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**End-of-Life Care: Legislative Proposals on
Advance Directives and Dying in Place
Submission by DIGNITAS - To live with dignity - To die with dignity
Forch, Switzerland**

for and on behalf of the 49 Hong Kong members of DIGNITAS
submitted in electronic format to eolcare@fhb.gov.hk

In response to the invitation of views on the Legislative Proposals on Advance Directives and Dying in Place, our non-profit membership association DIGNITAS – To live with dignity – To die with dignity (hereafter abbreviated as ‘DIGNITAS’) wishes to communicate that we support the proposal and would like to share some information, and general as well as specific observations.

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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 suffering and 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 end-of-life choices, including assisted suicide and voluntary euthanasia, and advance health care planning and palliative care 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, as Professor Sophia Chan points out in the Consultation Document. During the congress of the Swiss General Practitioners in 2011² 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. Who would not want to live as long as possible if one’s quality of life, which includes health, is good by one’s personal point of view? However, medical advances have led to a vastly increased capacity to keep people alive without, in some cases, providing any real benefit to their health³ – prolonging life to a point much further in the future than some patients would want to bear it. More and more people wish to add life to their years – not years to their life, and therefore, most importantly, have choices in regarding of shaping the end of 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 had to start choosing more violent methods. The consequence of this: lonely, risky suicide attempts, of which the majority fail, with dire consequences for the individual and his loved ones as well as for third persons.⁴

2) Who is DIGNITAS and why does DIGNITAS write this submission?

DIGNITAS is a Swiss non-profit membership association, a help-to-life and right-to-die dignity advocacy group, founded 17 May 1998 by Swiss human rights attorney-at-law Ludwig A. Minelli. Many years earlier, in 1977, he had already founded SGEMKO, the Swiss Society for the European Convention on Human Rights, a non-profit membership association spreading information about the European Convention for the Protection of Human Rights and Fundamental Freedom (ECHR). At an early stage, Mr. Minelli and his colleagues have been convinced that where there is the individual’s right to life as enshrined

¹ In: Epistulae morales LXX ad Lucilium

² Congress of Swiss General Practitioners in Arosa, 31 March - 2 April 2011

³ British Medical Journal 2012, <http://www.bmj.com/content/bmj/345/bmj.e4637.full.pdf>

⁴ See the speech by DIGNITAS “Suicide-Prevention must be complemented by Suicide-Attempt-Prevention”: <http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-wf-kongress-suizidversuche-e-15062012.pdf>

in article 2 of the ECHR, there also must be the individual's right to die – the personal right to have control over the end of his or her own life. Many years later, in 2011, the European Court of Human Rights (ECtHR) confirmed this opinion in the case of HAAS v. Switzerland, application no. 31322/07⁵.

DIGNITAS being a human rights orientated organisation posed the question: if in Switzerland, why not in other countries? Isn't it discriminatory, if access to a self-determined dignified end of life depends on domicile/residence and citizenship? The ECHR condemns such discrimination in article 14⁶. Therefore, the logic consequence for DIGNITAS was and is a) to allow non-Swiss residents and non-Swiss citizens to access the possibility of medically assisted dying (assisted/accompanied suicide) in Switzerland, which obviously includes people of Hong Kong, and b) to advocate for implementation of options to plan ahead in matters of health care, and also 'the last human right', the practice of Switzerland, in other countries too.

Today, DIGNITAS, together with its independent partner organisation DIGNITAS-Germany in Hannover, also a non-profit membership association, counts over 10,000 members worldwide of whom 49 reside in Hong Kong.

In its 21 years of operation, DIGNITAS has been involved in several leading legal cases dealing with the 'right to die' at the European Court of Human Rights and others more and DIGNITAS has been consulted by committees, panels and representatives of parliaments, from England, Scotland, Sweden, Victoria Australia, Canada and others more, in matters regarding the implementation of laws to introduce choices for individuals so they may plan ahead and put in practice their wishes on controlling their destiny, their final stretch of life.

3) **General observations: end-of-life-choices and suicide attempt prevention**

Many people sign up as members of DIGNITAS because they wish to have the safety of the option for a self-determined end of life. Most of these members, those who suffer from a grievous and/or terminal suffering, will finally make use of palliative care in their home country. One of their fears is to end up in a hospital bed incapacitated, deprived of autonomy and therefore other-determined, or worse as a "vegetable", that is, without consciousness being kept alive. The safety of knowing that one has choices and that one's wishes and will has to be respected by law, because it is implemented in the law, allows people to better cope with their illness and suffering.

Moreover, having access to legal end-of-life choices lifts fears, thus relieves pressure on the individual, and such makes an important contribution to reduce the high number of lonely risky "do-it-yourself" suicide attempts and deaths by suicide. The World Health Organisation points out that "close to 800,000 people die due to suicide every year"⁷ and "for each suicide, there are more than 20 suicide attempts"⁸. In 2018, in Hong Kong 910 people ended their lives by suicide⁹, and applying the figure stated by the WHO there have been more than 17,000 people attempting suicide. It is sometimes overlooked that end-of-life choices and suicide (attempt) prevention are – should be seen as – connected to each

⁵ <http://hudoc.echr.coe.int/eng?i=001-102940> paragraph 52

⁶ http://www.echr.coe.int/Documents/Convention_ENG.pdf page 13

⁷ <https://www.who.int/news-room/fact-sheets/detail/suicide>

⁸ https://www.who.int/mental_health/prevention/suicide/suicideprevent/en

⁹ <https://csrp.hku.hk/statistics>

other¹⁰, because it is often assumed that such attempts are primarily by people in a life crisis and people with a psychiatric illness. Even though this applies to some cases, it is still a fact that there are people who take to “hard methods” to end their days due to their grievous and/or terminal illness, and without having a legal option to end their suffering in a self-determined manner they are more at risk. For this reason, a comprehensive approach is necessary.

4) General observations: Planning ahead

In the 21 years of DIGNITAS’ existence, two individuals from Hong Kong have made use of the option of a self-determined self-enacted and physician-supported ending of suffering and life accompanied with DIGNITAS in Switzerland¹¹. For all DIGNITAS-members, being assisted and accompanied through the final stage of their life towards their self-chosen end was and is an issue of major importance. DIGNITAS always encourages members to have their next-of-kin and friends at their side during the entire process, including the final days.

However, if these Hong Kong residents had had more legal safety as to their end-of-life wishes, there would have been the chance for them to find help at home; they might not have felt the need to turn to DIGNITAS and make the strenuous journey to Switzerland to put in practice their wishes in regard of a self-determined end of suffering.

The first and arguably most important step to prepare for the known and the unknown is to think, consider and discuss about end-of-life wishes.

One can only define for oneself whether one’s *own* life still holds quality, based on one’s personal measure of value. Nobody can gauge whether someone else’s quality of life is sufficient. The healthy cannot step into the shoes of a suffering person and judge whether that individual’s life has quality, nor can they decide whether or not it makes sense to continue living.

The first step in such preparation is to think about one’s *measure* of value in regard to one’s own life. What is it that I want to happen in a specific situation, for example when facing a severe illness or if I cannot handle my own affairs anymore? What should happen if, for whatever reason, I can no longer interact with my environment and thus cannot express my will?

One can pose these and many similar questions, think about them, decide on an answer and put these decisions in – preferably written – instructions. Of course it is also possible to decide *not* to decide and not to do any such instructions. This is a personal choice. When it comes to medical instructions, some people think “my doctor will know what is best for me”. Of course, this has to be respected and such confidence in medical professionals and a functioning health care is a good thing. Others favour maximum independence and self-determination and they assume responsibility for this by planning ahead.

Whatever one’s choice, it is important to discuss one’s perception and values concerning “suffering and end-of-life issues” with people one trusts; such people are usually close

¹⁰ Compare DIGNITAS’ submission to the Joint Committee on End of Life Choices South Australia, page 13 ff <http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-submission-end-of-life-choices-south-australia-31072019.pdf>

¹¹ <http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2018.pdf>

family member and friends, but could also be one's medical doctor. An open exchange on one's personal perceptions and wishes creates understanding and trust.

One needs to be aware that matters surrounding one's end in life do not just concern oneself and one's own right to self-determination, but one must also take into account the fact that we all bear a responsibility towards our loved ones. In an emotionally difficult situation, the loss of a loved one is at least a bit less burdensome if people do not have to ask themselves: "What would he/she have wanted?" Preparation also takes into account the position of medical doctors and nurses; they too are relieved if essential questions have been answered in advance.

An Advance Directive is the one probate instrument. Discussing the issue and putting in writing one's wishes at a time when one has capacity of judgment to become effective at a time one has lost capacity for whatever reason, offers important advantages:

- It gives loved ones safety and clarity and relieves them from potentially having to make difficult decisions without knowing the personal wishes of their family member;
- It gives safety and clarity to health care professionals – nurses, medical doctors, etc. – treating the patient;
- It strengthens the individuals' self-responsibility and feeling of being in control of his or her destiny which can significantly add to his or her quality of life, because the feeling of being 'at the mercy of the course of the illness' can be soothed;
- This strengthening of the individual in a difficult health situation also reduces the risk of desperate suicide attempts;
- And it therefore adds to a general positive development of public health

Obviously, these advantages can only unfold if Advance Directives are effective, that is, implemented in the law as a personal, legally enforceable instruction of an individual.

In Switzerland, the Swiss Civil Code article 370 ff. makes Advance Directives legally binding as of January 1st 2013¹². Some people use this option to express their wishes in regard of health care treatment they would like to receive or not in the future. It has brought about a positive development of strengthening the self-responsibility of individuals just as much as safety and clarity for loved ones and health care professionals.

5) Specific observations: Advance Directives as to the Consultation Document

As to most questions in the Consultation Document, DIGNITAS agrees with the proposals set out. There are a few aspects to discuss, for which DIGNITAS suggests that in view of legislation the Government reconsiders its position and amends the conditions.

5.1) Consultation question 7

Though it is pointed out in the Consultation Document (paragraph 2.1) that "...advance directives are usually made by patients with serious irreversible illnesses...", it should be kept in mind that indeed "some people may wish to make an advance directive while healthy". The statement "but it is not easy for them to make decisions and sign an advance directive" (paragraph 4.16) appears a pretext argument. In fact, for the healthy it is even

¹² <https://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a370>

easier to make an advance directive, since they are not in the situation of feeling their time running out due to, for example, a terminal illness.

As far as it could be assumed that the public is not (yet) sufficiently “aware of the pros and cons of making an advance directive when healthy” Hong Kong’s efforts to make the public aware of this option is the right approach. Generally, it is in the personal responsibility and choice of individuals, moreover of healthy people, to research what options in regard of advance health care planning are available to them. The wish for end-of-life choices and self-determination does imply individual’s assuming responsibility of getting informed. It is positive that there is no limitation for health individuals signing an advance directive.

5.2) Consultation Document questions 11 and 12

DIGNITAS finds that the Government's proposed condition of an advance directive only being valid if it is made and modified in the presence of two witnesses of whom one is a medical practitioner is not in line with the fundamental principle “respecting a person’s right to self-determination” (paragraph 4.8 (a)). Especially for people who are alone and/or disabled it can be a considerable hurdle. On the other side, people who are healthy would, obviously, not necessarily have a relation to a medical practitioner. Moreover, people making an advance directive may prefer to keep this a private matter, at least so for some time.

Setting up a valid advance directive should be made as easy as possible. As the Government admits, “the requirement of a witness is not mandatory under the common law framework”. This is also the case under Swiss Law. The Hong Kong Government should adhere to the present common law situation and not implement unnecessary hurdles for people who wish to legally determine that they would not want to be kept alive when having lost their faculties.

5.3) In regard of “what is a valid and applicable advance directive”, Consultation Document page 9, Consultation Document questions 17 and 18

DIGNITAS finds that the condition that an advance directive becomes applicable only when the patient suffers from “pre-specified conditions” is too narrow, and that this may be a contradiction to the fundamental principle “respecting a person’s right to self-determination” (paragraph 4.8 (a)). Specifically, DIGNITAS recommends to discuss whether the catalogue of conditions set out in the Consultation Document in paragraph 4.26 should be enhanced, especially since it is acknowledged in paragraph 4.27 that “a patient may still choose to adopt other advance directive forms with other additional pre-specified conditions”.

The proposal by the Government leads to a “two-class advance directive system” in which one class is those who use the model form with the (limited) group of pre-defined conditions and such have better chances of having their wishes respected – whilst others who would wish to cover further conditions are without safety since “treatment providers may challenge the validity” of the advance directive and such make it non-applicable.

One example of the pre-specified conditions in paragraph 4.26 worth reviewing is the “state of irreversible coma”. Despite the merits of modern medical science, there are still cases of uncertainty; it can hardly be said for sure whether a coma is really one hundred percent irreversible. In the advance directive model form by DIGNITAS, offered to its members, this is solved by specifying the number of days in a coma after which the individual wishes not

to be further kept alive artificially. The specified conditions is: “If I have been in a coma or persistent vegetative state for more than 14 days XXX days”

A further example, connected with the aforementioned condition of a coma, is the condition of having lost one’s mental capacity due to dementia. As the Consultation Document rightly points out, the “...population is ageing rapidly”. With higher life expectation, the probability to encounter a dementia illness such as for example Alzheimer’s disease is rising. There are nearly 10 million new cases of dementia every year and it is one of the major causes of disability and dependency among older people worldwide¹³.

There are people who do not wish to be (kept) alive in a situation of advanced dementia, when they cannot any longer recognize people close to them or they have lost control of their bladder and/or bowels. In regard of the pre-specified conditions, it should be discussed if dementia falls into the category of b) and/or c) stated in paragraph 4.26 of the Consultation Document. If not, it should be included. The pre-specification could be words as follows: “If brain damage or a process of loss of brain function has been established and I have lost my sense of time and place for more than XXX days or if I no longer recognize people close to me or have lost control of my bladder and/or bowels.”

6) General observations – Dying in Place

Recent research and reports indicate that despite good health care provided in hospitals, hospices and homes for the elderly there is a significant number of suicide attempts and deaths by suicide in such institutions¹⁴. This indicates that a feeling of being “parked and caught in an institution from where there is no return” can arise that leads to (additional) suffering, emotional distress – something that would be less of an issue when having the comfort of being able to pass one’s final days and weeks at home. The Hong Kong Government’s approach to promote dying in place as outlined in the Consultation Document is a welcome measure to improve the quality of life for severely suffering individuals.

7) Conclusion

DIGNITAS very much welcomes the consultation and discussion for legislation on Advance Directives and Dying in Place. It brings the issue of end-of-life-questions to the level where it should be addressed, the legislation.

For any question you may have, please do not hesitate to contact us; the board of DIGNITAS – To live with dignity – To die with dignity is happy to give oral evidence if members of the Food and Health Bureau and the Government would wish so.

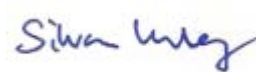
Yours sincerely

DIGNITAS

To live with dignity - To die with dignity



Ludwig A. Minelli



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¹³ https://www.who.int/health-topics/dementia#tab=tab_2

¹⁴ Referred to in: <http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-jersey-11092019.pdf> page 3