option anymore for their purpose and started to choose more violent methods. A further, parallel, development was the rise of associations focusing on patient's rights, the right to a self-determined end of life and the prevention of the negative effects resulting from the narrowing of options.

In England, as long ago as 1935 a Voluntary Euthanasia Society was formed and the year after, a Voluntary Euthanasia Bill was discussed in the House of Lords.

In Switzerland, 30 years ago, EXIT (German part of Switzerland) was founded, in the same year as EXIT-ADMD (French part of Switzerland), and shortly afterwards the first associations to offer the option of an accompanied suicide to its members. Later, associations like EX INTERNATIONAL, DIGNITAS and SUIZID-HILFE followed, the only difference between these organisations being mainly the acceptance or not of members residing in countries other than Switzerland. As a result of the above-indicated aspects and other developments in modern society, the focus of all associations has widened to include working on suicide preventive issues directly or indirectly, especially suicide attempt prevention.

Today, EXIT has 60,000 members, EXIT-A.D.M.D. 17,500 and EX INTERNATIONAL approximately 700 members. DIGNITAS, together with its independent German partner association DIGNITAS-Germany in Hannover, counts over 6,000 members worldwide of whom almost 900 reside in the United Kingdom³.

² Congress of Swiss General Practitioners in Arosa, March 31st – April 2nd, 2011, see online: <http://www.arosakongress.ch>

³ <http://www.dignitas.ch/images/stories/pdf/statistik-mitglieder-wohnsitzstaat-31122011.pdf>

In the more than 14 years of DIGNITAS’ existence, 207 members of DIGNITAS residing in England and Wales – and a further 10 members from Northern Ireland and Scotland – have made use of the option of an accompanied suicide in Switzerland⁴. For all members, being assisted and accompanied through the final stage of their life towards their self-determined end was and is an issue of major importance. DIGNITAS always encourages members to have their next-of-kin and/or friends at their side during this stage, as well as on their journey and at the accompaniment itself.

However, the present legal situation in England and Wales, just as much as in the rest of the U.K., has the appalling effect that this very important support towards the end of life must take place shadowed by the fear of prosecution, sometimes even leading patients to decide to travel only with very few loved ones or even alone. This effect, deriving from the current legal situation, can only be seen as consequence of disrespect of human dignity by the state. For England and Wales, the publication by the Crown Prosecution Service (CPS) of the “Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide” in February 2010⁵, sparked by the court case of DEBBIE PURDY, did not change this; in fact, it could not change the legal status quo as this authority simply does not have the competence to change the law – only Parliament can do so.

The fact that suicide as such is not a crime (anymore) in the U.K., yet aiding, abetting, counselling or procuring the suicide of another or an attempt by another to commit suicide (Suicide Act 1961) *is* a crime, finds a different approach in Swiss law: whilst in Switzerland, too, suicide as such is not a crime, article 115 of the Swiss Criminal Code states:

“Whoever, from selfish motives, induces another person to commit suicide or aids him in it, shall be imprisoned for up to five years or pay a fine, provided that the suicide has either been completed or attempted.”

The obvious difference is the ‘selfish motives’: whilst in the U.K. the law basically threatens to punish assistance in suicide whatever the motive, Swiss law makes a clear distinction of motives, excluding assistance out of non-selfish motives, and thus gives a basis for assisted (accompanied) suicide – made possible by associations like EXIT, DIGNITAS and others.

DIGNITAS very much welcomes the All Party Parliamentary Group proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life: it brings the issue of end-of-life-questions to the level where it should be addressed, the legislation.

⁴ As per November 2012; for other countries see: <http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2011.pdf>

⁵ http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.pdf

2) Article 8 § 1 of the European Convention on Human Rights (ECHR) and the right to a voluntary death

On March 8th, 1951, the U.K. ratified and later implemented in its law the European Convention on Human Rights, to which all European states now adhered (with the exception of Belarus and the Vatican). Since then, in specific cases, set legal situations may be questioned whether they would be in line with the basic human rights enshrined in the ECHR. However, 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"⁶. The ECHR is a living instrument and its text and case law need to be taken into consideration when raised in court cases just as much as in legislation.

In the judgment of the European Court of Human Rights in the case of *DIANE PRETTY v. the United Kingdom* dated April 29th, 2002⁷, at the end of paragraph 61, the Court expressed the following:

"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 the mentioned judgment *DIANE PRETTY*, 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 November 3rd, 2006, the Swiss Federal 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 Convention stating:

⁶ Convention for the Protection of Human Rights and Fundamental Freedoms, page 5, available online: http://www.echr.coe.int/NR/rdonlyres/D5CC24A7-DC13-4318-B457-5C9014916D7A/0/CONVENTION_ENG_WEB.pdf

⁷ Application no. 2346/02; Judgment of a Chamber of the Fourth Section, available online: <http://cmiskp.echr.coe.int/tkp197/view.asp?action=html&documentId=698325&portal=hbkm&source=externalbydocnumber&table=F69A27FD8FB86142BF01C1166DEA398649>

“The right of self-determination in the sense of article 8 § 1 ECHR includes the right to decide on the way and the point in time of ending one’s own life; providing the affected person is able to form his/her will freely and act thereafter.”⁸

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

“It cannot be denied that an incurable, long-lasting, severe mental impairment similar to a somatic one, can create a suffering out of which a patient would find his/her life in the long run not worth living anymore. Based on more recent ethical, juridical and medical statements, a possible prescription of Sodium Pentobarbital is not necessarily contra-indicated and thus no longer generally a violation of medical duty of care . . . However, utmost restraint needs to be exercised: it has to be distinguished between the wish to die that is expression of a curable psychic distortion and which calls for treatment, and the wish to die that bases on a self-determined, carefully considered and lasting decision of a lucid person (‘balance suicide’) which possibly needs to be respected. If the wish to die bases on an autonomous, the general situation comprising decision, under certain circumstances even mentally ill may be prescribed Sodium Pentobarbital and thus be granted help to commit suicide.”

And furthermore:

“Whether the prerequisites for this are given, cannot be judged on separated from medical – especially psychiatric – special knowledge and proves to be difficult in practice; therefore, the appropriate assessment requires the presentation of a special in-depth psychiatric opinion...”

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

On January 20th, 2011, the European Court of Human Rights rendered a judgement⁹ and stated in paragraph 51:

”in the light of this jurisdiction, the Court finds that the right of an individual to decide how and when to end his life, provided that said individual was in a position to make up his own mind in that respect and to take the appropriate action, was one aspect of the right to respect for private life under Article 8 of the Convention”

⁸ BGE 133 I 58, page 67, consideration 6.1. To be found on-line: <http://www.bger.ch/index/jurisdiction/jurisdiction-inherit-template/jurisdiction-recht/jurisdiction-recht-leitentscheide1954.htm>

⁹ Application no. 31322/07; Judgment of a Chamber of the First Section (in French), available online: http://cmiskp.echr.coe.int/tkp197/view.asp?action=html&documentId=880260&portal=hbkm&source=extern_albydocnumber&table=F69A27FD8FB86142BF01C1166DEA398649

Even though the European Court of Human Rights thus confirmed the statement of the Swiss Federal Court and also recognized that someone's decision to determine the way his or her life will end is part of the right to self-determination protected by article 8 § 1 of the Convention, it failed to postulate a positive obligation for the contracting states of the Convention to give those individuals, who would like to make use of this right, an entitlement against the state to make access possible to the necessary means for safely making use of such right.

There are further cases pending at the said Court which rest upon this very issue of which one is the case of ULRICH KOCH against Germany¹⁰. In this case, the applicant's wife, suffering from total quadriplegia after falling in front of her doorstep, 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 commit suicide at her home; at the same time, obviously, he claimed a violation of his own rights as well. On July 19th 2012, the Court decided that the German Federal Institute for Drugs and Medical Devices' decision to reject his wife's request and the German Administrative Courts' refusal to examine the merits of his motion interfered with his right to respect for his private life under article 8 of the Convention. However, the Court did not decide whether this interference was justified; the Court only decided that the German courts unlawfully rejected Mr. Koch's right to raise own claims. The case is not yet finalised as it has been requested to be referred for re-consideration to the Grand Chamber of the Court.

In light of the fact that the Court confirmed the judgment of the Swiss Federal Court, declared admissible the case of Mr. Koch and because of respect for human personal autonomy, which the Court acknowledges as an important principle in order to interpret the guarantees of the Convention, further legal developments are to be expected.

Dignity and freedom of humans mainly consists of acknowledging the right of someone with full capacity of discernment to decide even on existential questions for him- or herself, without outside interference. Everything else would be paternalism compromising said dignity and freedom. In the judgment DIANE PRETTY v. the United Kingdom, the Court correctly recognized that this problem will present itself increasingly within the Convention's jurisdiction, due to demographic developments.

We would like to emphasize that in this context, since the case of ARTICO v. Italy (judgment of May 13th, 1980, series A no. 37, no. 6694/74¹¹), the developed practice (so-called ARTICO-jurisdiction) is of major importance. In paragraph 33 of said judgment the Court explained:

¹⁰ Application no. 479/09, to be found online: <http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-112282>

¹¹ To be found online: <http://cmiskp.echr.coe.int/tkp197/view.asp?action=html&documentId=695301&portal=hbk&source=externalbydocnumber&table=F69A27FD8FB86142BF01C1166DEA398649>

“The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective; . . .”

As the Convention, in the frame of the guarantee of article 8 § 1, comprises the right or the freedom to suicide, then everyone who wishes to make use of this right or freedom has a claim that he or she shall be enabled to do this in a dignified and humane way. Such individuals should not be left to rely on methods which are painful, which comprise a considerable risk of failure and/or endanger third parties. The available method has to enable the individual to pass away in a risk-free, painless manner and within a relatively short time. Such a method must also consider aesthetic aspects in order to enable relatives and friends to attend the process without being traumatized.

3) The protection of life and the general problem of suicide

In the judgment *DIANE PRETTY v. the United Kingdom* mentioned earlier, the Court rightly paid great attention to the question of the influence of article 2 of the ECHR – the right to life, especially the aspects of protection for the weak and vulnerable. In the meantime, the 14 years of experience of the US-American state of Oregon derived from its “Death With Dignity Act” shows that the question of the weak and vulnerable does not pose a problem in reality: neither the weak nor the vulnerable nor those with insufficient (or even without) health insurance would choose the option of physician assisted suicide, but in fact the self-confident, the above-average educated, the strong ones.¹²

Yet, the principle of protection of life cannot be seen only in the light of the individual life of a single person who wishes a self-determined end to his or her life; it must also be applied in questions regarding public health.

Until now, national and international debates on assisted suicide and euthanasia never realized that, apart from the small number of individuals who wish to end their life due to severe suffering with one of the few available methods (palliative care, assisted suicide, etc.), there is a problem on a much larger scale which questions the sanctity of life: the general problem of suicide and suicide attempts.

In the year 2010 there were, in England and Wales together, 4,488 registered suicides (deaths given an underlying cause of intentional self-harm or an injury/poisoning of undetermined intent) in adults aged 15 years and over; the total for the U.K. was 5,608¹³.

¹² See the death with dignity act annual reports of the Department of Human Services of the state of Oregon, to be found online: <http://public.health.oregon.gov/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>

¹³ Publications of the Office for National Statistics, to be found online: <http://www.ons.gov.uk/ons/taxonomy/index.html?nscl=Suicides+and+Intentional+Self-harm>

On average, in England, one person every two hours dies as a result of a suicide attempt, with men aged 35 to 49 being the group with the highest suicide rate¹⁴. Many other states, like Switzerland, show a very high number of suicides and even higher counts of failed suicide attempts. In response to the request regarding information on suicide and suicide attempts in Switzerland from Andreas Gross, a member of the Swiss National Council, the Swiss government rendered its comments to the parliament on January 9th 2002¹⁵: it explained that, based on scientific research (National Institute of Mental Health in Washington), Switzerland might have up to 67,000 suicide attempts annually – that is 50 times the annual number of 1,350 of fulfilled (and registered) suicides. Thus, the risk of failure of an individual suicide attempt is up to 49:1!

Given the results of the scientific research mentioned before, suicide attempts in England and Wales must be estimated to be up to 224,400 per year; for the whole U.K. up to 280,400. Even if the ratio of failed suicide attempts to officially registered suicides was 'only' 9:1, as some psychiatrist, therapists and coroners assume (according to the afore mentioned comments of the Swiss government), there would still be 44,880 suicide attempts in England and Wales, with 56,080 in the U.K. in total.

Referring to the previously mentioned ARTICO-jurisdiction: no matter whether the risk is 49:1 or 'only' 9:1, it indicates that an individual can only make use of the right to end his or her life self-determinedly by accepting such a high risk of failure and therefore an unbearable (further) deterioration of his or her state of health. This signifies however, that the right to end ones life self-determinedly under the conditions currently found in England and Wales, the U.K. and most other contracting states of the ECHR is neither practical nor efficient.

The negative and tragic result of 'clandestine' suicides is diverse:

- high risk of severe physical and mental injuries for the person who attempts suicide;
- psychological problems for next-of-kin and friends of a suicidal person after their attempt and their death;
- personal risks and psychological problems for rescue teams, the police, etc., who have to attend to the scene at or after a suicide attempt;
- enormous costs for the public health care system, especially costs arising from caring for the invalid, and costs for a country's economy (for example due to delay of trains) and costs for the public sector (rescue teams, police, coroner, etc.)¹⁶

¹⁴ Report on the consultation on preventing suicide in England, p. 2 and 22, to be found online:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128463.pdf

¹⁵ Online (in German): http://www.parlament.ch/d/suche/seiten/geschaeft.aspx?gesch_id=20011105

¹⁶ See the study of PETER HOLENSTEIN: <http://www.dignitas.ch/WeitereTexte/Studie%20Suizidkosten.pdf>. In Switzerland, in the year 1999, there were 1'269 registered suicides leading to estimated costs of 65,2 Million Swiss Francs; given that the estimated number of suicide attempts is considerably higher (based on information provided by forensic psychiatrists, coroners, etc., the study calculates with a suicide attempt rate that is

Despite the enormous number of committed/fulfilled and failed suicide attempts and their negative effects, governmental measures towards an improved suicide and suicide attempt prevention are few. Some programs seem to focus very much on narrowing access to the means of suicide and a lot of money is spent on constructing fences and nets on bridges¹⁷ and along railway lines. However, these measures do not tackle the problem at its root. By all means, it must be the aim of all efforts to reduce the number of suicides, especially the number of unaccompanied 'clandestine' suicides, and, of course, the much higher number of suicide attempts. For this, the starting point of effective suicide attempt prevention is looking at the root of the problem: the taboo surrounding the issue, the wall of fear of embarrassment, rejection and losing one's independence.

Authorities' restrictions and prohibitions in connection with assisted dying also raise the question of violation of article 3 of the European Convention of Human Rights, the prohibition of torture which states that no one shall be subjected to torture or to inhuman or degrading treatment or punishment. Article 3 could be violated for example if a palliative treatment is made with insufficient effect, thus on the one hand constituting a prohibition of passive euthanasia and on the other hand a forced medication; if physical and emotional suffering and pain of a certain minimum level are given, such approach could possibly fulfill the notion of an inhumane treatment. In the judgment *DIANE PRETTY v. the United Kingdom* mentioned before, the Court avoided to look into the aspect of the states' positive duty to protect from such inhumane treatment in cases of assisted dying. There is room to look into this aspect more closely in future cases¹⁸.

4) Suicide prevention – experience of DIGNITAS

Everyone should be able to discuss the issue of suicide openly with their General Practitioner, psychiatrists, carers, etc. The taboo which surrounds the topic must be lifted. The possibility of – anonymously as well as openly – using a help-line is a very important service provided by some institutions¹⁹. However, for many people 'talking about it' does not suffice: they seek the concrete option of a painless, risk-free, dignified and self-determined death, to put an end to their suffering.

DIGNITAS' experience with all people – no matter whether they suffer from a severe physical ailment or other impairment, or wish to end their life due to a personal crisis – shows that giving them the possibility to talk to someone, for

10 to 50 times higher than the registered suicides), these costs could well be around 2'431,2 Million Swiss Francs.

¹⁷ For example, the construction of a net at the Golden Gate Bridge in San Francisco, USA, is estimated to cost some 45 to 50 million US \$, see: <http://www.ggsuicidebarrier.org/index.php>

¹⁸ See: STEPHAN BREITENMOSER, The right to assisted dying in the light of the ECHR (Das Recht auf Sterbehilfe im Lichte der EMRK), in: Frank Th. Petermann, Assisted Dying – Basic and practical questions (Sterbehilfe – Grundsätzliche und praktische Fragen), p. 184 ff, St. Gallen, 2006.

¹⁹ In England provided for example by The Samaritans, see <http://www.samaritans.org>

example at our organisation, openly and without fear of being put in a psychiatric clinic, has a very positive effect: they are – and feel that they are – being taken seriously (often for the first time in their life!); through this, they are offered the possibility of discussing solutions to the problem(s) which led them to feeling suicidal in the first place. They are not left to themselves and rejected like many suicidal individuals who cannot discuss their suicidal ideas with others through fear of being ostracized or deprived of freedom in a mental institution for some time.

Furthermore, through their contact with DIGNITAS, not only are their suicidal ideas taken seriously but they also know that they are talking to an institution which could in fact, under certain conditions, arrange for a 'real way out'. This aspect of authenticity cannot be underestimated.

This 'talking openly' unlocks the door to looking at all thinkable options. These include convincing the individuals in a personal crisis to visit a crisis intervention centre, referring severely suffering terminally ill to a hospice or the palliative ward of a appropriately equipped clinic, suggesting alternative treatments, directing patients who feel ill treated by their General Practitioner to other physicians, and so on; always depending on the individual's needs. Over one third of DIGNITAS' daily 'telephone-work' is counselling individuals who are not even members of the association who thus receive an 'open ear' and initial advice free of charge.

The experience of our organisation, drawn from over 14 years of working in the field of suicide prophylaxis and suicide attempt prevention, shows that – paradoxically – the option of an assisted suicide without having to face the severe risks inherent in commonly-known suicide attempts is one of the best methods of preventing suicide attempts and suicide. It may sound absurd: in order to prevent suicide attempts, one needs to say 'yes' to suicide. Only if suicide as a fact is acknowledged, accepting it generally to be a means given all humans to withdraw from life and also accepting and respecting the individual's request for an end in life, the door can be opened to 'talk about it' and tackle the root of the problem which made the individual suicidal in the first place.

Knowing about a 'real' option will deter many from committing suicide through insufficient, undignified means. Furthermore, in the preparation of an accompanied suicide, next-of-kin and friends are involved in the preparation process and encouraged to be present during the last hours: this gives them a chance to mentally prepare for the departure of a loved one and thus give their support and affection to the suicidal person until the very end of life.

At this point, we need to take a look at the two main arguments of opponents to legislation of any form of assisted dying: they argue that any form of legalisation could pressure 'vulnerable' individuals to end their life, for example because they would be pushed by loved ones not to be a burden on them anymore.

And it is suggested that legalisation would create a ‘slippery slope’, an unstoppable increase in numbers. The general understanding may be that individuals under the age of 18 or 16, people who are dependent on medical care and those who suffer from a loss of capacity to consent (for example due to dementia) would be classified as vulnerable. However, it is now acknowledged – especially in the very instructive annual reports of the Ministry of Health of the US-American State of Oregon²⁰ – that assisted suicide has absolutely nothing to do with ‘vulnerable’ individuals. Furthermore, ‘vulnerable’ is a pretext argument which distracts from the real problem: those who become suicidal yet are left alone with their problems, because there is still a taboo surrounding this issue, because the individual’s fear of being put in a psychiatric clinic or fear of having his or her suicidal thoughts denounced, belittled, ignored or dismissed. These individuals are the really vulnerable ones. The Journal of Medical Ethics carried an article with the title “Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in vulnerable groups”²¹. The problem-related relevant part of the abstract of this article has the following wording:

“Background: Debates over legalisation of physician-assisted suicide (PAS) or euthanasia often warn of a ‘slippery slope’, predicting abuse of people in vulnerable groups. To assess this concern, the authors examined data from Oregon and the Netherlands, the two principal jurisdictions in which physician-assisted dying is legal and data have been collected over a substantial period.

Methods: The data from Oregon (where PAS, now called death under the Oregon ‘Death with Dignity Act’, is legal) comprised all annual and cumulative Department of Human Services reports 1998–2006 and three independent studies; the data from the Netherlands (where both PAS and euthanasia are now legal) comprised all four government-commissioned nationwide studies of end-of-life decision making (1990, 1995, 2001 and 2005) and specialised studies. Evidence of any disproportionate impact on 10 groups of potentially vulnerable patients was sought.

Results: Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the

²⁰ Death with Dignity Act annual reports of the Department of Human Services of the state of Oregon, to be found online: <http://public.health.oregon.gov/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx>

²¹ Journal of Medical Ethics 2007;33:591-597; doi:10.1136/jme.2007.022335, to be found online: <http://jme.bmj.com/content/33/10/591.abstract>

focus of this study, none have been uncovered in Oregon; among extralegal cases in the Netherlands, there was no evidence of higher rates in vulnerable groups.

Conclusions: Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS or euthanasia will have disproportionate impact on patients in vulnerable groups. Those who received physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.”

Besides, not every individual who may be seen by third parties as vulnerable would personally share this view. One needs to bear in mind: There is a fine line where protection turns into undesired paternalism.

As to the ‘slippery-slope’ argument, we adhere to a statement of the full professor (‘Ordinarius’) for law ethics at the University of Hamburg, Germany, Dr. iur. REINHARD MERKEL, who looked into this argument in his report “Das Dammbrech-Argument in der Sterbehilfe-Debatte” (“The slippery-slope argument in the euthanasia debate”)²²: In this report he emphasized that arguments of this nature have always been the most misused instruments of persuasion in public debates on controversial subjects. They have always been the probate residuum of ideologists and demagogues.

Furthermore, based on the experience of the Zürich City Council, we now know that allowing to perform assisted suicide even in nursing homes for the elderly does not lead to any rise of such assisted (accompanied) suicides: of the 16,000 residents in Zürich homes for the elderly, only zero to two assisted suicides per year have taken place since the authorities allowed associations like EXIT, DIGNITAS and others to access such homes in 2002.

The issue is not whether someone would take advantage of assisted suicide: in fact, the majority of members of DIGNITAS who have requested the preparation of an accompanied suicide and who have been granted the ‘provisional green light’ do not make use of the option after all. Based on a study on our work, research into 387 files of members of DIGNITAS, who – through the given procedure in our organisation – received a basic approval from a Swiss physician, a ‘provisional green light’²³ as we call it, that he or she would issue the necessary prescription for an assisted suicide, 70 % did not contact us again after such notification. Only 14 % made use of the option of an assisted suicide, some after quite a long time²⁴. For many, the prospect of such a prescription signifies a return to personal choice at a time when their fate is very much governed by their

²² in: FRANK TH. PETERMANN, (ed.), Sicherheitsfragen der Sterbehilfe (Safety questions in assisted dying), St. Gallen 2008, p. 125-146

²³ For an explanation, read the general info-brochure of DIGNITAS, page 6 - 7, available online: <http://www.dignitas.ch/images/stories/pdf/informations-broschuere-dignitas-e.pdf>

²⁴ Extract of the study (available in German) online: <http://www.dignitas.ch/images/stories/pdf/studie-mr-weisse-dossier-prozentsatz-ftb.pdf>

suffering. It enables many to calmly wait for the future development of their illness and not to prematurely make use of an accompanied suicide, let alone take to a 'clandestine' suicide attempt with all its risks and dire consequences.

This shows that a liberal solution, which entirely respects the suicidal human being, offers more sophisticated results than solutions which in such situations deprive individuals of their dignity, personal freedom and responsibility for themselves.

5) General remarks on the proposed Assisted Dying Bill

As the All Party Parliamentary Group quite rightly puts it in the consultation paper: "Having to travel to Switzerland to die is not satisfactory for a number of practical, emotional and economic reasons..." In fact, no one should be forced to leave his or her home in order to make use of the basic human right of deciding on the time and manner of the end of his or her life. The current legal status of assisted dying in England and Wales as well as in many other countries is not only "inadequate and incoherent" as The Commission on Assisted Dying puts it on the front side of its final report²⁵, the situation is in fact a disgrace. It forces citizens to travel abroad in order to have freedom of choice. Besides the emotional strain and strength it takes to travel abroad in a deplorable state of health, the fact that only individuals with at least a minimum of financial resources – something that certainly not everyone in England and Wales has – can afford to travel to Switzerland (even though DIGNITAS offers reduction or even exemption of costs under certain circumstances) in order to make use of the option of a self-determined end in life, is by all means an unacceptable discrimination.

Clearly, the public is in favour of freedom of choice in these 'last issues'²⁶. Already in 1983 more than 76 % Britons answered 'Yes' when asked "About a person with a painful incurable disease; Do you think that doctors should be allowed, by law to end the patient's life, if the patient request it?"²⁷ This public attitude was made very clear in votes in the Canton of Zürich, Switzerland, on 15 May 2011: two fundamental-religious political groups brought two initiatives to the people's vote, of which one initiative aimed to prohibit the current legal possibility of assisted suicide entirely whilst the other aimed to prohibit access for non-Swiss citizens and non-residents of the Canton of Zürich. The result was overwhelming: even though a large part of the media had tried for years to scandalise the work of DIGNITAS through inaccurate, dumb tabloid-style press cover-

²⁵ See online: <http://www.demos.co.uk/publications/thecommissiononassisteddying>

²⁶ See for example the First Report of the Select Committee on Assisted Dying for the Terminally Ill Bill, to be found online: <http://www.parliament.the-stationery-office.co.uk/pa/1d200405/1dselect/ldasdy/86/8609.htm> or the BBVA Foundation Study European Mindset and others.

²⁷ British Social Attitudes Information System, see online: <http://www.britsocat.com>

age, the public voted by a huge majority of 85:15 and 78:22 against any narrowing of the current legal status quo²⁸.

If England and Wales (and other countries too) implements a law which allows a competent individual to have a safe, dignified, self-determined accompanied end in life in their own home, the ultimate goal of DIGNITAS – to become obsolete – will be in reach. Because, if people in England have a real choice, no English citizen needs to travel to Switzerland and become a 'freedom-tourist' (which is a term certainly more precise and appropriate than 'suicide-tourist') and thus DIGNITAS is not necessary anymore for them.

In the light of this, as mentioned before, DIGNITAS very much welcomes the All Party Parliamentary Group's proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life.

Based on experience drawn from over 14 years of operating, DIGNITAS very much adheres to the All Party Parliamentary Group's statement that "palliative care cannot prevent all suffering". Palliative care is 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 spiritual²⁹. Palliative care is widely accepted and practiced. It is the means of choice if the suffering of the individual is intolerable (in the personal view of the patient, of course) and the life expectancy is only a matter of a few days. It is certainly humanitarian and good practice in the sense of 'the Good Samaritan' to give a suffering, dying patient all the end of life care necessary and requested by the patient in order to soothe his or her ordeal.

Palliative care and assisted suicide are not two practices in conflict but in fact they have a complementary relationship even though sometimes the opposite is claimed, usually by opponents of assisted dying options. Almost every day DIGNITAS receives calls for help from patients stricken by the final stage of terminal cancer as well as their relatives and friends. As the administrative proceedings involved with the preparation of an assisted/accompanied suicide take quite some time, usually several weeks if not months, terminally ill patients are always recommended to pursue palliative treatment possibly leading to continuous deep sedation (sometimes also called terminal sedation). Thus, DIGNITAS has directed uncountable patients towards palliative care, has given advice how to access the support of specialist doctors, how to implement living wills in a way

²⁸ For links to the official statistics and a choice of media coverage on the results of the votes see online: http://www.dignitas.ch/index.php?option=com_content&view=article&id=26&Itemid=6&lang=en (on the site, scroll down to the comment/entry of 16 May 2011).

²⁹ Definition by the World Health Organisation, see online: <http://www.who.int/cancer/palliative/definition/en>

that it would give safety to the patient and also to the doctors practising palliative care, etc.

Voices claiming that palliative care “can solve anything” and “soothes any suffering” are not in touch with reality and try to mislead the public. There are severe sufferings for which medical science has still no cure, yet, for which palliative treatment is not an option or possibly only available in a very advanced late stage of that illness. Patients suffering from neurological illnesses such as Multiple Sclerosis, Multiple Systems Atrophy, Huntington’s Chorea, etc., or even more so quadriplegics³⁰ or patients suffering from a multitude of ailments related to old age³¹ are generally not *per se* eligible for palliative care and terminal sedation. These are, alongside terminal cancer, the ‘typical diagnosis’ why patient would seek (and in Switzerland usually obtain) the option of an assisted suicide. Certainly, these patients receive medical treatment for pain relief, but that cannot be compared with the dosages usually applied in end-of-life palliative care. Without doubt, such patients are experiencing severe suffering which can lead them to wish to end their life. In such cases, the wish for an accompanied (assisted) suicide is a personal choice which must be respected.

Still, we need to be clear about the fact that only a tiny minority of individuals would actually make use of an assisted suicide. First of all, for many, medical science offers relief, and second, for some – as Scottish MP Margo MacDonald who initiated the Assisted Suicide (Scotland) Bill quite rightly put it – “the legal right to seek assistance to end life before nature decrees is irrelevant due to their faith or credo”; yet there is a third important reason why in fact only a minority of patients would ‘go all the way’ and make use of an assisted dying: it’s the fact that ‘having the option gives peace of mind’. Having no hope, no prospect, not even the slightest chance of something to cling on is what we humans dislike most. We would like to have at least a feeling of being in control of things. Faced with a severe illness, patients usually ask their doctor: “will I get better?” or: “how much more time do I have?” but an exact medical prognosis is generally difficult if not impossible as the course of disease is different with each individual. In this situation, having options, including the option of a self-determined end in life in the sense of an ‘emergency exit’, can lift the feeling of ‘losing control’; this is what members of DIGNITAS tell us again and again. Legalising assisted dying is not about “doing it” but about “having the option of doing it”.

At this point, it is important to stress that all this is about assisted/accompanied suicide – not about euthanasia. The draft Bill speaks of “assisted dying”, however, quite clearly, from a ‘legal-factual’ perspective it is about suicide, a self-determined and self-induced end of one’s own life. It is about the personal decision of a competent individual assuming responsibility for his or her own life

³⁰ Such as for example the rugby-player Daniel James who was left paralysed with no function of his limbs, pain in his fingers, spasms, incontinence and needing 24 hour care after a sports accident.

³¹ Such as for example the well-known British conductor and musician Sir Edward Downes

and also about this individual being able to self-administer the lethal drug – not about a third person making decisions on behalf of this individual and taking actions to induce death. It is always the patient who is in charge, who decides which steps will be taken – until the very last moment. "Euthanasia" is a term rooted in the Greek language, meaning "good, mild, gentle death". However, its use and meaning ranges from all sorts of help at the end of life, to putting down animals, and to atrocities of the holocaust during WWII. Active euthanasia must be considered as murder or manslaughter and is a crime in Switzerland just as much as it is a crime in England and Wales.

In this context one needs to remember that much of the U.K. media – especially the tabloids – are notorious for spreading nonsense such as there being the option of "euthanasia" at a "Dignitas-clinic" where people would take "poison" or a "lethal cocktail", etc.; thus not only showing their incompetence but also their irresponsibility towards their actual task of informing the public in an accurate, balanced way. Truncating, falsifying, scandalising, a "me-too"-attitude and the incapacity to research and read: a large part of the media uses any opportunity to create hype in order to sell their TV, online and print products. What is even worse, the misleading words in fact cause a lot of suffering for which the media ignorantly denies responsibility. More than once we have had people from abroad, some of them in a quite deplorable state of health, showing up at DIGNITAS' doorstep because they believed the nonsense of a "clinic" where one can "check in and be put down". How distressing for them and for us too when we have to tell them that they have been misled by the media and that they have to go back home because DIGNITAS are not be able to help them right away.

Questions of life and death have always been subject to sensationalism. Deliberately or unintentionally generating life just as well as deliberately ending life can be well considered as the primary sensation to which the media has related to for centuries. Today's media – and even many politicians – mainly draw their existence from offering their consumers a daily motive for emotional outrage. The Zürich full professor in sociology, KURT IMHOF, made this clear in an interview that he granted the "Neue Zürcher Zeitung" (NZZ) on December 8th, 2007, stating that the result of such media coverage lies much further within the field of fiction than fact.

DIGNITAS favours the option of assisted (accompanied) suicide such as Swiss law allows them to practice and which the Swiss associations have been offering to their members for almost 30 years now. Assisted (accompanied) suicide implies the following:

- The individual is respected in his or her request to have an end to his or her suffering.
- This request is explicitly expressed by the individual, not only once but several times during the process of preparation and re-confirmed even in the final minute prior to the assistance. (In the case of accompanied suicide in Swit-

zerland, this is the moment prior to handing over the lethal drug to the individual).

- The individual expresses his or her desire to end his or her life not only verbally but undertakes the last act in his or her life him- or herself. (In the case of accompanied suicide in Switzerland, this is the action of the individual actually drinking the lethal drug or absorbing it in another form such as feeding it him- or herself through a PEG-tube or intravenous).
- All actions are based exclusively on the explicit will of the individual.
- With assisted/accompanied suicide, the individual always has to do the last act himself or herself; without such final act of the individual, there will be no ending of life. Thus, the taboo of ending someone's life actively (on request by the patient, which would be voluntary euthanasia or even without such request which would be non-voluntary, active euthanasia) does not have to be broken.
- Access to the option of an assisted suicide has a very important, yet all too often overlooked suicide attempt preventative effect, as already outlined earlier in this submission.

However, these aspects of assisted/accompanied suicide cannot hide the fact that with assisted suicide 'only', some individuals would be excluded from assistance in dying: an individual in a coma or suffering from advanced dementia would not be able to express his or her will, would not have sufficient capacity to consent and/or simply would not be able to do the last act which brings about the end of life him- or herself. For these situations, a different approach will be necessary and is already in place to some extent at least: the strengthening and implementation of the already wide-spread and widely accepted Patient's Advance Decisions (also called Patient's Advance Directives or Patient's Living Will) and possibly even regulations on how to implement (voluntary and non-voluntary) euthanasia such as in The Netherlands, Belgium and Luxembourg. Still, based on DIGNITAS' experience, the large majority of requests for an individual's dignified end in life can be covered by assisted (accompanied) suicide. Obviously, the All Party Parliamentary Group's proposal for a Bill adheres to the Swiss and Oregon model, which is about self-determined and self-induced ending of life by competent adults.

6) Comments on the 20 specific questions raised in the consultation document on the proposed Assisted Dying Bill.

Question 1 – If adequate safeguards can be found to allow assisted dying (assistance to die for terminally, mentally competent adults only) and no healthcare professional is obliged in any way to assist a patient to die, would you support a change in the law on assisted dying? The intention of the proposed law change is to ensure that patients at the end of life have choice over the manner and tim-

ing of their death, and that all patients are properly protected against potential abuse.

The short answer is 'Yes'. However, one needs to carefully analyse the meaning of terms such as 'adequate', 'terminally' and 'potential abuse'. We have dealt with all these aspects in this submission as far as possible.

Question 2 – Do you think upfront safeguards before an assisted death (as set out in the draft Bill) or retrospective safeguards after an assisted death (under the current law) are most effective for protecting patients?

As far as we can see, the draft Bill not only sets out upfront but also retrospective safeguards (such as the reporting of the death by assisted dying to a Monitoring Inspectorate which investigates the cases). This makes sense as the current law in England and Wales does not consider the special circumstances of proceedings with assisted dying; therefore, the retrospective safeguards after an assisted death under the current law are not sufficiently effective.

One should bear in mind that safeguards do not only protect patients but also their loved ones and third persons.

Generally, in setting up safeguards/eligibility criteria, one needs to be very careful not to be too rigorous, that is, to set up a system which turns the right to have access to assisted dying into a "mission impossible". One needs to bear in mind that there is a fine line between protection and undesirable paternalism. DIGNITAS defends the right of an individual to have access to a self-determined, dignified and risk-free end in life in the case that individual chooses this option. Following, we shall comment on those safeguards set out in the consultation paper pages 22 – 26 which DIGNITAS finds problematic, these are:

- 1) *two doctors* assess whether the patient meets the eligibility criteria
- 2) the patient has a *terminal illness* with a *prognosis of twelve months* or less to live
- 3) the two doctors would have to check, evidence and record that the patient has mental capacity to make the decision
- 4) the two doctors would have to check, evidence and record that the patient *is aware* of palliative, hospice and other support care available to them
- 5) if either doctor has any concerns that the patient does not meet these four criteria they *can* refer the patient to another health or social care professional for a second opinion
- 6) the patient must be able to prove that they are an adult (aged 18 and over)
- 7) the patient must be able to prove that they have been a resident of England and Wales for at least the previous year
- 8) the patient makes a formal written request which is *witnessed by an independent person*

- 9) the patient must wait for a period of at least 14 days – or 6 days if he or she is expected to die within one month – after the declaration takes effect before they can ask the attending doctor (or another registered doctor or nurse who has been authorised to do so by the attending doctor) to pick up the medication and deliver it to their home
- 10) the doctor or nurse remains on the premises, but does not have to be in the same room

Regarding point 1) – *two doctors* assess whether the patient meets the eligibility criteria

First, we need to look in general at the issue of having some sort of ‘gatekeeper’ giving consent (or not) for an assisted/accompanied suicide:

Up front, there can be only one person making the final decision on whether to continue with life or put an end to it: the individual him- or herself. As stated before, DIGNITAS favours the possibility of assisted (accompanied) suicide which implies that a) the individual has the capacity to consent and thus rationally express his or her will to end his or her life and b) the individual is able to carry out the final act which puts an end to his or her life (for example drinking the lethal barbiturate) by him- or herself.

Basically, any intervention by third parties with requests by individuals who wish to end their life stands in conflict with the individual’s right to self-determination and thus implies paternalism. However, we must not ignore the fact that some form of ‘gate keeping’ would make sense: the request of a patient stricken with terminal cancer must not be lumped together with the request of a young man suffering after the breakdown of the relationship with his girlfriend. Whilst both requests are to be taken seriously and should be respected up-front – this being the base of an authentic suicide-attempt prevention approach – the patient suffering from cancer certainly needs a different kind of attention to his or her request than the young man. In the first case, counselling on alternative options such as palliative care and the preparation of at least an option to an assisted suicide (what we at DIGNITAS call the ‘provisional green light’) are the means of choice, whilst in the latter case counselling making it clear that “other parents have beautiful daughters too” should take place. However, as already stated, in both cases the principle of respecting person’s request to end their life and certainly not denouncing, belittling, ignoring or dismissing that request should be the rule. Individuals who express a wish to end their suffering have valid personal reasons to do so – they want to be acknowledged and heard and not simply be dismissed as “being in a crisis” or even committed to a psychiatric clinic.

In this context, one should not overlook the fact that several completely different types of suicidal individuals may be found who are rarely comparable one to

another. Quite a number of commonly heard phrases – like “a suicide attempt is normally just a cry for help”, “80 % of people who have survived a suicide attempt would not like to repeat it”, “someone who talks about suicide will not do it” – are simply “thought savers” (an expression created by the American journalist LINCOLN STEFFENS, a friend of President Theodore Roosevelt³²).

“Thought savers” are a way to stop thinking about a particular problem without solving it. It is quite significant that such “thought savers” are very common in relation to the suicide problem. With a “thought saver”, one may get rid of the problem, belittling it so that it appears no longer worth thinking about. Hardly anyone asks, for instance when speaking of a “cry for help”: why does this person feel the need to undertake the risk of a suicide attempt in order to find help, instead of talking to other people and saying that they need help? In the special case of a suicidal situation, the reason for the “cry for help” without words is the risk of losing one’s liberty (due to being put in a psychiatric clinic) or the risk of not being taken seriously or being rejected (deprived of affection) if one talks to someone else about suicidal ideas. At DIGNITAS, we hear again and again how individuals felt a major relief after having had the opportunity of speaking to us openly about their idea to attempt suicide: these individuals acknowledge that being taken seriously and receiving honest information on the possibilities at the end of life and the risks involved with a self-attempted suicide helped them to ease the urgency of the feeling of wanting to die as soon as possible.

In Switzerland, the ‘gate keepers’ are basically medical doctors. Only a medical doctor can prescribe the lethal drug Pentobarbital of Sodium which is the one drug of choice for a dignified, risk-free and painless accompanied suicide. However, many medical doctors understandably argue that they should not be burdened with the responsibility of being the one and only gate-keepers of access to a self-determined end in life.

This last aspect even takes on more weight when it comes down to asking psychiatrists to serve as a part of the ‘gate-keeping’. As mentioned before, the Swiss Federal Court set the prerequisite of a “special in-depth psychiatric opinion”. Yet, it ignored the fact that psychiatrists regularly face an important conflict of interest in such cases: psychiatrists earn their income through the existence of mental disorders in other individuals. Therefore, if psychiatrists are asked to carry out appraisals (which would mean that such a patient could end his or her life), then these psychiatrists, in some health-care systems, from an economic point of view, are compelled to accept a reduction of their income. Amongst medical doctors, psychiatrists (more or less like paediatricians) are the category of medical doctors with the smallest income, and the economic conflict of interest is obvious. In addition, there is a psychological conflict of interest: from the statistics on causes of deaths it can clearly be seen that medical doctors have the highest rate of suicide amongst all occupational groups. Amongst the

³² In: The Autobiography of Lincoln Steffens

medical doctors, psychiatrists have an even higher rate of suicide than their colleagues not specialising in psychiatry, with women being at a higher risk than men³³, and the suicide of patients is traumatic for psychiatrists³⁴. Therefore, and for this very reason, a psychological conflict of interest arises for medical doctors and above all psychiatrists: if he or she helps a patient to realise his or her wish for a self-determined end to life by establishing an in-depth appraisal, then he or she further reduces the already low barrier against his or her personal suicidal tendencies by which he or she sees his or her existence endangered. This is known in analytic psychology as transference and countertransference.

The Swiss scientist FRANK TH. PETERMANN showed in his publication “Capacity to Consent (Urteilsfähigkeit)”³⁵, the numerous problems which derive from intending to make medical doctors and psychiatrists the ‘gate-keepers’ of assisted suicide.

Through giving third parties the responsibility for deciding whether somebody who requests an assisted death should be eligible for assistance, paternalism over individuals is enforced instead of strengthening the self-determination of individuals, a result which is in direct contradiction with the meaning and content of the ECHR.

Adhering to the case of HAAS v. Switzerland mentioned before – during which the individual contacted 170 psychiatrists yet did not find a single medical doctor acknowledging his request – as well as the general reluctance of medical doctors towards end-of-life-questions, DIGNITAS feels that having to find two doctors who would both need to accept the request, would be a prerequisite too strict, a hurdle too high. If the majority or even all medical doctors in England refuse to assess requests for personal reasons – which it is their right to do – then getting a formal request acknowledged becomes almost or entirely a “mission impossible”. Even in Switzerland, which has a model of (at least) one medical doctor assessing the patient’s request for an assisted suicide, this requirement is the “bottleneck” of dealing with requests for assisted suicide as it is very difficult to find cooperating, liberal medical doctors.

Adhering to the Swiss and Oregon model in which only doctors may prescribe the lethal drug for assisted suicide, the Assisted Dying Bill’s scheme of involving health professionals is practicable and sensible. However, in the light of the above considerations, it should be implemented in the Assisted Dying Bill that **one** doctor (“the attending doctor”) is sufficient to assesses the formal request of a patient and that this doctor is not obliged but free to choose contacting a colleague (an “independent doctor”) in order to obtain a second opinion.

³³ Several studies, for example ‘suicide by medical professionals’ (Suizidalität bei Medizinerinnen und Medizinern), see online: http://www.thieme.de/viamedici/medizin/aerztliches_handeln/suizid_arzt.html

³⁴ See the first UK study of trainee psychiatrists’ experience of patient suicide, to be found online: <http://bjp.rcpsych.org/content/178/6/494>

³⁵ FRANK TH. PETERMANN, capacity to consent (Urteilsfähigkeit), pages 81 – 85, cipher 228-234

Regarding point 2) – the patient has a *terminal illness* with a *prognosis of twelve months* or less to live

It is generally and widely accepted that individuals suffering from a terminal, painful illness such as most forms of cancer should be eligible for assistance with a self-determined end in life or even euthanasia. However, there are further ‘categories’ of suffering individuals who would be eligible for assistance (under the “Swiss model”), for example, patients suffering from fatal, progressive conditions such as Amyotrophic Lateral Sclerosis (Motor Neurone Disease), Multiple Sclerosis, Parkinson’s, Multiple Systems Atrophy and Huntington’s Chorea, etc., paraplegics and quadriplegics³⁶ and elderly people whose life has become too arduous as the result of a multitude of ailments related to old age³⁷. Furthermore, individuals suffering from mental illness also have a right to a self-determined end in life as long as they have capacity to consent: the Swiss Federal Court, in its decision of November 3rd 2006³⁸ acknowledged this, as mentioned before.

Overall, limiting access to assisted suicide to certain individuals automatically leads to a discrimination against those excluded. What is even worse, those excluded are exposed to the high risks connected with ‘clandestine’ suicide attempts via inadequate means with all the dire consequences for them, their loved ones and third parties. From a humanitarian perspective, restricting an individual’s access to a risk-free, dignified and assisted/accompanied suicide cannot be justified.

Furthermore, from a legal, human rights perspective, setting up categories which would include and exclude certain individuals from having access to a self-determined end in life could constitute an unlawful discrimination. Article 14 of the ECHR states:

“Prohibition of discrimination

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.”

As mentioned earlier in this submission, the European Court of Human Rights has a well-established standing on the practicability and efficiency of its guaranteed rights and freedoms through its ARTICO-jurisdiction:

³⁶ Such as for example the rugby-player Daniel James who was left paralysed with no function of his limbs, pain in his fingers, spasms, incontinence and needing 24 hour care after a sports accident.

³⁷ Such as for example the British conductor Sir Edward Downes who at the age of 84 suffered from heart and blood pressure problems, arthritis in the back and the knees, prostate problems, and was almost entirely deaf and blind.

³⁸ BGE 133 I 58, to be found on-line: <http://www.bger.ch/index/jurisdiction/jurisdiction-inherit-template/jurisdiction-recht/jurisdiction-recht-leitentscheide1954.htm>

“The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective;...”³⁹

Given that, as mentioned before, the European Court on Human Rights basically acknowledged the right of an individual to decide how and when to end his or her life, a narrowing of access to this right could constitute a conflict with the Convention.

Generally, the European Court on Human Rights has stated on several occasions that the ECHR has to be read as a whole. The Convention revolves around the idea of ‘man’ as a mature individual, fully responsible for his or her actions. This is the form of the enlightened individual in the sense of the philosopher IMMANUEL KANT, that is as an individual who has freed him- or herself from self-inflicted immaturity and thus from governmental, religious and other social paternalism.

Again, as with point 1) dealt before, DIGNITAS acknowledges that in legislation one has to “draw a line somewhere” in order to establish a legal frame. However, the notion of ‘terminal illness’ is not an appropriate eligibility requirement as it is too narrow and above all discriminating – and thus should be done away with.

As to the requirement a prognosis of twelve months or less to live, we would like to draw attention to the fact that exact medical prognosis is generally difficult if not impossible as the course of disease is different with each individual. The draft Bill states in Article 2,(1),(b): “...is reasonably expected to die within...” However, what is the meaning of ‘reasonably’? The consultation paper mentions on page 43 that doctors would substantiate this. Yet, in fact, no health professional will ever be able to accurately answer a patient asking “how much more time do I have?” Whilst doctors may use statistical data and their experience to give an estimate of when someone is ‘reasonably expected to die’, each doctor’s interpretation of ‘reasonably’ may be different. In conclusion, there is too much room for interpretation which can lead to discrimination in dealing with requests of patients.

DIGNITAS feels that a certain ‘life expectancy’, just like the notion of ‘terminal illness’ is not an appropriate eligibility requirement: it is too narrow, it is vague and it is discriminating – and thus should be done away with.

Regarding point 3) – two doctors would have to check, evidence and record that the patient has mental capacity to make the decision

Mental capacity to make an informed decision is the basis for individuals not only

³⁹ Case of ARTICO v. Italy (judgment of May 13th, 1980, series A no. 37, no. 6694/74), paragraph 33, to be found online: <http://cmiskp.echr.coe.int/tkp197/view.asp?action=html&documentId=695301&portal=hbkm&source=externalbydocnumber&table=F69A27FD8FB86142BF01C1166DEA398649>

to express their will but also to ensure that such will is effective in the frame of the given legal system. The Mental Health Act 2005 states in part 1, 'the principles', articles (2), (3) and (4): "A person must be assumed to have capacity unless it is established that he lacks capacity" and "...is not to be treated as unable to make decision unless all practicable steps to help him to do so have been taken without success" as well as "...not to be treated merely because he makes an unwise decision".⁴⁰ This corresponds to the approach of all jurisdictions – as far as we can see – which, up front, presume any adult to be mentally competent unless they fail to meet certain given criteria which could lead one to assume that their capacity might be limited or even lacking; for example such as is enshrined in Swiss Civil Code article 16 which states:

"A person has capacity to consent within the meaning of the law if he or she does not lack the ability to act rationally by virtue of being under age or because of mental illness, mental incapacity, inebriation or similar circumstances"⁴¹.

Any individual – with at least a minimum of physical autonomy – no matter whether mentally competent or not, can commit suicide; however, it is clear that if it shall be a rational, well-considered decision with involvement of third persons, mental capacity to make an informed decision must be given. However, in line with the fact that legally every adult is assumed to have capacity unless it is established that this is not the case, the wording of this point should be changed to: '...would have to check, evidence and record that the patient does not show any signs of lacking capacity'.

Apart from this, as stated before regarding point 1), it should be implemented that one doctor ("the attending doctor") is sufficient.

Regarding point 4) – two doctors would have to check, evidence and record that the patient *is aware* of palliative, hospice and other support care available to them

From DIGNITAS' point of view, to check that someone is "aware" of something leaves too much room for interpretation: where is the point at which someone is aware of and understands something? A doctor with a paternalistic, conservative approach could give the patient a hard time by claiming that they are not (yet) fully aware of what the multitude of alternative options includes. Therefore, we feel that the notion of "is aware" should be changed to "has been informed". This would still satisfy (and confirm) that alternative options to assisted dying have been proposed, yet it does away with the risk of a doctor giving a patient a hard time. Additionally, as stated before regarding point 1 and point 3) above, it should be implemented that one doctor ("the attending doctor") is sufficient

⁴⁰ See online: <http://www.legislation.gov.uk/ukpga/2005/9/section/1>

⁴¹ See online: <http://www.admin.ch/ch/e/rs/2/210.en.pdf>

Besides this, DIGNITAS very much supports the aspect of exploring and suggesting alternatives such as palliative, hospice and other support care as long as the patient has no obligation to consider these alternatives. In fact, at all times of contact between a patient and his or her medical doctor and other health care professional, an in-depth exploring and suggesting of treatments and alternatives should take place. Common sense would lead one to think that this is already implemented in the general practice of health care but, unfortunately, this is not the case. From our long-standing experience we see again and again that patients are not being sufficiently informed by their medical doctors. A large part of DIGNITAS' counselling work is telling inquirers about patient's rights, about palliative care options and so on. At DIGNITAS, we even have medical doctors and nurses contacting us to inquire how they could help their patients. To some extent, this is hardly surprising: during their studies to become medical doctors, end-of-life issues are hardly mentioned in lectures, if at all; sometimes the subject is discussed during a few hours on 'medical ethics' but the issue should be tackled in a 'matter-of-fact' approach, not in the frame of ethical theories. Thus, DIGNITAS strongly suggests intensifying the exploring alternatives aspect beyond the proceedings in the frame of an Assisted Dying Bill.

Regarding point 5) – if either doctor has any concerns that the patient does not meet these four criteria they *can* refer the patient to another health or social care professional for a second opinion

The draft Bill states in paragraph 5 that "A person [doctor, nurse, pharmacist and any other person who might be involved in the process due to the nature of their work; according to page 16 of the consultation paper] shall not be under any duty . . . to participate in anything authorised by the Act to which that person has a conscientious objection".

Obviously, a patient's freedom of choice to request, make use of or decline assisted dying needs to go hand in hand with anyone's freedom of choice to participate or not participate in proceedings that lead to putting in practice a patient's choice.

On the other hand, the consultation paper on page 40 and 43 states that "If the patient cannot easily make their own arrangements to see another doctor, their doctor must ensure that arrangements are made, without delay, for another doctor to take over their care" – referring to the guidance for doctors of the General Medical Council.

DIGNITAS feels that there is some contradiction or at least room for confusion in this. Therefore, the Assisted Dying Bill should be clearer and include the aspect that a doctor rejecting a patient's request due to conscientious objection *must* refer them to another doctor. This, especially in the light of what we have

pointed out regarding point 1) above, the reluctance of doctors to give hand to fulfilling a patient's wish for a self-determined end in life.

Regarding point 6) – the patient must be able to prove that they are an adult (aged 18 and over)

This safeguard aspect takes legal age as the 'starting point' of being able to access the option of an assisted/accompanied suicide. But how about under 18-year-old individuals? Wouldn't maybe a 17 year old terminal cancer patient have just as much insight into his or her suffering and have the mental capacity to make an informed, rational decision on ending his or her own life self-determinedly? For example, article 19 of the Swiss Civil Code states that "Minors or wards of court with the capacity to consent may assume obligations by their own acts only with the consent of their legal representatives" yet, „without such consent, they may acquire benefits which are free of charge and exercise strictly personal rights"⁴². Obviously, minors have and may also exercise personal rights. DIGNITAS acknowledges that in legislation one has to "draw a line somewhere" in order to establish a legal frame; thus, the criterion of legal age makes sense, however, one shall not oversee the aspect of discrimination due to age.

Regarding point 7) – the patient must be able to prove that they have been a resident of England and Wales for at least the previous year

We have the impression that the All Party Parliamentary Group tries to strike a balance between assisted dying legislation which, at least for some time, exclude "foreigners" to access such services and, on the other hand, the liberal approach in Switzerland – confirmed in the people's vote of 15th May 2011 – that no one needs to be a resident in order to access assisted dying in this country.

Article 1,(2),(c),(ii) of the draft Bill sets a prerequisite of one year residency in England and Wales, yet, why couldn't it be 9 months or 6 months? Or just one month? Why couldn't such prerequisite – in line with the "Swiss model" – be done away with altogether?

As mentioned before, limiting access to assisted suicide to certain individuals automatically leads to a discrimination against those excluded. From a humanitarian perspective, restricting an individual's access to a risk-free, dignified and assisted/accompanied suicide cannot be justified.

Furthermore, also mentioned earlier in this submission, from a legal, human rights perspective, setting up categories which would include and exclude certain individuals from having access to a self-determined end in life could constitute an unlawful discrimination; we again refer to article 14 of the ECHR.

⁴² See online: <http://www.admin.ch/ch/e/rs/2/210.en.pdf>

In the light of these considerations, DIGNITAS recommends the all Party Parliamentary Group to do away with the one-year residency prerequisite or at least turn to a more liberal approach.

Regarding point 8) – the patient makes a formal written request which is *witnessed by an independent person*

We do not see a reason why a patient should have to find an independent person to witness the signing of the formal request of the relevant person. In fact, in practice it could be very difficult for a patient to find a witness, especially if they live alone or if they face rejection to their desire for assisted dying. This would unnecessarily limit the liberty of a suffering person to choose and access assisted dying. Furthermore, it could make the patient prone to rejection, to emotional-social exclusion by those who they ask to be a witness and above all, prone to risking a 'clandestine' suicide attempt with all its dire consequences. DIGNITAS proposes that this prerequisite is done away with, yet that the 'attending' doctor would investigate into the patient's free decision to do the request, witness the signing and inform the patient that they can revoke their request at any time.

Regarding point 9) – the patient must wait for a period of at least 14 days – or 6 days if he or she is expected to die within one month – after the declaration takes effect before they can ask the attending doctor (or another registered doctor or nurse who has been authorised to do so by the attending doctor) to pick up the medication and deliver it to their home

Such waiting periods should not be implemented, because, for a terminal cancer patient for example suffering from bone metastases which are known to cause extreme pain, even 6 days is a very long time. DIGNITAS proposes the "Swiss model" which has that once consent is given to the request – in Switzerland this would be after the 2nd consultation with the one doctor – access to end the suffering is immediately available to the patient.

As mentioned before: having options, including the option of a self-determined end in life in the sense of an 'emergency exit', can lift the feeling of 'losing control'; this is what members of DIGNITAS tell us again and again. Prolonging the waiting – and suffering! – for another 14 or 6 days, whilst one or several doctors have already given their consent to the assisted dying, is not only unnecessary but simply inhumane.

Regarding point 10) – the doctor or nurse remains on the premises, but does not have to be in the same room

We feel that there is contradiction in the draft Bill in this point. On the one hand,

the consultation paper states on page 25 that the presence of a doctor or nurse ensures that the process can be monitored to ensure it is being done correctly – on the other hand such doctor or nurse does not have to be in the same room as the patient. This does not make sense. If the process is to be monitored to ensure it is being done correctly – which we feel to be very much necessary – then the doctor or nurse should remain in the same room.

We recommend the All Party Parliamentary Group to consider the “Swiss model” which is not ‘only’ about “assisted” but in fact about “accompanied” dying. With DIGNITAS, there are always two experienced professionals present during the entire process, from welcoming the individual and his or her loved ones, sorting out the paperwork (such as the ‘voluntary death declaration’, the ‘disposition of personal belongings’, etc.), assessing the competence, self-determination and decidedness of the individual once again, preparing the lethal drug, taking care of the loved ones present in the last hour, and dealing with the proceedings after the demise of the individual (calling the police and the coroner and helping them with all issues relating to the authorities’ investigation, calling the funeral parlour, etc.). This professional attendance to all needs of the individual, to his or her close ones, and also to the requirements of ensuring safety during the process and control mechanisms makes all the difference.

Question 3 – Should any other additional eligibility criteria be added?

Regarding changes to the eligibility criteria, we refer to our comments on question 2, points 1 to 10 above.

Question 4 – Would you prefer assisted dying to be available to people with a prognosis of one year / six months / three months?

We refer to our comments on question 2, point 2 above.

Question 5 – Are you satisfied with the arrangements proposed in the Bill for assessing these eligibility criteria? (We would welcome any suggestions for additional arrangements for assessing these eligibility criteria)

We refer to our comments and suggestions on question 2, points 1 to 10 above.

Question 6 – Should it be a requirement that one of the two assessing doctors has a certain level of knowledge and experience of end-of-life-care?

As to the issue of involving two doctors (‘attending’ and ‘independent’ doctor) for the assessment of a request, we have commented on this above, on question 2, point 1.

As to the ‘attending’ doctor (and other health care professionals involved in the proceedings) having a certain level of knowledge, the short answer is ‘Yes’. As pointed out above, regarding question 1, point 10, professional attendance to all needs of the individual, to his or her close ones, and also to the requirements of ensuring safety during the process and control mechanisms is very important. Such professional attendance can only be reached if those involved in the proceedings have a certain level of knowledge and experience of end-of-life-care.

Question 7 – Are you satisfied with the proposals for the waiting / ‘cooling off’ period?

The short answer is ‘No’. We refer to our comments on question 2, point 9 above.

Question 8 – Are you satisfied with the proposal that two doctors, acting independently of each other (and referring the patient for further assessment by other professionals where necessary), assess the patient’s eligibility for assisted dying?

As to the issue of involving two doctors (‘attending’ and ‘independent’ doctor) for the assessment of a request and the aspect that a doctor could refer the patient for further assessment by other professionals (such as, for example psychiatrist), we have commented on this above, on question 2, point 1.

Question 9 – Should the doctor or nurse remain on the premises until the patient dies?

The short answer is ‘Yes’, however, the doctor or nurse should not only remain on the premises but be present in the room until the patient dies – as outlined in our comment regarding question 2, point 10 above.

Question 10 – Would you prefer a doctor-led or legal-led (or another) assessment and safeguarding model for assisted dying?

Answering this question in depth would go beyond the scope of this submission. Obviously, the models in place in the US-states of Oregon and Washington, in the Benelux and in Switzerland are all doctor-led. However, DIGNITAS feels that assisted dying is not so much a matter of whether a doctor-led, legal-led or any other thinkable model is favoured, but much more a matter of how any model strikes a fair balance between the right of an individual to decide how and when to end his life and suicide attempt prevention aspects as pointed out in this submission.

Question 11 – Do you have any suggestions for how the process could be made less onerous for patients while maintaining their safety?

In the consultation paper, page 31, it says “Accessibility . . . to protect people who may be vulnerable...” Regarding this notion of ‘vulnerable’ people, we would like to refer to what we have stated above in chapter 3 ‘The protection of life and the general problem of suicide’ and especially in chapter 4 ‘Suicide prevention – experience of DIGNITAS’.

As to for how the process could be made less onerous for patients while maintaining their safety, we refer to our comments on question 1, points 1 to 10; our suggestions are in line with the “Swiss model” and procedures at DIGNITAS; in summary:

- one (and not two) ‘attending’ doctors assessing the patient’s request (point 1)
- doing away with the notion of ‘terminally ill’ and the prerequisite of ‘reasonably expected to die within one year’ (point 2)
- changing the notion that a doctor would have to check, evidence and record that a patient ‘is aware’ of palliative, hospice and other support care into ‘is informed’ (point 4)
- clarifying the notion “...doctor has any concerns . . . can refer the patient to another...” (point 5)
- doing away with the notion of a one-year residency prerequisite or at least turn to a more liberal approach (point 7)
- doing away with the prerequisite that the patient making the formal written request requires a witness (point 8)
- doing away with the 14 – respectively 6 days – ‘cooling off’ period (point 9)
- as to maintaining – in fact improving – patients safety: making sure that a health care professional remains in the same room as the patient (point 10)

Question 12 – Should it be the patient’s responsibility to find a second doctor, should the attending doctor be able to refer the patient to an independent doctor or should there be a clear mechanism for patients to find an independent doctor?

As to the issue of involving two doctors (‘attending’ and ‘independent’ doctor) for the assessment of a request and the aspect that a doctor could refer the patient for further assessment by other professionals (such as, for example psychiatrist), we have commented on this above, on question 2, point 1

Question 13 – Are you satisfied that the functions of the Monitoring Inspectorate are appropriate?

We understand that the Monitoring Inspectorate “can track cases and investigate

where there is any concern related to doctors', nurses' or pharmacists' practice or patient's eligibility" and/or "investigates cases of potential non-compliance or malpractice and refers individuals involved to the police and/or appropriate professional regulatory bodies" (pages 24, 25 and 26 of the consultation paper).

DIGNITAS feels that such a Monitoring Inspectorate is sensible and would serve as an element of securing quality and safety of the proceedings in line with an Assisted Dying Bill. However, the consultation paper provides too few details as to competence, responsibilities and control mechanisms of the proposed Monitoring Inspectorate in order to definitely answer question 13.

Question 14 – Do you have any suggestions as to any existing organisations that would be better suited to take on these functions than the proposed Monitoring Inspectorate?

No.

Question 15 – Are you satisfied with this proposal [of the Registrar General producing an annual report]?

Yes.

Question 16 – Do you support the inclusion of a 'sunset clause'?

The short answer is 'No', given that Parliament is always at liberty to repeal or amend laws.

Question 17 – Do you have any comments on the suggestions of areas to be covered by the Code of Practice?

As to the wording "assessing whether the person has the mental capacity to make such a decision" (page 33 of the consultation paper) we refer to our comment on question 1, point 3. The wording needs to be changed as it is in conflict with the current law.

Furthermore, we note that on said page 33 the consultation paper speaks of "*informing* a person of the treatment and end-of-life care options available to them" instead of "...doctors would have to check, evidence and record that the patient *is aware* of palliative...." We have dealt with this issue in our comment on question 2, point 4 and outlined that indeed 'has been informed' is the better choice.

Regarding areas to be covered by the Code of Practice, DIGNITAS feels that the wording "...and any other matters as needed relating to the operation of the law"

is too ambiguous and does not allow to answer question 17, respectively provide suggestions of areas to be covered. What are these "other matters as needed"? In any case, a Code of Practice would quite likely need to include aspects such as whether or not a doctor should refer a patient to a colleague if they have objections to the patient's request and it should also include aspects regarding the tasks of a health care professional being present in the last hours of patient making use of assisted dying in line with the Assisted Dying Bill.

Question 18 – What training and support should be available to doctors and other healthcare professionals in the event of a change in the law on assisted dying?

We do not know about training and support options regarding end-of-life questions already in place in England and Wales, however, from our long-standing experience out of contacts with doctors, patients, their loved ones and different organisations, we see that there is certainly insufficient knowledge amongst doctors and health care professionals in this field. We refer to our comment on question 2, point 4 and recommend that end-of-life issues such as aspects of the Assisted Dying Bill should:

- become a (mandatory) part of lectures at university for those who study medical science or any subject related to health care (such as for example studies in psychology)
- be integrated (mandatory) in training programmes for nurses
- be implemented (mandatory) in (certainly already existing) further education programmes for doctors and other healthcare professions

Furthermore, the option of (free of charge and voluntary) debriefing / psychological supervision (intravision) should be available to all those professionals who are involved in proceeding related to the Assisted Dying Bill. At DIGNITAS, everyone, no matter whether they work in the office or act as a befriender, can choose to see a professional (outside, independent of the organisation) for debriefing / supervision and the organisation will pay the expense.

Question 19 – Do you have any other comments on the draft Bill?

At this point, we add an extract⁴³ of the philosophical and political principles guiding the activities of DIGNITAS which we feel may well serve as a basis for a further development of the draft Bill and any consideration of end-of-life-issues:

The fundamental values of DIGNITAS are based on values that the Swiss state has upheld since the founding, in 1848, of the modern federation, and the further de-

⁴³ From the booklet/brochure „How DIGNITAS works“, available online: <http://www.dignitas.ch/images/stories/pdf/so-funktioniert-dignitas-e.pdf>

velopment of these values on a national and international level since then.

The starting point is the liberal position that in a free state any freedom is available to a private individual provided that the availing of that freedom in no way harms public interests or the legitimate interests of a third party. As John Stuart Mill stated:

“Over himself, over his own body and mind, the individual is a sovereign.”⁴⁴

These values are:

- Respect for the freedom and autonomy of the individual as an enlightened citizen
- Defending this freedom and autonomy against third parties who try to restrict those rights for some reason, whether ideological, religious or political
- Humanity which seeks to prevent or alleviate inhumane suffering when possible: probably the most shining example of this in our history, on a national and international level, led to the founding of the Red Cross
- Solidarity with weaker individuals, in particular in the struggle against conflicting material interests of third parties
- Defending pluralism as a guarantee for the continuous development of society, based on the free competition of ideas
- Upholding the principle of democracy, in conjunction with the guarantee of the constant development of fundamental rights

Respect for the freedom of individuals:

Respect for the freedom of individuals in the form of an enlightened citizen who takes on personal responsibility (a “citoyen” in the sense of the political philosopher from Basel, ARNOLD KÜNZLI, who died in 2008⁴⁵); he also reveals, among other things, that – in contrast to earlier law – constructive law valid today no longer punishes a suicide attempt.

Freedom from the expectations of a third party:

It is also clear that every person on Swiss soil is entitled to the freedom to live his or her life independent of the individual ideological, religious or other types of ideas of a third party.

No one has the right to impose or even attempt to impose his or her individual ideological, religious or political beliefs on another. Muslims should not do it to Christians, Jews or Buddhists. Christians should not do it to Jews or those of other beliefs and a believer should not do it to an unbeliever – not even using the indirect method of a governmental regulation.

⁴⁴ JOHN STUART MILL, *Essay on Liberty*, Library of Liberal Arts edition, p. 13.

⁴⁵ As described in his essay „Bourgeois und Citoyen: Das Doppelgesicht unserer Gesellschaft“, in: Michael Haller, Max Jäggi, Roger Müller (Ed.), *Eine deformierte Gesellschaft, Die Schweizer und ihre Massenmedien*, Basel 1981, p. 299 ff.)

In this case, the state should be the guarantor of a pluralistic society and must forbid anything that would restrict this pluralism or lead it in a certain direction in the interest of a specific ideological viewpoint.

Humanity:

When addressing the question of whether a person who wishes to die should be offered help, humanity needs to be the central focus.

The term "humanity" is admittedly vague in and of itself; however, it plays an important role for example in the "Declaration of Geneva", which was adopted by the General Assembly of the World Medical Association in 1948 and last amended in 2006.

Although this declaration does not make any reference to medically assisted suicide, it does begin with the formulation:

"I solemnly pledge to consecrate my life to the service of humanity"

The declaration also contains the following as its final sentences:

"I will maintain the utmost respect for human life; I will not use my medical knowledge to violate human rights and civil liberties, even under threat".

Since experience shows, however, that it is difficult to interpret the undefined terms of humanity, respect or even dignity as such, in the end the only help comes from the decision to stop and consider what is the true objective of medicine instead of relying on interpretation.

The German medical ethicist EDGAR DAHL from the Giessen Clinic formulates it this way⁴⁶:

"Medicine consists first and foremost of prevention, diagnosis and therapy. This means that it strives to avoid disease, identify disease and treat disease. One could conclude from this that the objective of medicine is to maintain the health of the individual. In fact, the Declaration of Geneva states that "The health of my patient will be my first consideration". As enlightening as this declaration appears to be, it is however incomplete. A look at palliative medicine is sufficient to show that a doctor's duty is not at all limited to simply maintaining health. For example, palliative doctors spend their days and nights caring for patients whose health cannot be restored.

Based on this, it would seem more suitable to consider the objective of medicine to be the alleviation of human suffering. Looking at it this way, we would also be encouraged by asking ourselves why medicine is committed to avoiding, identifying, and treating disease. The fight against disease is

⁴⁶ In his essay „Im Schatten des Hippokrates / Assistierter Suizid und ärztliches Ethos müssen sich nicht widersprechen“, published in „Humanes Leben – Humanes Sterben“, 4/2008, p. 66-67, Augsburg, Germany.

not an objective in itself. Rather, this fight is taken up to protect us from physical and emotional suffering, which tends to accompany illnesses.

By fulfilling its objective to alleviate human suffering, medicine is however continually bound to respecting the self-determination of human beings. No one is allowed to treat a patient against his or her will. That doctors are only permitted to introduce or terminate medical procedures with the express permission of the patient is now a generally accepted fact. For example, whether or not a life-prolonging procedure is introduced or terminated is always and exclusively dependent on the agreement of the patient involved.

When medical ethics, as described above, are based on the alleviation of suffering and the respect of self-determination, it should be obvious that these ethics are completely compatible with assisted suicide, since a doctor who fulfils the request of a terminally-ill patient to stop all further therapy and prescribe a lethal medication is alleviating suffering and respecting self-determination."

A policy that is aimed at doing everything possible to prevent every suicide without taking into account the will of the person concerned violates humanity. Whoever acts in this way, forcing people to attempt to bring about their own death in a violent manner, and thus accept the possibility of inhumane risks, is acting inhumanely.

Is it somehow humane to allow a person to achieve his or her own will by attempting something, such as that reported by an interested person from Scotland who e-mailed DIGNITAS in 2008, and to accept the consequences thereof?

"Dear Dignitas. My name is J.(xx) H.(xx). I am 19 years old, and live in Scotland, UK.

About 2 months ago I attempted to commit suicide by jumping off a multi storey car park. My attempt failed, and instead of dying, I write this e-mail to you from my hospital bed.

I crushed both of my feet, broke my leg, broke my knee, broke my sacrum (part of my pelvis) and most devastatingly, broke my spine, in 3 places, which has resulted in a degree of paralysis in my legs. I spent 6 weeks in hospital in my home town of Edinburgh, and was then transferred to a special spinal rehabilitation hospital in Glasgow.

I am told that I will need to spend 6 months at this hospital, and that I will be in a wheelchair for the rest of my life. I now have a loss of sexual function, which seems unlikely to return, as well as huge problems managing my bowels and bladder (I cannot feel them moving).

I was already suicidal, and now that I will be disabled for the rest of my life, at such a young age, I truly cannot bear the prospect of life. I am only 19, and I now have the grim reality of 60 years in a wheelchair. The physical pain I am in alternates between bearable and completely unbear-

able. Perhaps the pain will ease off with time, but this is not a certainty. There are times every day where I scream with pain, due to being moved in bed, hoisted into the wheelchair etc.

I would like to ask if I could be considered for an assisted suicide, as I am completely certain I would like to end my life, and believe I should have the right to do so.

I would be too afraid to try and kill myself again, given the devastating effects of my first failed attempt. It would also be much more difficult to attempt suicide from a wheelchair. I only wish that my country was humane enough to let a person die.

Please consider my letter, I hope to hear a response,
J(xx) H.(xx)"

In this message, which must horrify every person who has any feelings whatsoever, the author has not yet shared what the problem was that motivated him to attempt suicide in the first place.

However, one thing is certain: If, after becoming suicidal, he had had the opportunity to talk with other people about his problem without having to fear that he would be immediately admitted to a psychiatric ward, his fate would have most certainly been different. People would have tried to show him that there were also solutions other than suicide for his problem in order to give him a real chance to solve the underlying problem without resorting to violence against himself. This way, he would not have had to accept the risks that have now marred him in such a devastating way. Under humane conditions of this kind, he would have certainly had a real chance to overcome his suicidal tendencies.

In this context, it is especially important to ask why it is ethically commendable to put a severely suffering animal to death, but it is impossible to allow a severely suffering human to end his or her own life, without having to accept the inconceivable risks of failure and additional self-mutilation. What abstruse ideas could lead someone to declare that what is humane for a person to do to a suffering animal is unethical if done to a suffering human, especially since an animal *cannot* express itself in human speech, yet a human can clearly state his or her will?

Solidarity for the interests of those who are weaker:

Solidarity with, and protecting the interests of, people who are considered weaker, especially in the struggle against the conflicting – and often financially motivated – interests of third parties, is one of the fundamental qualities of the Swiss public spirit.

The principle "One for all and all for one" is not fully realised in the narrow limitations of that which the state directly encourages as solidarity based on the laws it creates, but rather it is only fully realised in the broader field of social

solidarity in civil society, that is, turning a certain group of people towards another group that is in need of special help.

Plurality:

The defence of a pluralistic system is equally important because it alone guarantees that the free competition of ideas, and thereby the further development of society, remains possible.

Democracy and basic rights:

Further significant fundamentals of our shared existence include the principles of democracy within that sphere which is not left up to the individual's own discretion as a consequence of his or her basic rights.

In this context, it must be said that a representative survey on the topic of assisted suicide found that 75 % of the evangelical population and 72 % of the Roman-Catholic population would claim the possibility of assisted suicide for themselves and thus endorsed it⁴⁷.

Citizens are not the property of the state:

Finally it must also be said that people who inhabit a country should never be degraded by being considered the property of the state. They are the bearers of human dignity, and this is characterised most strongly when a person decides his or her own fate. It is therefore unacceptable for a state or its individual authorities or courts to choose the fate of its citizens.

Question 20 – Do you have any comments on the Declaration form (Schedule 1)

The Declaration form should be changed in accordance with the comments/suggestions provided by DIGNITAS in the submission.

7) Conclusion

“No one shall set upon a long journey without having thoroughly said goodbye to loved ones and no one shall set upon such journey without careful preparation”. At a time in which lonely, unassisted suicides among older people, in particular, are increasing sharply – as a result of the significant increase in life expectancy and the associated health and social problems of many men and women who have become old, sick and lonely – careful and considered advice in matters concerning the voluntary ending of one's own life is gaining relevance. Furthermore, developments in modern medical science have also led to a

⁴⁷ in “Reformiert”, August 29th, 2008; GALLUP TELEOMNIBUS survey from 3-12 July 2008 through ISOPUBLIC, Schwerzenbach, online (in German): http://www.reformiert.info/files_reformiert/1492_0.pdf

significant prolonging of life. Yet, there are individuals who explicitly would like to add life to their years – not years to their life.

It is about time that law makers respected the will of the people and implemented sensible solutions that allow individuals, who so choose, to have a dignified, self-determined end to life at their own home, surrounded by those close to their hearts.

In the light of this, DIGNITAS very much welcomes and supports the efforts and work of the All Party Parliamentary Group and hopes that an Assisted Dying Bill for England and Wales reaches a majority of open ears in Parliament.

We close these considerations with words by DAVID HUME, one of the most famous philosophers of the last 300 years⁴⁸:

„If Suicide be supposed a crime, 'tis only cowardice can impel us to it. If it be no crime, both prudence and courage should engage us to rid ourselves at once of existence, when it becomes a burthen. 'Tis the only way, that we can then be useful to society, by setting an example, which, if imitated, would preserve to every one his chance for happiness in life, and would effectually free him from all danger of misery.“

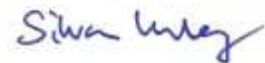
Yours sincerely

DIGNITAS

To live with dignity - To die with dignity
Secretary General



Ludwig A. Minelli



Silvan Luley

⁴⁸ DAVID HUME, Of Suicide, <http://ebooks.adelaide.edu.au/h/hume/david/suicide> , in fine.