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Committee Secretary, Senate Legal and
Constitutional Affairs Committee
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Canberra, ACT 2600
Australia

Forch, 20 August 2014

Medical Services (Dying with Dignity) Exposure Draft Bill 2014

A Bill for an Act relating to the provision of medical services to assist terminally ill people to die with dignity, and for related purposes

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

as requested, submitted in electronic format, by email to euthanasia.sen@aph.gov.au as an attached pdf

Contents of this submission

1) Introduction

"The best thing which eternal law ever ordained was that it allowed us one entrance into life, but many exits. Must I await the cruelty either of disease or of man, when I can depart through the midst of torture, and shake off my troubles? . . . Are you content? Then live! Not content? You may return to where you came from"[1]. These are not the words by a protagonist of the many organisations around the world representing the interests of people who wish for freedom of choice in ending one's life self-determinedly today, but the words of Roman philosopher LUCIUS ANNAEUS SENECA who lived 2000 years ago, in his letters dealing with moral issues to Lucilius.

In recent years, questions dealing with the subject of (assisted) suicide and euthanasia have arisen again 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 2011[2] 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 Switzerland, over 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 association to offer the option of an accompanied suicide to its members. Further not-for-profit member's societies like EX INTERNATIONAL, DIGNITAS, SUIZIDHILFE and LIFECIRCLE 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

[1] In: Epistulae morales LXX ad Lucilium
[2] Congress of Swiss General Practitioners in Arosa, March 31st - April 2nd, 2011: http://www.arosakongress.ch

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 73,000 members, EXIT-A.D.M.D. over 19,000 and EX INTERNATIONAL approximately 700 members. DIGNITAS, together with its independent German partner association DIGNITAS-Germany in Hannover, counts over 7,000 members worldwide of whom 76 reside in Australia[3].

In the over 16 years of DIGNITAS' existence, 18 members of DIGNITAS residing in Australia have made use of the option of a self-determined ending of suffering in Switzerland[4]. 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, forcing an Australian resident to travel 16,531 kilometres (which is the air-line distance Canberra to Zürich) when all that he or she wishes is to have a self-determined end of suffering and life, can only be seen as a disrespect of human dignity. Furthermore, the present legal situation in Australia has the additional appalling effect that the very important support towards the end of life by next-of-kin and/or friends must take place shadowed by the fear of prosecution. Sometimes, this even leads patients to decide to travel to DIGNITAS only with very few loved ones or even alone.

This legal situation is approached quite differently under Swiss law: whilst in Switzerland, like in Australia, 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 Australia 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 DIGNITAS, EXIT and others.

DIGNITAS very much welcomes the proposal for a Bill or an Act relating to the provision of medical services to assist terminally ill people to die with dignity, and for related purposes: it brings the issue of end-of-life-questions to the level where it should be addressed, the legislation.

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3 http://www.dignitas.ch/images/stories/pdf/statistik-mitglieder-wohnsitzstaat-31122013.pdf
4 http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2013.pdf

2) The freedom to decide on time and manner of one's own end from a European Human Rights perspective

All European states (with the exception of Belarus and the Vatican) have adhered to the European Convention on Human Rights (ECHR)[5]. In specific cases, set legal situations may be questioned whether they would be in line with the basic human rights enshrined in the ECHR. The European Court of Human Rights[6] has developed a most valuable jurisdiction on basic human rights, including the issue of the right to choose a voluntary death. According to its preamble, this international treaty is not only a fixed instrument, "securing the universal and effective recognition and observance of the rights therein declared" but also aiming at "the achievement of greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realisation of human rights and fundamental freedoms"[7]. The ECHR' text and case law may serve as an example and could be taken into consideration in legislation in Australia, which is why Dignitas herewith outlines some of its most important rulings in relation to a self-determined end of suffering and life.

In the judgment of the European Court of Human Rights in the case of DIANE PRETTY v. the United Kingdom dated April 29th, 2002[8], 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."

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5 The Convention: http://www.echr.coe.int/Documents/Convention_ENG.pdf
Member States: http://www.conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=005&CM=8&DF=25/07/2014&CL=ENG

6 http://www.echr.coe.int/Pages/home.aspx?p=home

7 Convention for the Protection of Human Rights and Fundamental Freedoms, page 5: http://www.echr.coe.int/Documents/Convention_ENG.pdf

8 Application no. 2346/02; Judgment of a Chamber of the Fourth Section: http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-60448

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

> "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."[9]

In that decision, the Swiss Federal Supreme 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 Supreme 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 judgement[10] and stated in paragraph 51:

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[9] BGE 133 I 58, page 67, consideration 6.1: http://relevancy.bger.ch/php/clir/http/index.php?lang=de&type=show_document&page=1&from_date=&to_date=&from_year=1954&to_year=2014&sort=relevance&insertion_date=&from_date_push=&top_subcollection_clir=bge&query_words=&part=all&de_fr=&de_it=&fr_de=&fr_it=&it_de=&it_fr=&orig=&translation=&rank=0&highlight_docid=atf%3A%2F%2F133-I-58%3Ade&number_of_ranks=0&azaclir=clir#page240

[10] Application no. 31322/07; Judgment of a Chamber of the First Section (in French): http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-102939

> ”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”

Even though the European Court of Human Rights thus confirmed the statement of the Swiss Federal Supreme 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 then 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.

In the case of ULRICH KOCH against Germany, 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 end her ordeal by committing suicide at her home. In its decision of July 19th, 2012, the European Court of Human Rights declared the applicant’s complaint about a violation of his wife’s Convention rights inadmissible, however, the Court held that there had been a violation of Article 8 of the Convention in that the [German] domestic courts had refused to examine the merits of the applicant’s motion[11]. The case is now pending at the Administration Court of Cologne, and depending on their decision, the case might well continue on to the German Federal Constitutional Court and then again to the European Court of Human Rights.

In a further case, GROSS v. Switzerland, the European Court of Human Rights further developed its jurisdiction. The case concerned a Swiss woman born in 1931, who, for many years, had expressed the wish to end her life, as she felt that she was becoming more and more frail and was unwilling to continue suffering the decline of her physical and mental faculties. After a failed suicide attempt followed by inpatient treatment for six months in a psychiatric hospital which did not alter her wish to die, she tried to obtain a prescription for sodium pentobarbital by Swiss medical practitioners. However, they all rejected her wish, one felt prevented by the code of professional medical conduct being that the woman was not suffering from any illness, another was afraid of being drawn into lengthy judicial proceedings. Attempts by the applicant to obtain the medication to end her life from the Health Board were also to no avail.

[11] Application no. 479/09, Judgment of the Former Fifth Section: http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-112282

In its judgment[12] of May 14th, 2013, the European Court of Human Rights held in paragraph 66:

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

In conclusion, the Court held that Swiss law, while providing the possibility of obtaining a lethal dose of sodium pentobarbital on medical prescription, did not provide sufficient guidelines ensuring clarity as to the extent of this right and that there had been a violation of Article 8 of the Convention. The case was referred to and is now pending at the Grand Chamber of the Court.

In light of these judgments 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.

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. 6694/74[13]), the developed practice (so-called ARTICO-jurisdiction) is of major importance. In paragraph 33 of said judgment the Court explained:

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

Dignity and freedom of humans mainly consists of acknowledging the right 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 issue will present itself increasingly – not only within the Convention's jurisdiction,

[12] Application no. 67810/10; Judgment of a Chamber of the Second Section: http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-119703
[13] http://hudoc.echr.coe.int/sites/eng/pages/search.aspx?i=001-57424

but internationally – due to demographic developments and progress of medical science.

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 European Court of Human Rights rightly paid great attention to the question of the influence of 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.[14]

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/or 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 2012, there were, in Australia 2535 registered suicides (underlying cause of death determined as intentional self-harm)[15]

On average, almost seven individuals die every day in Australia as a result of a suicide attempt; 75% of them male, with the highest age-specific suicide rates in

[14] See the death with dignity act annual reports of the Department of Human Services of the US State of Oregon: http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx

[15] http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2012~Main%20Features~Key Characteristics~10009

the group of 45 to 49 and over 80 years age groups[16]. 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 2002[17]: 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 Australia must be estimated to be up to 126,750 per year. Even if a lower ratio of an estimated 30 attempts for every completed suicide applied (as stated by the Australian suicide prevention charity Lifeline[18]), or, even lower, 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 25,350 annual suicide attempts in Australia.

Referring to the previously mentioned ARTICO-jurisdiction of the ECHR: 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 Australia 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.)[19]

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[16] http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by Subject/3303.0~2012~Main Features~Age~10010

[17] Online (in German): http://www.parlament.ch/d/suche/seiten/geschaefte.aspx?gesch_id=20011105

[18] https://www.lifeline.org.au/About-Lifeline/Media-Centre/Suicide-Statistics-in-Australia/Suicide-Statistics

[19] See the study of PETER HOLENSTEIN: http://www.dignitas.ch/images/stories/pdf/studie-ph-der-preis-der-verzweiflung.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

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 bridges 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 the prohibition of torture, such as enshrined in article 3 of the European Convention of Human Rights, which states that no one shall be subjected to torture or to inhuman or degrading treatment or punishment. A violation could occur for example if a palliative treatment is made with insufficient effect; 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 of Human Rights avoided to look into the aspect of the states' positive duty to protect individuals from such inhumane treatment in cases of assisted dying, but there is room to look into this aspect more closely in future cases[20].

4) Suicide prevention – experience of DIGNITAS

Everyone should be able to discuss the issue of suicide openly with their General Practitioner, psychiatrist, 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 institutions[21]. 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

(based on information provided by forensic psychiatrists, coroners, etc., the study calculates with a suicide attempt rate that is 10 to 50 times higher than the registered suicides), these costs could well be around 2'431,2 Million Swiss Francs.

[20] 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.

[21] In Australia provided for example by Lifeline https://www.lifeline.org.au or the Samaritans http://www.thesamaritans.org.au

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[22]. 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 16 years of working in the field of suicide prophylaxis and suicide attempt prevention, shows that – paradoxically – the option of an assisted/accompanied 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 paradoxical: 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 attempting/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 legalisa-

[22] See 'The counselling concept of DIGNITAS', http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-how-dignitas-safeguards-eth-21072014.pdf page 10 ff.

tion 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 Oregon[23] – 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"[24]. 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

[23] Death with Dignity Act annual reports of the Department of Human Services of the US State of Oregon: http://public.health.oregon.gov/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

[24] Journal of Medical Ethics 2007;33:591-597; doi:10.1136/jme. 2007.022335: http://jme.bmj.com/content/33/10/591.abstract

> minorities, compared with background populations. The only group with a heightened risk was people with AIDS. While extralegal cases were not the 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 Dammbruch-Argument in der Sterbehilfe-Debatte" ("The slippery-slope argument in the euthanasia debate")[25]: 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 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 three assisted suicides per year have taken place since the authorities allowed associations like EXIT, DIGNITAS and others to access such homes in 2002[26].

The issue is not whether someone would make use 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'[27] 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. On-

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

[26] See the interview with Dr. Albert Wettstein, former Chief of the Zürich City Health Service (available in German) online: http://www.derbund.ch/schweiz/standard/Natuerlicher-als-mit-Schlaeuchen-im-Koerper-auf-den-Tod-zu-warten/story/13685292?track

[27] For an explanation, read the general info-brochure of DIGNITAS, page 6 - 7: http://www.dignitas.ch/images/stories/pdf/informations-broschuere-dignitas-e.pdf

ly 14 % made use of the option of an assisted suicide, some after quite a long time[28]. 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 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 individual who wishes to end his or her suffering, offers more sophisticated results than action which in such situations deprive individuals of their dignity, personal freedom and responsibility for themselves.

5) General remarks on the proposed Medical Services (Dying with Dignity) Act 2014

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 Australia and in many other countries is not only "inadequate and incoherent" as the UK Commission on Assisted Dying put it on the front side of its final report[29], the situation is in fact a disgrace for any country which would be considered a part of the modern and democratic Western world. It forces citizens to travel abroad in order to have freedom of choice. In this context it should be pointed out that only individuals with at least a minimum of financial resources – something that certainly not everyone in Australia has – can afford to travel to Switzerland in order to make use of the option of a self-determined end of suffering and life, which is an unacceptable discrimination against those who are not so well off. DIGNITAS' statutes allow for reduction or even total exemption of paying costs to DIGNITAS,[30] however, the person still would have to bear costs for travelling, accommodation, etc. besides bearing the burden of a long journey which is even more strenuous in a deplorable state of health.

Clearly, the public is in favour of freedom of choice in these 'last issues'[31]. This public attitude was made very clear, for example, 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

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

[29] http://www.demos.co.uk/publications/thecommissiononassisteddying

[30] http://www.dignitas.ch/index.php?option=com_content&view=article&id=11&Itemid=52&lang=en

[31] See for example the national Australian research conducted in late 2012 by Newspoll http://gallery.mailchimp.com/d2331cf87fedd353f6dada8de/files/A21_The_Right_to_Choose.pdf , the First Report of the UK Select Committee on Assisted Dying for the Terminally Ill Bill: http://www.parliament.the-stationery-office.co.uk/pa/ld200405/ldselect/ldasdy/86/8609.htm , the ISOPUBLIC/GALLUP Poll http://www.medizinalrecht.org/ wp-content/uploads/2013/03/Results_opinion_poll_self-determination_at_the_end_of_life.pdf and others more.

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 coverage, the public voted by a huge majority of 85:15 and 78:22 against any narrowing of the current legal status quo[32].

If Australia (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 very goal of the DIGNITAS-organisation is closer in reach: to become obsolete. Because, if people in Australia have a real choice, no Australian 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 proposal of a Bill for an Act relating to the provision of medical services to assist terminally ill people to die with dignity, and for related purposes.

Voices claiming that palliative care "can solve anything" and "soothes any suffering" are not in touch with reality and try to mislead the public. 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 spiritual[33]. Palliative care is widely accepted and practiced. It is one of 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.

However, based on experience drawn from over 16 years of operating, DIGNITAS very much adheres to Dr. Rodney Syme and palliative care consultant Fiona Randall that "one of the outstanding developments in medical care in the past 40 years has been palliative care", yet that "the goal [of impeccable relief of pain and other symptoms] is unachievable and the expectations generated by the philosophy of palliative care are unrealistic"[34]. There are sufferings for which medical science has still no cure, yet, for which palliative treatment is not an option or possibly only applicable in a very advanced late stage of that illness, given that these illnesses are not terminal as such, at least not in the short run. Patients

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[32] 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 website, scroll down to the comment/entry of 16 May 2011).

[33] Definition by the World Health Organisation: http://www.who.int/cancer/palliative/definition/en

[34] http://www.theage.com.au/comment/at-lifes-end-we-should-respect-peoples-choices-20140815-104cob.html

suffering from neurological illnesses such as Amyotrophic Lateral Sclerosis (Motor Neurone Disease), Multiple Sclerosis, etc., or even more so quadriplegics[35] or patients suffering from a multitude of ailments related to old age[36] are generally not *per se* eligible for palliative care and terminal sedation because they are not suffering from a life-threatening illness as such. Long-time degenerative neurological disease 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 applied in end-of-life palliative care. Without doubt, such patients are experiencing severe suffering which can lead them to wish to end their suffering and life self-determinedly. In such cases, the wish for an accompanied (assisted) suicide and/or voluntary euthanasia is a personal choice which must be respected.

Palliative care and self-enacted ending of suffering and life 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 freedom of choice in 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 also 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 patient's advance directives / patient's living wills in a way that it would give safety to the patient and also to the doctors practising palliative care, etc.

One needs 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 – as late Member of the Scottish Parliament Margo MacDonald's rightly put it in her first proposal for an Assisted Suicide Bill for Scotland, a proposal with similar aims as the Medical Services (Dying with Dignity) Bill 2014 for Australia – for some people the legal right to seek assistance to end life before nature decrees is irrelevant due to their faith or credo[37]; 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 suicide: 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.

[35] Such as for example the British 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.
[36] Such as for example the well-known British conductor Sir Edward Downes
[37] http://www.scottish.parliament.uk/S4_MembersBills/Final_version_as_lodged.pdf

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 ending of suffering and 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 suicide and voluntary euthanasia 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 the personal decision of a competent individual assuming responsibility for his or her own life – 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.

In this context one needs to remember that much of the 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. 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[38].

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 over 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 Switzerland, 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

[38] Article (in German) online: http://www.nzz.ch/aktuell/startseite/medienpopulismus-schadet-der-aufklaerung-1.595885

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: there are cases of patients who have lost all control over their bodily functions, including the ability to swallow, so that they would not be able to self-administer the lethal drug in any way and therefore voluntary euthanasia is the only option. Furthermore, 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 suffering and life him- or herself. For the latter 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). 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.

6) Comments on specific aspects of the proposed Medical Services (Dying with Dignity) Act 2014.

mentally competent adult

Mental capacity to make an informed decision is the basis for individuals not only to express their will but also to ensure that such will is effective in the frame of the given legal system. The common law recognises – as a 'long cherished' right – that all adults must be presumed to have capacity until the contrary is proved. Where capacity is contested at law, the burden of proof lies with the person asserting the incapacity.[39] For example, the UK Mental Health Act 2005 states in part 1, 'the principles', articles (2), (3) and (4): "A person must be as-

[39] http://www.alrc.gov.au/publications/70.%20Third%20Party%20Representatives/adults-temporary-or-permanent-incapacity

sumed 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 is capable of judgement within the meaning of the law if he or she does not lack the capacity to act rationally by virtue of being under age or because of a mental disability, mental disorder, intoxication or similar circumstances"[41].

Any individual – with at least a minimum of physical autonomy – no matter whether mentally competent or not, can attempt and/or 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. This criterion in the Australian Draft Bill matches the 'Swiss model' on assisted suicide and it is appropriate.

suffering intolerably

As far as we can see, there is no definition of "suffering intolerably" in section 4 of the Medical Services (Dying with Dignity) Bill 2014, however, in section 10 it states "experiencing pain, suffering, distress or indignity to an extent unacceptable to the person". Therefore, it seems clear that it is the person who decides on the question whether the suffering is intolerable. However, maybe, this aspect could be more clearly addressed.

Human beings are individuals. Every suffering person experiences his or her situation differently. There is no such thing as "the one typical terminally ill patient" and there is no "typical suffering which would make the individual eligible for a certain end-of-life care". Physical and mental pain is subjective; it can be judged only to a minor degree by third parties. A humanitarian approach demands that the individual is seen as such, not just as "one patient amongst many others".

Certainly, no-one would seriously consider ending his or her own life if, from his or her personal point of view, this life was not intolerable. The requirement of the individual finding his or her suffering intolerable makes sure that all action towards an assisted/ accompanied suicide only takes place if the individual

[40] http://www.legislation.gov.uk/ukpga/2005/9/section/1
[41] http://www.admin.ch/ch/e/rs/2/210.en.pdf

in question actually wishes this to happen; said person has to communicate how he or she feels and thus has to express his or her will. For self-determined assisted dying, this is a requirement that can not be done without.

suffering . . . from a terminal illness

It is generally and widely accepted that individuals suffering from a physical terminal illness such as most forms of cancer, Amyotrophic Lateral Sclerosis (Motor Neurone Disease), Multiple Sclerosis, etc. 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") yet who are not affected by a terminal illness *per se*, such as, for example, paraplegics and quadriplegics[42] or patients suffering from Parkinson's, Multiple Systems Atrophy and Huntington's Chorea. Furthermore, individuals suffering from mental illness should 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 2006[43] acknowledged this, as mentioned before.

Overall, limiting access to assisted dying 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. Referring to chapter 2 of this submission, 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."

[42] 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.

[43] BGE 133 I 58: http://relevancy.bger.ch/php/clir/http/index.php?lang=de&type=show_document&page=1&from_date=&to_date=&from_year=1954&to_year=2014&sort=relevance&insertion_date=&from_date_push=&top_subcollection_clir=bge&query_words=&part=all&de_fr=&de_it=&fr_de=&fr_it=&it_de=&it_fr=&orig=&translation=&rank=0&highlight_docid=atf%3A%2F%2F133-I-58%3Ade&number_of_ranks=0&azaclir=clir#page240

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:

> "The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective;..."[44]

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 basic human rights such as enshrined in 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.

DIGNITAS acknowledges that in legislation one has to "draw a line somewhere" in order to establish a legal frame. However, the notion of 'terminal' is not appropriate eligibility requirement as it is too narrow and above all discriminating – and thus should be changed.

the person is at least 18 years of age

Section 12(1)(a) 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"[45]. Obviously, minors have and may also exercise personal rights. DIGNITAS again 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.

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

[45] http://www.admin.ch/ch/e/rs/2/210.en.pdf

Australian resident and citizen

Providing access to assisted dying for people living in and (cumulative) being a citizen of Australia only, is again, as we see it, an approach to "draw the line somewhere". However, as it is well known, the Swiss legal situation in regard of assisted suicide has a more liberal approach. The background is a humanitarian approach: what is the difference between a person suffering from terminal cancer in Australia and another person living just off the coast in another country? Is it not inhumane and a discrimination to give access to a dignified, self-determined ending of suffering to the one person and, at the same time, tell the other person "your passport has the wrong colour"?

The term "suicide tourism" is often (mis)used; however, people from abroad coming to DIGNITAS are not suicide tourists. They are, in fact, "freedom tourists" or "self-determination tourists".

medical practitioner(s)

As far as we understand, the Draft Bill sets a schedule in which only medical practitioners are permitted to provide dying with dignity medical services. At this point, we need to look in general at the issue of having some sort of 'gate-keeper' – in this case medical practitioners – 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.[46]

In other words: 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 Roosevelt[47]). "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, it is NGO/NPO member's societies like Exit and DIGNITAS are the ones with decades of experience and trained staff to take care of the requests by individuals wishing to end their life and arrange for accompanied suicides in the framework of the Swiss law. Still though, 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.

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[46] See 'The counselling concept of DIGNITAS', http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-how-dignitas-safeguards-eth-21072014.pdf page 10 ff

[47] In: The Autobiography of Lincoln Steffens

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 it is set out in the Medical Services (Dying with Dignity) Bill 2014, section 12(1)(e). 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 be seen that medical doctors have the highest rate of suicide amongst all occupational groups. Amongst the 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 men[48], and the suicide of patients is traumatic for psychiatrists[49]. Therefore, and for this very reason, a psychological conflict of interest arises for medical practitioners and above all psychiatrists: if he or she helps a patient to realise his or her wish for a self-determined end to life, 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)"[50], 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 an individual's human rights.

In the "Swiss model", with DIGNITAS, if a person wishes to start the procedure towards an assisted/accompanied suicide in Switzerland, he or she (as well as having had to register beforehand) has to place a formal request[51] with DIGNITAS

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[48] Several studies, for example 'suicide by medical professionals' (Suizidalität bei Medizinerinnen und Medizinern): http://www.thieme.de/viamedici/medizin/aerztliches_handeln/suizid_arzt.html

[49] See the first UK study of trainee psychiatrists' experience of patient suicide: http://bjp.rcpsych.org/content/178/6/494

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

[51] For details see page 6 of the info-brochure of DIGNITAS: http://www.dignitas.ch/images/stories/pdf/informations-broschuere-dignitas-e.pdf

which is then assessed by the organisation as well as at least one (of the organisation independent) Swiss medical doctor. If such medical doctor gives basic consent to the request (which is the 'provisional green light') and if the individual then wishes to move to the next stage, which would be at least one mandatory consultation with this medical doctor possibly followed by the actual accompanied suicide, the individual in question will have to make a second request expressing his or her wish to make use of said 'provisional green light'.

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 section 12 which obliges the person to find three different registered medical practitioners, the third one being a psychiatrist, each making a statement, that is, acknowledging the request, would be a prerequisite too strict, a hurdle too high.

If many or even all medical practitioners and psychiatrists in Australia refuse to assess / acknowledge requests for dying with dignity – which certainly it is their right to do (freedom to "opt out", as set out in Section 11(2)(a)) – then getting the requests acknowledged becomes almost or entirely a "mission impossible", especially in the light of needing three medical practitioners giving consent. 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.

Therefore, it should be implemented in the Dying with Dignity Bill that the one, the first medical practitioner's statement is sufficient and that he or she is free to choose contacting a colleague in order to obtain a second opinion, but this not having to be a prerequisite.

Furthermore, the prerequisite of a qualified psychiatrist confirming that the person is not suffering from a treatable clinical depression in respect of the illness, as set out in section 12(1)(e), is a further unnecessary hurdle which makes the path to a self-determined end in life a medical-bureaucratic steeplechase. It is turning upside down the earlier mentioned Common Law's recognition that all adults must be presumed to have capacity until the contrary is proved. In fact, section 12(1)(e) is setting the presumption that every person who wishes for a dignified and safe end of suffering and life is not fully mentally competent.

waiting period of 7 days

Regarding the proposed waiting period of 7 days, as set out in section 12(1)(l), between the first indication of the person to the first medical doctor and signing the relevant part of the Certificate of Request: Such a waiting period should not be implemented, because, for a terminal cancer patient for example suffering

from bone metastases which are known to cause extreme pain, 7 days is a long time. DIGNITAS proposes the "Swiss model" which has a one-formal-request approach, involving one medical doctor, whom the patient can contact and access again as soon as a 'provisional green light' for assisted suicide is given. A fixed waiting period is not necessary as automatically, 'straight-forward' requests will be acknowledged quicker whilst more complicated 'cases' would take more time to assess.

informing the person of medical treatments available

This approach set out in section 12(1)(h)(ii) is valuable. In fact, during the entire proceedings an in-depth exploring and suggesting of treatments and alternatives should take place, to explore and suggest alternatives such as changes in medical routine, counselling, hospice and respite care, etc., without the person having the obligation to consider these alternatives. 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 at DIGNITAS see again and again that patients are not being sufficiently informed through the public health system. A large part of DIGNITAS' counselling work is telling inquirers about palliative care options, health care advance directives, patient's rights, 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 Dying with Dignity Bill. However, it must be clear that the person should not have the obligation to follow any of these suggestions. Anything else would be paternalism, in conflict with an individual's personal rights to follow a medical treatment or to reject life-prolonging measurements.

denying access to dying with dignity in favour of palliative care

Section 13(3) could be an "escape route" for medical practitioners not to provide the support to a badly suffering person. There is no definition of what is "palliative care options reasonably available to the person", which could give a medical practitioner too much room to argue that there are such options. In fact, this section rules palliative care over access to a self-determined death with dignity. From DIGNITAS' experience, it is exactly those patients who wish for "control until the last breath" that would like to have an alternative option to palliative care and thus wish for a law, a proceeding which allows them to regain such control over their destiny. From DIGNITAS' point of view, this section 13(3) un-

dermines the object, the entire Dying with Dignity Bill and therefore this section should be done away with.

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 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 respect the will of the people and implement 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 would like to congratulate and thank everyone involved in the making of this Medical Services (Dying with Dignity) Bill 2014 Exposure Draft and hopes it finds a majority of open ears and minds in Parliament, just like Lord Falconers Assisted Dying Bill for England and Wales, which has been supported by a majority in its second reading.[52] The Dying with Dignity Bill is an important step forward towards respecting the human right of individuals to decide on their time and manner of end in life, which has been confirmed by the European Court of Human Rights (see chapter 2 of this submission), this right being set out in a frame within which such proceedings take place, implemented in domestic law, thus making it clear for everyone. Legal certainty is the base for the functioning of a (democratic) society. DIGNITAS supports this Bill – despite its current flaws which certainly can still be addressed – as it aims at respecting and implementing values of humanity. In this context, we refer to the philosophical and political principles guiding the activities of DIGNITAS[53] which we feel may well serve as a basis for any consideration of end-of-life-issues.

We close these considerations with words by DAVID HUME, one of the most famous philosophers of the last 300 years[54]:

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[52] http://www.dignitas.ch/images/stories/pdf/politik-gb-debate-assisteddyingbill-protokoll-18072014.pdf

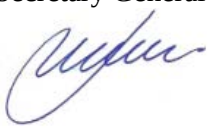
[53] See the booklet/brochure „How DIGNITAS works": http://www.dignitas.ch/index.php? option=com_content&view=article&id=23&Itemid=84&lang=en

[54] DAVID HUME, Of Suicide, http://ebooks.adelaide.edu.au/h/hume/david/suicide , in fine

„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



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