

The “Swiss system” of assisted dying – and beyond

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30 March 2019

Stockholm, Sweden

booklet to complement the talk and discussion

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Introduction

“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”

This statement can be found in the judgment of the European Court of Human Rights, case of DIANE PRETTY v. the United Kingdom, dated 29th April 2002, at the end of paragraph 61. It highlights one of the challenges of our times: despite living longer and longer, due to the achievements of medicine and other health improvements, a time may come when one feels that barely living is not sufficient, because one's quality of life does not correspond with one's personal views anymore.

More and more people wish to add life to their years – not years to their life. And they wish to determine the course of their life, including the last stretch and the end of it. 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 turn to more violent methods.

The wish to choose and determine one's destiny is not new. All through history there have been individuals with strong personal views about their quality of life. The wish to choose and the right to die are not an entirely new phenomenon. It did become more accentuated through Enlightenment, and the formation of democratic states and the idea of citizens as individuals with personal rights and freedoms. Likeminded individuals form groups to exchange and bring forward their ideas. In England, a right-to-die organisation was founded already in the 1930s, the VES – Voluntary Euthanasia Society. Similar organisations have appeared since then. One of them is DIGNITAS – To live with dignity – To die with dignity.

In a short speech, it is only possible to briefly touch on some points. The following pages offer some more information, though, as it is in the nature of the issue, still only glimpses. DIGNITAS – To live with dignity – To die with dignity deals with all of these issues, and more.

Who is DIGNITAS – To live with dignity – To die with dignity?

DIGNITAS – To live with dignity – To die with dignity (this the correct and full name; ‘DIGNITAS’ is just a short version; used hereafter for easier reading) is a Swiss help-to-live and right-to-die non-profit member society founded on May 17th 1998 in Forch, near Zürich, by Ludwig A. Minelli, an attorney-at-law specialising in human rights. In accordance with its articles of association, DIGNITAS has the objective of ensuring a life and an end-of-life with dignity for its members and of helping other people to benefit from these values. This is reflected in the full name and the logo of the organisation: DIGNITAS – *To live with dignity – To die with dignity*. As one can see, the aspect of a dignified life comes first. It is DIGNITAS’ first and most important task to look for solutions which lead towards re-installing quality of life so that the person in question can carry on living. At the same time, if solutions towards life do not seem to be possible, options for a dignified death are also looked at.

Today, DIGNITAS, together with its independent sister association DIGNITAS-Germany in Hannover, which was founded on 26th September 2005, has some 9,500 members in 90 different countries around the world.



DIGNITAS has an office in Forch and a house near Zürich where accompanied suicides may take place, for members from abroad and for Swiss residents if they cannot be helped at their home. There are 28 people working for the two DIGNITAS organisations, almost all of them part-time, comprising board members, an office team doing mainly

advisory work and a team of companions / befrienders who assist with accompanied suicides.

In fact, DIGNITAS’ work extends far beyond “assisted dying” and comprises suicide attempt prevention, litigation and political work to further develop laws regarding human rights concerning freedom of choice and self-determination in life and in “last matters”, planning ahead with healthcare advance directives, counselling in palliative care, and so on. DIGNITAS is a protection of life and quality-of-life organisation.

One third of DIGNITAS’ daily “telephone work” is advisory work for individuals from around the world who are not members of the association.

This extends beyond suffering people who seek help, to medical professionals, lawyers, students, researchers, etc. Additionally, DIGNITAS runs a free-of-charge online forum with more than 4,200 registered users. Set up as a self-help community, it allows people with suicidal thoughts to share their feelings and support one another to cope better in hard times. It is taken care of by a professional mediator and two IT technicians.

Furthermore, DIGNITAS assesses requests for the preparation of an accompanied suicide for those members who send the relevant documents, and tries to obtain a “provisional green light” from an independent Swiss physician for such an accompaniment with DIGNITAS. The option to bring a dignified end to one’s suffering and life at a self-chosen moment in time (if quality of life does not allow one to carry on any more) is the “emergency exit door” which helps people to feel better because they regain independence and control over their destiny. That control reduces the pressure on them to resort to a lonely and risky suicide attempt (of which the vast majority fail, with dire consequences).

DIGNITAS does not restrict its services to Swiss residents. DIGNITAS, as a human rights oriented’ organisation, posed the question: if in Switzerland, why not in other countries? Isn’t it discriminatory, to base access to a dignified end of life on country of domicile or residence and citizenship? The ECHR condemns such discrimination in article 14. Therefore, the logic consequence for DIGNITAS was

- 1) to allow non-Swiss residents and non-Swiss citizens to access the possibility of an assisted/accompanied suicide in Switzerland and
- 2) to advocate for implementation of ‘the last human right’ (such as Swiss practice) in other countries too.

This is why DIGNITAS ignores political borders and works internationally. Since the start, DIGNITAS has engaged in many court cases which concerned questions around “last human rights”, especially at the European Court of Human Rights in Strasbourg. Furthermore, DIGNITAS has engaged in law-making discussions and proceedings by handing in submissions and law proposals in many states.

DIGNITAS works on overcoming several barriers: breaking the taboo on “being tired of life”, questioning set legal situations and moral conceptions, adapting these to human rights, and implementing freedom of

choice, self-determination, independence through providing information and observing self-responsibility.

DIGNITAS' philosophy

On 16th May 1998, the general assembly of Exit (Swiss German part) in Zürich took place. The director of Exit at the time, Peter Holenstein, had proposed to the board of Exit that the organisation should engage in the reduction of the number of suicides and suicide attempts. However, conservative forces within Exit could not understand such a progressive approach to widen the focus to public health and developments in society in general. With an aim to deselect Holenstein, circles around the board arranged for an additional 300 Exit members to additionally attend the general assembly. Peter Holenstein was booed down and his fellow combatant Ludwig A. Minelli, at the time legal counsellor of the director of Exit, had no chance to speak at the assembly. The proposal went down in the noise and Holenstein was deselected.

Having lost, that small group of visionaries decided to stick to the concept of suicide attempt prevention, to add legal further development and, in the light of the circumstances, to realise it in a new non-profit member society. Overnight, Ludwig A. Minelli wrote the statutes, and on Sunday 17th May 1998 the member society “DIGNITAS – To live with dignity – To die with dignity” was founded. One day later, the organisation was already operational.

DIGNITAS took on distinct philosophical principles. The starting point of the principles guiding the work of DIGNITAS is the progressive-liberal position that in a free state any freedom is available to a private individual provided that availing oneself of that freedom in no way harms public interests or the legitimate interests of a third party. These values are:

- Respect for freedom and autonomy of the individual as an enlightened citizen;
- Defending this freedom and autonomy against third parties who try to restrict those rights for some reason, whether ideological, religious, political, economical or greed for power;
- Humanity which seeks to prevent or alleviate inhumane suffering when possible: probably the most shining example of this in our history, on a national and international level, led to the founding of the Red Cross;

- Solidarity with weaker individuals, in particular in the struggle against conflicting material interests of third parties;
- Defending pluralism as a guarantee for the continuous development of society based on the free competition of ideas;
- Upholding the principle of democracy, in conjunction with the guarantee of the constant development of fundamental rights.

In a liberal-democratic state, rights and freedoms enshrined in the constitution and/or human rights charter cannot and shall not be limited to points listed therein and exclude others, which over time gain significance. Constitutions and the European Convention on Human Rights are “living instruments”: barriers based on its contents are to be regularly reviewed by case law and, if need be, further developed.

People are not property of the state. They are the bearers of human dignity, and this is characterised most strongly when a person decides his or her own fate. The state or its individual authorities may not determine the fate of its citizens. As the British philosopher and economist John Stuart Mill put it: *“Over himself, over his own body and mind, the individual is sovereign”*.

The freedom to shape one’s life includes the freedom to judge one’s own quality of life. To personally shape one’s own life, including the option to determine the time and manner of one’s own end in life, is a basic freedom and human right. In the words of the European Court of Human Rights, judgment no. 31322/07, HAAS v. Switzerland, dated 20th January 2011, paragraph 51:

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

However, departing on such a “long journey” entails responsibility. All individuals are part of society. Therefore, one should not set out on this journey without careful preparation, nor without having said appropriate goodbye to loved ones.

The goal of DIGNITAS

No non-Swiss person should be forced to travel to Switzerland in order to

have a self-determined, self-enacted, safe and accompanied ending of his or her suffering. Everyone should have access to such an option in his or her home, as an additional choice alongside palliative care measures (including palliative/continuous deep sedation), having treatment discontinued based on instructions given in personal health care advance directive, or the accompanying of dying individuals. DIGNITAS' goal is that everybody can make use of such options at home.

The core goal of DIGNITAS is to become obsolete, to disappear as soon as possible. When regulations regarding freedom of choice and self-determination in life and life's end similar to those available in Switzerland are implemented in all other countries, nobody will have to turn to DIGNITAS and Switzerland anymore. Nobody shall become a "freedom tourist" or "self-determination tourist" (which is certainly a more appropriate term than the tabloid-style "suicide or death tourist"). And when the work of organisations like DIGNITAS has been implemented in the health care and social welfare system, such organisations will no longer be necessary.

However, as long as many countries' governments and legal systems disrespect their citizens' basic human right to choice and self-determination in life and life's end, ban the topic with a taboo, and force them either to turn to lonely risky suicide attempts or to travel abroad instead, DIGNITAS will serve as an information provider and "emergency exit".

The Pros and Cons of striving for more quality of life

According to the World Health Association WHO, life expectancy (from birth) in Sweden has increased over the years to 84 for women and 81 years for men. This is similar to other industrialised "western world" countries.

The fact is that we live longer and longer. There are many reasons for this: developments in medicine, material prosperity, education, improved hygiene, more awareness of one's health, etc.

Quality of life, the subjective measure of well-being, is influenced by several factors. Health is one of them, and is arguably the most important. The constitution of the World Health Organisation (WHO) states:

„Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity“

and furthermore:

„The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition“

Alongside material prosperity and education, self-confidence and the wish for individual fulfilment have been developing; at least in our “western hemisphere” many people can shape their life – in the frame of the legal and social order – the way they want to lead it, the way they feel it to be appropriate in accordance with their personal values.

Without doubt, all this is a wonderful thing. Who does not wish to stay healthy and, at the same, to time live longer?

However, this development has also its downsides. Every day we are confronted with the ideal of the slim, omnipotent, suntanned and fit-as-a-fiddle individual. Advertising shows us again and again further possibilities of what we can do good for our mind, our body and our soul. Our performance-orientated society demands personal efforts to increase quality of life. Askew and chubby are “out”, the nose wants to be straightened and the wrinkle smoothed.

We are led to believe that good looks and being healthy are the norm and we act as if we could live forever young and fit. „Heroes don’t die – they just fade away“. That life is *limited* has faded from our perception. We have “outsourced” suffering to care homes and rehab clinics. Dying is for later and somewhere else, rarely at home: the transition from life to death takes place in hospices, homes for the elderly and palliative care wards of hospitals. It is neatly filed away and sealed off from the pulse of life so that the functions of a well-oiled, performance-orientated society are not impaired. It seems that we have forgotten how suffering and death, just as much as joy and birth, are a part of life.

One day reality catches up with us, often when we are unprepared: we may be confronted with a life-crisis, face the consequences of an accident or isolation, we fall ill, we get old and frail.

Referring back to the European Court of Human Rights judgment in the case of PRETTY; indeed we live longer and, thanks to the developments in medicine, in better health – but a point can be reached when “only” living

is not enough because the quality of one's life no longer confirms to one's personal preferences.

Blinkers and ditches

Quality of life and self-determination, even in "last matters", are discussed widely in public. However, quite often, a deep ditch is dug between different approaches of help, as if there was only one solution for a specific life-, suffering- or life's end situation. Single aspects are taken out of context.

Additionally, those who seek help due to their suffering are on a roller coaster of feelings: support conveys safety and social reassurance, but also a feeling of dependency. People who seek help are seeking the maximum possible independence, yet they feel helpless because they are unable to act alone. Often, their anger, grief and frustration grow due to the abilities they have lost or the possibilities that are unavailable. One may feel ashamed for not-being-able, or not-being-capable anymore.

In the fields of medicine, nursing, psychological therapy and psychiatry as well as social care, sometimes one can see that awareness for the individuality and complexity of the single case is missing or blanked out. The person is not seen as an individual subject but as an object, as a case.

A further issue is expertise: specialists are sometimes so focussed on their own field of know-how that they possibly no longer recognise certain features. The known therapy is the only right one!

There are palliative care specialists who emphasise that, with sufficient palliative care, every form of suffering can be soothed. They insist therefore, that further options are not necessary, certainly not assisted dying made possible by organisations such as DIGNITAS.

In certain circumstances personal elements may stand in the way: ego, striving for power, difficulties accepting the possibility of being rejected as a therapist, and inability to recognise the risk of providing help which sub-consciously puts one's own needs before those of the patient. What was it that the individual really wants?

Some like to refer to the "protection of life" (derived from the right to life) and to "medical ethics" or to "guidelines by ethic commissions".

However, the right to life does not mean a duty to live. Furthermore, one cannot and should not withdraw from one's professional and human

responsibility by simply delegating thinking and deciding to a commission. And, after all, it is still up to the individual to decide on what treatment he wants or not.

Why are some “experts” digging ditches between the different options one can choose between in the field of help with suffering?

Their motives are multi-layered and may include monetary, ideological and power-seeking elements. What these experts have in common is that they all wear blinkers whilst tending their little garden. They seem to have forgotten that the person sitting in front of them is a human being. They seem to have also forgotten the content of the Declaration of Geneva of the World Medical Association:

“I solemnly pledge to dedicate my life to the service of humanity”

and furthermore:

“I will not use my medical knowledge to violate human rights and civil liberties, even under threat”.

What are the consequences? Some people will turn away from their doctor or therapist and look for another medical professional – and in the best case they will find the treatment which they feel is appropriate. Others might incur a treatment mistake and have to bear the consequences in addition to their initial problem. It is possible that developments in medical science might offer a new approach, a solution. Certainly, in many cases they will get off lightly. But if not?

All this may seem to be too harsh a criticism. The fact is, though, that at DIGNITAS we are faced with the negative results of these blinkers and ditches daily.

Suicide attempt prevention

Suicide attempt prevention is a sort of roof over the daily work of DIGNITAS. In the light of the downsides of striving for more quality of life and the challenges with blinkers and ditches, we need to look at the consequences.

What happens to a person in a reduced physical and emotional state who does not feel that their needs are being met, does not feel that they are being noticed and taken seriously and who plunges into a downward spiral of failure and dwindling hope for improvement? What if the condition

further deteriorates until he or she sits at the bottom of a deep hole and only sees the sky up above – and heaven's exactly where he or she wants to go?

Until now, national and international debates on assisted suicide and/or (voluntary) euthanasia have hardly recognised the fact that, apart from the small number of individuals who, due to their deteriorating health, wish to end their suffering with one of the few available methods (palliative care, assisted/accompanied suicide, rejection of treatment and refusal of food and drink, etc.), there is a problem on a much larger scale which questions the sanctity of life: the general problem of suicide and suicide attempts.

Many industrialised modern states show a high number of suicides and even higher counts of failed suicide attempts. The World Health Organisation WHO estimates that 800,000 people worldwide die by self-harm every year and that “there are many more people who attempt suicide every year”.

In response to a request regarding information on suicide and suicide attempts in Switzerland lodged by Andreas Gross, a former member of the Swiss National Council, the Swiss government rendered its comments to the parliament on 9th January 2002: 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 number of 1,350 of fulfilled (and registered) suicides of that year. Thus, the risk of failure of an individual suicide attempt is up to 49:1!

According to information provided by the Swedish National Board of Health and Welfare, the Socialstyrelsen, there are on average some 1,200 deaths through suicide in these latest years. This means that, in Sweden, up to 60,000 suicides were attempted. Do not forget that this number is based “only” on officially recorded suicides: sometimes suicides are not recognised and therefore not registered statistically as such, for example self-inflicted accidents by car or motorbike. Even if the number of suicide attempts is “only” ten times higher than the officially registered suicides, there are still 12,000 people who attempted suicide, 10,800 of whom have to bear the consequences of having failed. And it is important to remember that third parties also have to bear consequences: relatives and friends, police, emergency doctors, firefighters, train drivers...

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”, “not all people who are hospitalised due to self-harm may have intended to die by suicide” – are simply ‘thought savers’ (an expression of Lincoln Steffens, 1866-1936, American Journalist). ‘Thought savers’ are a way to stop thinking about a particular problem without solving it. With a ‘thought saver’, one may get rid of the problem, belittling it so that it appears no longer worth thinking about. It is quite significant that such ‘thought savers’ are very common in relation to the suicide and suicide attempt problem. 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? The answer is: 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.

The negative and tragic result of ‘clandestine’ suicides is diverse:

- enormous costs for the public health care system, especially costs arising from caring for the invalid, costs for the public sector (rescue teams, police, coroner, etc.) and costs for a country’s economy;
- high risk of severe physical and mental injuries for the person who attempts suicide;
- psychological problems for those unintentionally but directly getting involved in the suicide attempt, such as train drivers;
- 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 the scene at or after a suicide attempt.

The consequence of failed suicide attempts, expressed in costs which society has to bear, is enormous. The study „The price of despair – On the costs due to suicides in Switzerland” (“Der Preis der Verzweiflung – Über die Kostenfolgen des Suizidgeschehens in der Schweiz“), based on 1,296 suicides registered in 1999 in Switzerland, suggests a yearly cost of over 65 million Swiss Francs due to police operations, work of the authorities,

property damage, death-related costs such as paid-out life insurances and pension, etc. With suicide attempts, in addition to the work of police and authorities, further factors have to be taken into consideration: ambulance treatment, stays of different length in hospitals, work of the intensive care team, support care due to possibly lifelong disability, therapies, etc., which incur costs. The study takes 30,000 suicide attempts as a base whilst assuming that half of these people would not suffer health consequences. However, even this figure resulted in approximate costs of 2,369 million Swiss Francs.

Some governmental 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. This is the usual suicide prevention approach which is generally about:

- restricting access to means of suicide by deliberate decisions or by developing improved technological processes;
- sometimes rather hesitant safety measures in places (so-called ‘hot-spots’) where many suicide attempts have taken place;
- limiting public awareness of suicides in the media and pushing for the issue of suicide to be kept private.

It is provocatively said that suicide prevention deals mainly with the reduction of deaths due to suicide, aiming at one death less in the statistics. To achieve this, it is sufficient if the suicide attempt fails. Obviously, this is a rather limited, statistical approach which – to little surprise – has not significantly reduced the number of suicide attempts. And, what is worse, the taboo surrounding suicide is almost always upheld.

As long as suicide prevention is an issue for people and groups who oppose individual freedom of choice and self-determination regarding life and one’s own end in life, who wear blinkers and dig ditches while rejecting the idea of suicide, little will change in this regard.

Suicide *attempt* prevention reaches further. The starting point of effective suicide attempt prevention is looking at the root of the problem: the taboo surrounding the issue, the stigmatization, the wall of fear of embarrassment, rejection and losing one’s independence.

In the light of the enormous number of committed/fulfilled and failed suicide attempts and their negative effects, measures towards an improved program of suicide and suicide attempt prevention are of the essence.

No matter whether the risk is 49:1 or ‘only’ 9:1, it indicates that in countries which do not have physician-supported accompanied suicide or voluntary euthanasia, 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, also harming close persons (for example family and friends) and third persons (for example train drivers if someone jumps in front of a train). This signifies that the right to end one’s life self-determinedly and by own action under the conditions currently found in most countries is neither practical nor efficient.

Assisted dying has a suicide attempt preventive effect, and this is a reason why DIGNITAS implemented this aspect into its work right from the start.

Switzerland has a progressive-liberal law which allows access to an accompanied/assisted suicide not only – as is the case in the US state of Oregon – for individuals who are considered to be terminally ill and within six months of dying.

By comparing statistics published by the Swiss Federal Statistical Office and the Oregon Health Authority, it can be observed that in Switzerland the number of lonely “do-it-yourself” (DIY) suicides has decreased significantly over the past 20 years whilst in Oregon it has not. This indicates that broader eligibility criteria for assisted dying results in more effective reduction of the number of DIY-suicide and suicide-attempt.

The prospect of having access to the option of a self-determined, safe and accompanied end of suffering reduces the risk of such attempts, because it alleviates the individual’s pressure of desperation and feeling of “there is no way out”.

Moreover, DIGNITAS’ many years of experience show that only a very small number of people who enrol as a member take advantage of the option of an accompanied suicide. A study, including investigation into 387 files of DIGNITAS members by a German student, found that only around 14% of all those who receive a “provisional green light” actually make use of an accompanied suicide.

Furthermore, even after more than 30 years of such assisted dying practice being in place in Switzerland, only around 1.5 % of all deaths take place by accompanied suicide.

The starting point of successfully safeguarding (and improving the quality of) life is a progressive-liberal approach which includes respect for the individual and involves accepting a paradox: if risky lonely suicide attempts with their dire consequences are to be prevented, suicide as such has to be accepted at a fundamental level. The taboo surrounding the issue – the wall of fear of embarrassment, rejection and losing one's independence – has to be lifted.

Naturally, people who wish for an end of their suffering and life have personal reasons. If their wish is taken seriously and if they are supported to scramble out of their deep hole, they regain farsightedness. This indicates that the person has to be met where he or she is. And this in turn demands opening the door to a conversation without moralising, without taboo and without paternalism.

Opening that door leads to a conversational atmosphere in which the individual can discuss the reasons why they do not see sufficient quality in their life anymore and why they do not want to continue living. In general, everyone wants to go on living and to enjoy sufficient quality of life. People only wish to end it all because they cannot see how to go on living in the specific situation which they feel to be unbearable and unacceptable. It is for these reasons that DIGNITAS has developed a comprehensive open-outcome advisory concept.

DIGNITAS' advisory concept

Anyone may get in touch with DIGNITAS, no matter what their reason. And in the frame of DIGNITAS resources, *everyone* receives advice and support. This includes guidance on health care advance directives (advance decisions), directing people at an acute risk of suicide towards crisis intervention centres, giving guidance on palliative care, providing information about other helping organisations as well as expert physicians, etc.

DIGNITAS focuses on giving advice adapted to the individual situation. The common denominator for anyone doing such advisory work should be:

- 1) break the taboo surrounding suffering, suicide and death;
- 2) be there and listen;
- 3) take people seriously;
- 4) talk openly and honestly with them;

- 5) do not shunt them into the “mentally-ill corner” or stigmatise them in any other way;
- 6) talk in a fact-orientated way, especially about suicide and the high risks of ‘clandestine’ suicide attempts; and
- 7) provide advice in a comprehensive and open-outcome manner, that is in all directions.

What does this mean?

Break the taboo Take the dark sides of life for what they are, that is, part of life. That’s simple and difficult at the same time. It is essential to think about and to be at ease with these matters oneself before meeting people who are possibly afraid to talk about them.

Be there and listen A GP once told us the story of an elderly regular patient who came into his practice complaining about a bit of knee pain. Being under time pressure, the GP did not pay much attention and simply gave him some salve to soothe the pain before rushing on. The old man went home and committed suicide. This is surely an extreme case but it indicates that, to hear the story *behind* the story, one needs to listen very carefully and ask questions.

Take people seriously Even if the explanation about suffering given by the person who seeks help sounds absurd, it is essential to take notice and to take him or her seriously. It is that person’s reality and they should be met in that place. The most incredible stories come from life itself.

Talk openly and honestly Quite obviously, the person seeking help makes contact with a professional because he or she wants and needs expert know-how. Making light of the problem and attempting to diminish its seriousness, “verbal dilution”, is counterproductive. The disappointment of finding out that one has not been dealt with honestly by a professional to whom one has given one’s trust hurts even more when reality catches up, and it undermines one’s ability to trust in future.

No stigmatisation Tired of suffering = tired of living = suicidal = depressed = mentally ill. This chain of thinking is a widespread and *false* conclusion. It is fuelled by a “psychiatrisation” in medicine and everyday life, such as can be seen from the latest expansion of the Diagnostic and Statistical Manual of Mental Disorders DSM-5. Quite unnecessarily, the person seeking help is “classified”, “labelled”, declared to be sick. However, the person should be met at eye level!

Talk about facts The taboo surrounding suicide leads to a lot of suffering. Concealing, trivialising or scandalising the issue is out of place because suicide and suicide attempts have been – and still are – a reality, a possible human act.

Comprehensive and open-outcome The phrase “informed consent” includes the word “informed”. In talking with the person who seeks help about *all* the possible options in a specific situation of life and life’s end without having a particular outcome in mind, empowers the person to think about all of the options *and* one respects the person as an individual.

This approach can be applied to all people seeking information and help, no matter whether they are perfectly healthy, suffering from a physical or an emotional problem, or facing death.

Honest and professional advisory work on preparing for the known and the unknown in life and at life’s end is comprehensive and open-outcome, respects the individual, and does not impose the interests of the advisor on the person seeking advice.

It is our task, together with the person who seeks help, to look for sensible, reachable solutions to his or her problem – even if the solution in certain circumstances is “assisted dying”.

Plan ahead and prepare for the known and the unknown

Preparation I: think, consider, discuss

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? What is to happen to my body after my death? What about my assets? Should anyone be able to obtain access to my “digital personality”,

ranging from my email account to my profile on “social media” in order to work on these if necessary?

One can pose these and many similar questions, think about them, decide on an answer and put these decisions in – preferably written – instructions. But of course it is possible to decide *not* to decide and not to do any such instructions. When it comes to medical instructions, many 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 using the possibilities available to them.

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 family member and friends, but could also be one’s GP or the staff of an organisation like DIGNITAS. An open exchange on one’s personal perceptions and wishes creates understanding and trust. Trust offers security that one’s personal perceptions and wishes will most likely be followed. “Most likely” because there can be no absolute guarantee for this, just as there is no guarantee of reaching the aforementioned age of 85 or 81 years – or even greater – in good health (or at all).

When preparing, one obstacle has to be overcome in any case: the taboo which surrounds end-of-life issues.

Talking generally with other people about personal views on the quality of life and the value of one’s own life is *one* issue – it is quite *another* issue to express one’s own wishes on specific advance planning for one’s end in life. And it is even more difficult if one feels that one’s *own* life is not worth living anymore and thus one expresses the wish to end it

Despite the fact that for many years, polls have shown that the majority support self-determination and freedom of choice in “last matters”, dealing with the “great unknown of afterlife” is not easy.

In spite – or perhaps because – of this it is worth thinking about these “difficult issues” and discussing them with loved ones. 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.

Preparation II: Advance Decisions / Living Will

Many people are afraid of finding themselves in a hopeless condition or unconscious and connected to machines in a hospital, being kept alive artificially for a certain period of time. From a certain point in time on, they decide to reject surgery and therapy. It can be said of such people that they would like “to give life to their years, not years to their life”.

In order to prepare for future treatment and care, there is one probate instrument: Advance Decisions, also called Living Wills, Patient’s Instructions, Health Care Advance Directives, etc.

In Switzerland, the Swiss Civil Code article 370 ff made Advance Decisions legally binding.

The core element is that one has to write one’s Advance Decisions at a point in time when one does not lack capacity (of judgment / discernment) to do so. It comes into effect *only* if the person loses capacity for whatever reason; that is, they cannot make a decision or communicate anymore. In Advance Decisions one should name the people who will speak for the person who has made the Advance Decisions. This is of great importance: who does one appoint for this task? Who should bring the Advance Decisions to the attention of others and – even more importantly – who can enforce it, if necessary against resistance? Generally, valid Advance Decisions are legally binding. This means that if anyone knowingly ignores it they can face legal consequences. In jurisdictions which do not offer such legal base, one would have to test the validity of Advance Decisions in court and such further develop the law.

Therefore, an unambiguous text with clear-cut instructions is necessary. In Switzerland, it is possible to make use of set forms. In all cases, one has to pose the question: what is it that I want in a specific situation? How far shall I go? Should the life-sustaining machines be switched off after three or thirty days if I am brain-damaged and in a coma after an accident? Again, it is of importance to think about these points and to discuss them with loved ones. And again it is not just about one’s own best interest but

also about consideration for loved ones and other people affected, because clear Advance Decisions are very helpful for medical doctors and nurses.

Advice on making and enforcing Advance Decisions is part of the service offered by DIGNITAS. For its members, DIGNITAS provides a template form and, if necessary, support in enforcing these instructions.

Preparation III: Advance Care Directive

Similar to a Lasting Power of Attorney, the Swiss Civil Code, article 360 ff. provides an instrument which allows a person (the donor) to give another person (the donee) authority to make certain decisions on his or her behalf in the event that he or she no longer has capacity.

In other words, with an Advance Care Directive one determines an individual (or, even better, several individuals) who – similar to Advance Decisions – will speak and act for the donor who cannot do so anymore having lost their capacity of judgment. The individuals named in an Advance Care Directive can be asked to represent one's interest in three areas of life:

Personal care: this includes everything which touches upon the personality of the donor, such as their place of living, decision on their welfare (such as treatment, care and assistance) and many more private matters;

Financial care: the donee protects the financial interests of the donor and manages their income, makes payments, takes care of arrangements with their bank and so on;

Representation in legal issues: with this, the donee is granted the right to represent the donor in all affairs with authorities, courts and private individuals. For example, the donee may conclude a contract with an insurance company, sign the contract for a place in a care home, take care of the donor's tax declaration, etc.

Whilst for Advance Decisions it is possible to use forms to fill out, under Swiss law an Advance Care Directive is only valid if it is entirely written by hand – similar to a Last Will. As an alternative, public authentication / registration is possible.

In Switzerland, the Adult Protection Authority steps in if it becomes known that a person has lost capacity. This state authority has faced criticism for sometimes acting insensitively (and more). Whatever the reality in these cases, the fact is that this authority has an important role as

a sort of “protection net”. By law, the authority has to check whether an Advance Care Directive exists. Thus, if one does not wish the state authority to deal with one’s private matters, one simply needs to prepare oneself. Similar to Advance Decisions, different organisations offer template texts.

Preparation IV: Organ Donor

The achievements of medicine are impressive. People whose quality of life is diminished due to impaired functioning of the heart, kidneys, liver, etc. can possibly be helped with organ transplantation.

Since October 2004, in Switzerland, the Transplantation Act sets out the requirements for the use of organs, tissues or cells for transplantation purposes. Switzerland follows the positive approval approach which means that organs, tissue and cells may only be removed if the individual has consented to the removal. If no documented consent or refusal is available, the next of kin must be asked whether they are aware of the person having declared an intention to donate. If the next of kin are not aware of any such declaration, removal is possible if they give consent.

Many people, for example those suffering from diabetes needing regular dialysis, are waiting for a replacement organ. If one would like to possibly help people in such a situation one day, one should declare and document one’s will for example with an organ transplant ID or, in some countries, add one’s name to an Organ Donor Register.

Preparation V: Last Will

Swiss Civil Code article 467 says that *“any person who has the capacity of judgement and is at least 18 years old has the right to draw up a will disposing of his or her property in accordance with the limits and forms prescribed by law.”*

To go into details of how to make a last will here would go far beyond this short overview on “planning ahead instruments”.

But there is one important aspect, maybe: it does not matter whether one is wealthy or not. Heirs may quarrel over a valuable piece just as much as over objects with emotional value. Without a last will available, with each item one’s next of kin must ask themselves: what would he or she have wanted? This burden, which comes in addition to the grief brought about by loss of a loved one, can be lifted a little bit with clear instructions set out in a last will.

Preparation VI: email, memberships, web accounts, etc.

Who has a list with all service providers, for example with web shops that one has used for purchases and registered for this? Or an overview of all memberships, newspapers and magazine subscriptions, insurances, and so on? And, nowadays more and more importantly, one has a “virtual life”, that is, one’s own website, accounts with Facebook, Instagram, WhatsApp and other so-called “social media” services.

Even from quite early in life, paper and electronic connections, accounts and contracts with different service providers may exist long beyond one’s death.

In order to relieve one’s next of kin of administrative hassle, it is worthwhile drawing up an overview of all such connections – contact addresses, membership numbers, and so on. It is often the small things which make a big difference.

Preparation VII: the last resort

What should happen to my body after my demise? The response depends on religious affiliation, culture and personal preference. In Switzerland, one may not only choose between burial and cremation, but also on the type of grave and, in the case of cremation, even on choosing a place outside a graveyard. In the frame of the legal order, one’s personal wishes can be put in practice if one documents and communicates them.

Preparation and planning ahead is an aspect of self-determination. Self-determination draws upon self-responsibility. On the one hand, one takes responsibility for oneself by dealing with questions which play an important role in difficult situations in life. On the other hand, one takes responsibility towards one’s loved ones by clarifying questions which will inevitably arise. And thirdly, one takes responsibility towards the authorities, the medical professional and to other individuals and service providers.

Swiss law offers more than this. It also allows a person of sound mind to plan and put in practice a self-determined ending of suffering and life by own action involving support by medical doctors and accompaniment by organisations like DIGNITAS: the “Swiss system” of assisted suicide.

The legal base of the “Swiss system” of assisted dying

For many centuries, due to religious-fundamentalist intolerance and abuse

of clerical power, people who had committed suicide were often buried outside of graveyards and sometimes their families were punished, for example by seizure of their property. It was the development of humanistic and natural-scientific thinking as well as the growing separation of church and state in the wake of enlightenment, in the 17th/18th century, which brought about the decriminalisation of suicide.

Towards the end of the 19th century, expert committees and parliament discussed a unified Swiss criminal law and with this also the issue of assistance in suicide. It was found for example that a merchant who would have lost his good reputation/dignity due to bankruptcy should be able to ask a friend, who is officer in the army, to let him a gun and to show him how to use it so that he could end his suffering and life so as at least to save his honour. Such an assistance – the officer letting the gun and ammunition and giving instructions – was even considered to be a ‘Freundestat’, an ‘act of friendship’, which should not be punished. In those days, each Canton (each Swiss State) had still its own criminal law.

In 1918, this thought were adapted in the draft for a Swiss-wide criminal code and finally came into force on 1st January 1942 as article 115, stating:

“Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.”

The progressive-liberal base was kept, assistance in suicide remained and still is today exempt from punishment, but it was specified by the aspect that assistance done out of selfish motives should be a criminal act.

As examples for such selfish motives the Federal Council stated: if someone intended to inherit ‘earlier’ or if someone intended ‘to get rid’ of having to support a family member. Clearly, the aim was and is to sanction ‘pushing’ a person towards suicide out of a very immoral motivation.

The legal consequence, in the sense of ‘*e contrario*’: to help (assist) another person to commit suicide is not an offence and therefore not punishable as long as (s)he who helps does not have selfish motives in the sense of the examples stated above. Of course, in these specific circumstances of being assisted, the person self-determinedly ending his or her life must not lack capacity of judgment, in plain words: must be competent.

An interesting aspect is that in Switzerland, from 1848 until 1973, the Constitution generally prohibited priests/theologians to be elected into the Federal Parliament. From 1848 until 1920, the Liberal Party was the main force in the Swiss Federal Council and Parliament – at a time, when the big codifications of law such as the civil code, criminal code, etc. were drafted. One may dare to claim that these two aspects were influential for the still valid liberal-progressive approach in Switzerland.

Aspects of a severely ill and suffering individual was not really discussed in context of article 115 of the Swiss Criminal Code, but rather in context of article 114. The wording of article 114:

Homicide at the request of the victim

Any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request is liable to a custodial sentence not exceeding three years or to a monetary penalty.

“Homicide at the request of the victim” = killing on demand = voluntary euthanasia. Article 114 of the Swiss Criminal Code thus prohibits voluntary euthanasia, but offers relatively mild penalty if violated.

Note: because English is not an official language of Switzerland, the two translations of articles 115 and 114 are not official legal text; however, they are nonetheless provided on the website of the Swiss Federal Council.

Based on article 11 of the Swiss Federal Act on Narcotics and Psychotropic Substances and article 26 of the Swiss Federal Act on Medicinal Products and Medical Devices a Swiss medical doctor may prescribe narcotics under certain circumstances, mainly in line with the ‘recognized rules of medical science’ respectively ‘recognized rules of pharmaceutical and medical science’.

The Swiss Academy of Medical Science SAMS in 2018 issued guidelines on “handling dying and death”, saying that a medical doctor, based on a personal decision, may assist in suicide

At this time, these guidelines by the SAMS are not yet taken on by the Swiss Medical Association (FMH) which is the union of medical doctors in Switzerland, comprising some 95% of Swiss medical doctors and being the roof for 71 medical organisations. Only then the SAMS guideline could become statutory regulation for medical doctors who are a member of the FMH.

Still, both the SAMS and the FMH are private institutions which do not have any power to set law.

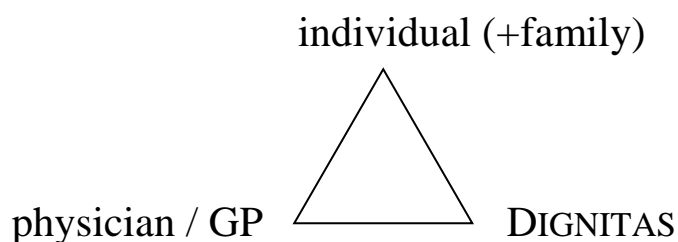
In fact ‘recognized rules of medical science’ do not really exist, and as far as they exist (such as the SAMS-guideline of 2018 to which courts and health authorities may refer for interpretation help if need be), their legal validity is questionable: they are not evidence-based professional rules, but opinions by a small group consisting, amongst others, of ethicist/moralists, because there is an ethics committee which raises its voice, the “National Advisory Commission on Biomedical Ethics” – which lacks a democratic base and it too has no power to set law.

The practical side of the “Swiss system”

Common denominator and in legal practice accepted is that a Swiss medical doctor (physician) can prescribe the psychotropic substance Sodium Pentobarbital for the purpose of an assisted suicide, if he/she:

- 1) checked the medical file = found that there is some medical diagnosis, a suffering;
- 2) has seen/spoken the patient and found that he/she really wants to self-determinedly end his/her suffering and life by own action;
- 3) found that the patient does not show signs of lacking capacity of judgment – therefore found the person to be able to make a rational decision on his/her end of life.

Based on the legal situation and this common denominator, in Switzerland, a system like a triangle developed 35 years ago:



In the ideal case, a relation develops between the patient, his/her treating physician and a private not-for-profit member’s society enabling assisted/ accompanied suicide such as DIGNITAS. That means: a patient experiencing severe suffering, maybe a terminal illness, would be of course under treatment and care of his general practitioner (GP)/physician and/or specialists. In the frame of this relation, the patient could express the wish for an assisted suicide. If the physician agrees, he would assure

the patient to help in this venture and recommend that he or she make contact with an organisation like DIGNITAS. Sometimes, a GP would contact DIGNITAS directly, explaining the situation of his or her patient. In any case, the patient would engage in a relation with an organisation like DIGNITAS no matter whether the physician agreed or not with the wish for an accompanied suicide.

The core point is that a medical doctor prescribes 15 grams of Sodium Pentobarbital (20 grams in rare cases of severe overweight of the patient) and gives the prescription to an employee of DIGNITAS. The employee would then fetch the medication from a pharmacy. Generally, the patient never receives the prescription or the medication to take it home. There are a few pharmacies which store/provide Sodium Pentobarbital. The medication is then used in the frame of an assisted/accompanied suicide, usually at the home of the patient living anywhere within Switzerland, in the presence of one or more employees (sometimes called companions or befrienders) of the organisation. Family and friends are always encouraged and welcomed not only to attend but in fact to get involved in the preparation procedure right from the start. If the patient does not make use of the medication on that particular day, an employee of DIGNITAS brings it back to the pharmacy.

There is the possibility that a medical doctor prescribes Sodium Pentobarbital *and* does the assistance/accompaniment himself/herself. However, today, being that the professional handling of requests for assisted/accompanied suicide and advisory work on alternative options such as palliative care and continuous deep sedation, voluntary refusal of food and fluids (VRFF), etc. is established with not-for-profit members' societies like DIGNITAS, physicians will rather leave the handling of preparation and accompaniment to such organisation.

Each case of assisted/accompanied suicide is immediately reported to the Swiss police. This prompts them, a state attorney (Switzerland does not have 'coroners'), and an official medical doctor (usually, but not necessarily, one from an Institute of Forensic Medicine) to come to the place of the accompaniment and investigate the case, that is, to check on the sort/manner of death (= ingestion of 15 grams of Pentobarbital), and to find out whether article 115 of the Swiss Criminal Code was violated or not. In order to make the situation up front less difficult for the authorities,

DIGNITAS provides them with the medical file, documents signed by the patient, the passport/ID, etc.

Since 1998, DIGNITAS has done over 2,500 accompanied suicides in cooperation with Swiss physicians. Never has there been a conviction of violation of article 115, let alone article 114, of the Swiss Criminal Code.

In conclusion, in Switzerland, assisted/accompanied suicide – also for patients suffering from psychiatric ailments, as long as they do not lack capacity of judgment – basically has been possible since 1942, even though there is no special law/act, regulating the details of such procedure, such as it is the case for example in The Netherlands, Belgium, Canada and several US-States.

This Swiss practice basing on freedom and self-responsibility was supported in a people's initiative (referendum) by 84% of voters in the Canton of Zürich on 15th May 2011. Despite – or really rather because of – this many years of relatively progressive-liberal practice, the number of those actually making use of an accompanied suicide is very small, only around 1,5%, in relation to the overall number of deaths in Switzerland.

Further activities of DIGNITAS

Practical and legal advice for the healthy, anyone who is suffering, the relatives and friends of (suffering) individuals, medical professionals, and, of course, counselling suicidal individuals takes up a large part of DIGNITAS' resources. Besides this advisory work, there are further fields of work in which DIGNITAS engages.

1) Taking matters to the courts

Further legal developments are an important part of DIGNITAS' work. Presenting legal questions in proceedings in order for Courts to deal with them allows further development of the right to live and die with dignity.

In 1977, many years before he founded DIGNITAS, Ludwig A. Minelli founded SGEMKO – the Swiss Society for the European Convention on Human Rights, a non-profit organisation spreading information about the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) and carrying out litigation to further develop human rights issues. With SGEMKO, he brought some of the first cases from Switzerland to the European Court of Human Rights (ECtHR) in Strasbourg – and won. And, even at that time, he and one of his

colleagues – attorney-at-law Manfred Kuhn, at that time vice president of Exit (German part of Switzerland), found that the right to life as stated in article 2 of the ECHR should have been complemented by the right to die, which later led to cases on this issue.

In 1999, Minelli published an article arguing this point in the Swiss Journal of Jurisprudence SJZ. Had he known that, later, the courts would follow his arguments...

In Switzerland, the ECHR came into force 28th November 1974. According to its article 34, it allows individuals, groups of individuals, and NGOs to file a complaint. As to Swiss law, winning a case at the ECtHR would give the right, within 90 days, to request a revision of the Swiss Supreme Court decision being appealed against.

Today, the jurisdiction of the European Convention on Human Rights covers all of Europe except for the Vatican, Belarus and Kosovo.

In 2004, a man called DIGNITAS explained that he was suffering from bipolar – manic-depressive – disorder, that he had attempted (and obviously failed) suicide twice, that he had been an in-patient in psychiatric clinics nine times and that he wanted DIGNITAS' help to end his suffering. At the time, knowing how difficult it was to obtain consent from Swiss physicians for an accompanied suicide in the case of a patient who was perfectly lucid yet suffering predominantly from a psychiatric ailment, DIGNITAS asked him whether he would be able to pull through at least for some time and challenge the Swiss legal *status quo* by requesting the means to suicide – 15 grams of the barbiturate Sodium Pentobarbital – directly from the Swiss health authorities and, if that was not accessible, to resort to the courts.

This was the starting point of legal proceedings conducted by DIGNITAS at several levels of jurisdiction which led the Swiss Federal Supreme Court, on 3rd November 2006, and the European Court of Human Rights (ECtHR), on 20th January 2011, to acknowledge:

“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”

Opponents of “freedom of choice in last issues” may claim that there is no right to die. The ECtHR decision brought about by DIGNITAS has proven them wrong, certainly within the jurisdiction of the European Convention on Human Rights.

According to its preamble, the ECHR 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*”.

In other words: there is room for development. All European right-to-die organisations should consider this and do what DIGNITAS has been doing since the start: challenging the law via the courts to gain more freedom of choice by arguing that the Constitution and the European Convention of Human Rights *do* enshrine end-of-life choice rights, and therefore laws / acts which contradict these fundamental rights would be unconstitutional and in conflict with the ECHR.

Since its founding, DIGNITAS has led or been involved in dozens of court cases. An example is the Carter vs. Canada case, which on February 6th 2015 led to the unanimous 9:0 decision by the Canadian Supreme Court to struck down the country’s Criminal Code laws prohibiting physician-assisted suicide. Another important success for DIGNITAS was the landmark decision of March 2nd 2017 by the Federal Administrative Court of Germany in regard of access to the means for ending one’s suffering and life by one’s own action, and the principle of a right to die: the general right to personality article 2,1 (right to life) in connection with article 1,1 (protection of human dignity) of the Basic Law (Constitutional Law) of Germany comprises the right of a severe and incurably ill patient to decide how and at what time his or her life shall end, provided that he or she is in a position to make up his or her own mind in that respect and to act accordingly. The Court found that, even though it was generally not possible to allow purchasing a narcotic substance for the purpose of suicide, there had to be exceptions, such as if a severely and incurably ill patient, due to his or her unbearable suffering, freely and seriously decides to wish an end to his or her life, and if there was no reasonable alternative available – such as to end curative treatment and resort to palliative care.

Such patients should not be barred from accessing prescribe narcotics for a dignified and painless suicide.

These are just two examples of how DIGNITAS works with court cases, with an aim to push boundaries and to implement more freedom of choice in life and life's end.

2) **Contributing to law-making proceedings**

Another important line of DIGNITAS' legal work is engaging in legislative proceedings. DIGNITAS wrote in-depth submissions for public inquiries / consultations of the Swiss Federal Council, the Crown Prosecution Service of England and Wales, the Scottish, Canadian, two Australian and New Zealand Parliaments, etc. Many expert committees and members of parliaments have visited DIGNITAS over the years.

In addition, DIGNITAS drafted a comprehensive law proposal to regulate assisted/accompanied suicide by non-profit associations (Accompanied Suicide Act – ASA) based on the “Swiss model”, which was presented to several countries' Parliamentary committees.

The most recent success with the contribution of DIGNITAS has been the vote of the Parliament of Victoria, Australia, to introduce the “Voluntary Assisted Dying Bill”.

Lobbying with the aim of convincing politicians and so winning positive parliamentary votes is a big challenge which takes a lot of effort, both in financial and time resources. In the UK for example, this approach has failed twice by quite a clear margin. Trying to introduce an assisted dying law via Parliaments implies a further problem: in order to increase the chance of obtaining a majority in favour, the assisted dying law proposed often needs to be “downsized” in scope – to a narrow model – so as to increase the chances of convincing some very sceptical minds.

As a result, this leads to suggesting law models giving only few individuals access to assisted dying, such as the “US-Oregon model” which reaches out to individuals with a terminal illness diagnosis and 6 months' life expectancy only. This model has several drawbacks:

- it discriminates against people who are not terminally ill and not expected to die within the next few months, so their human right to a self-determined, self-chosen end of their life is disrespected;
- it puts medical doctors in the impossible situation of having to estimate how long their patient might live, something which no serious doctor

can actually do with certainty, and more and more doctors are critical of this “estimate thing”;

- it does not help those people who (also) deserve respect and compassion: people suffering from long-term illnesses such as motor neurone disease, multiple sclerosis, multiple system atrophy, Parkinson’s, etc. – the long-term sufferers. It only helps individuals who are going to die in the short run who are more likely to be helped with palliative care and palliative deep sedation, such as patients with terminal cancer;
- it does not have the suicide attempt preventive effect a truly humanitarian and progressive end-of-life-choice model would have. It can be observed that in Switzerland the number of lonely do-it-yourself suicides has decreased over the past 15 years – whilst in Oregon it has not.

One may argue that an assisted dying law like the US-Oregon model is way better than not having a law giving at least some choice for suffering individuals. But why go for “second best” when there are more progressive-liberal law models in place which give people more choice and can be used as an example, such as in Switzerland, the Benelux countries and Canada? Why not to strive for real freedom of choice? It is about deciding between focusing on faster (and politically motivated) success on the one hand and focusing on implementing real freedom of choice offering care and compassion on the other hand. Generally, DIGNITAS will not settle for second best but aims for maximum self-determination and freedom of choice in life and life’s end, as only this approach takes people’s wishes for self-determination at life’s end seriously and improves public health.

The right and the freedom to decide on the time and manner of one’s own end in life is already in place – it needs to be further developed by the right to receive help putting this right into practice. According to Professor Axel Tschentscher at the University of Berne in Switzerland,
„it is for the State to justify narrowing access to medication for assisted dying but not for the citizen to plea receiving access to it.”

Alas, human rights are minority rights. They have to be fought for and defended, again and again, for the benefit of the citizens. In a democratic society, parliament and government have not received their power for their self-interest or by grace of God. They have, only temporarily, been given

such power by the citizens. This distinction should be kept in mind by elected politicians just as much as by citizens.

3) **Physician-supported accompanied/assisted suicide**

“One should not set upon a long journey without careful preparation and one should not set upon such journey without having appropriately said goodbye to loved ones”, says the founder of DIGNITAS.

Under certain circumstances, in the case of medically diagnosed severe or terminal illnesses, unbearable pain or unendurable disabilities, DIGNITAS can arrange the option of a legal accompanied suicide upon the explicit request of the individual member who wishes to end his suffering and life. There are many prerequisites linked to the arrangement of such a self-determined and self-enacted ending of life:

- the person has to be a member of the DIGNITAS-association
- the DIGNITAS Patient’s Instructions (Advance Decisions) provided upon registration as a member is essential
- the person must be mentally competent – not only at the time of the request but also in the last minute during the final act
- the person has to be able to carry out the final action which brings about death by his or her self.
- the person must send a written request to DIGNITAS comprising 1) a letter of motivation explicitly asking DIGNITAS to prepare an accompanied suicide, 2) a CV/biographical sketch providing personal background information and, most importantly 3) comprehensive historical and up-to-date medical reports showing diagnosis, treatments tried, medication, development of the illness, etc.
- DIGNITAS assess the request and look for a Swiss physician (independent of DIGNITAS) who also assesses the request and possibly grants a “provisional green light” – without this doctors’ consent there will not be an accompanied suicide
- the person will have at least two face-to-face consultations with the Swiss physician who initially provided the “provisional green light”

When the person has received the “provisional green light” and wishes to advance to an accompanied suicide, there are many details to be discussed with DIGNITAS such as a possible date, how to travel, where to stay, which family members and friends will travel with the person, etc. Additionally, further administrative effort and paperwork is necessary: for example,

people from abroad have to provide several official civil registry documents such as a birth certificate, proof of residency, etc. – Swiss law states that these have to be newly issued papers – so that the Swiss Civil Registry Office can register the demise and issue a death certificate.

Only if all the requirements are fulfilled can a Swiss physician write the prescription which allows DIGNITAS to procure the necessary medication for the accompanied suicide. It is a lethal overdose of a fast-acting barbiturate, Pentobarbital. After taking it, the patient falls asleep within a few minutes and drifts into a deep coma which passes peacefully and painlessly into death.

It is important to remember that, from the start of the proceedings right up to the very last day, access to the accompanied suicide could be denied, not only by the physician in one of the consultations but also by DIGNITAS – if, for example, the person shows severe signs of reduced mental capacity to the point at which the legal prerequisite for legal assistance in self-determinedly ending life is no longer met. In the course of the preparation proceedings, DIGNITAS and the Swiss doctors will establish several times whether the individual meets the pre-conditions which must be met for assistance with suicide, and whether the wish to die reflects the settled and declared will of the individual.

Gathering information, reflecting, writing the request, obtaining all the relevant documents, arranging the journey, talking it all over with loved ones: it all takes time and personal effort.

DIGNITAS' many years of experience shows that only a very small number of people who enrol as a member take advantage of the option of assistance with suicide. A study, including investigation into 387 files of DIGNITAS-members by a German student, found that only around 14% of all those who receive a “provisional green light” actually make use of an accompanied suicide.

Furthermore, even after over 30 years of such assisted dying practice being in place in Switzerland, only around 1.5% of all deaths take place by accompanied suicide. Of all DIGNITAS-members, less than 3% make use of an accompanied suicide.

This clearly shows that allowing the self-determined ending of suffering and life by a safe means within a carefully-prepared safe arrangement is, for many, just an “emergency exit door”: one is glad that it is there – and

hopes to never need it. Making possible this kind of arranged self-deliverance *is* suicide attempt prevention in action. In the words of British conductor Sir Edward Downes, during his consultation with the Swiss physician granting him the definite “green light” in 2009: *“This is a form of evolution, of humanity.”*

Old and new challenges

Many of the challenges that DIGNITAS deals with have their origins in unconventional concepts, the tendency to take things to their limits, and the conviction that the right to die is ‘the last human right’ and thus that there should not be any discrimination just because of a person’s place of residence.

“Why do you import such foreigners?” was the question which the General Prosecutor of the Canton of Zurich, the now-retired Andreas Brunner, asked DIGNITAS’ founder during their first meeting.

People with paternalistic thinking are suspicious of individuals being given the freedoms to decide and to choose. Those who wish to exert power and control over others – which may be politically, economically or religiously/morally motivated – defend their desired sphere of influence at all costs. The opponents of freedom of choice in last matters are numerous. Many recent attempts to narrow self-determination and freedom of choice in life and life’s end have been hidden under the disguise of “ethics”, “psychological health for society”, research and science.

There is a lot of work ahead, on several different issues:

1) Legal and political

Switzerland does not have a specific law or act regulating the procedure of professional accompanied/assisted suicide. However, this does not mean that there is no legal basis. In fact, there are a number of law articles and court decisions in place which build a robust framework and which have been the basis for the now 35 years of Swiss practice of accompanied suicide combined with further end-of-life help.

This practice, which has its roots in the tradition of freedom and self-responsibility, has been attacked again and again. Some politicians, religious-conservatives, pseudo-‘researchers’, self-declared ‘experts’, ‘ethics commission’ members, interest groups of psychiatrists, and ‘health authorities’ including the medical interest groups ‘Swiss Academy of

Medical Science' (SAMS) and 'Swiss Medical Association' (FMH), tend to be opposed to freedom of personal choice and will try to undermine the legal *status quo* on a political and legal level with the aim of narrowing the scope of help and reducing an individual's right to self-determination.

Unmasking their scheme, rebutting their attacks and "exporting" the "Swiss model" as far as possible, so that one day people will not need to turn to DIGNITAS and Switzerland anymore, is one of the most important activities of DIGNITAS. The freedom – and the right – to choose must be implemented worldwide, and defended!

2) Mentally competent individuals suffering from psychiatric ailments

Here is a quote from an e-mail that a young woman sent to DIGNITAS (in its original version, without any spelling mistake corrections):

"If a person with severe depression wants to die and has tried literally everything (medication, therapy, holistic approaches, etc.) they should be able to have control of their own life. If I am just going to continue to try to kill myself why shouldn't i be able to have help? If there is no help for the victim and all opportunities have been explored then why should i have to continue to suffer in agony? Do i want to live in a hospital for the rest of my life? no... Do i want to be sedated and on like 5 different medications for the rest of my life? no. Tell me, how is that living. Nobody wants to live like that in constant pain and agony."

Contrary to widely-held opinions, people suffering from mental health problems normally have sufficient capacity of discernment to decide whether they would like to continue living or, instead, to end their suffering and life. Therefore, and as a general rule, they are entitled to ask for an accompanied suicide and should receive assistance just as much as people suffering from physical health problems. Furthermore, access to this option needs to be made available in order not to expose these people to the high risks associated with clandestine suicide attempts.

But there is a difficulty in Switzerland: a prescription written by a Swiss physician is always required to obtain the Sodium Pentobarbital. Furthermore, in the case of the person suffering from a psychiatric ailment, a special in-depth medical appraisal by a psychiatrist is always required, and it must indicate that the person's wish to end their life is not a symptom of a treatable psychiatric ailment but is based upon the self-determined, carefully reflected and stable decision of a competent person.

In practice this means that DIGNITAS is only able to arrange an accompanied suicide for someone suffering from a psychiatric ailment if



the individual presents, in addition to their formal request with a medical file, the result of that special in-depth medical appraisal, and a Swiss psychiatrist can assess the request and (if appropriate) grant a “provisional green light”. Unfortunately, progressive-liberal psychiatrists accepting

the concept of self-determinedly ending one’s suffering by (assisted) suicide are quite rare.

3) Mentally competent old-agers

There has been a significant increase in life expectancy: in fact, it has almost doubled over the last 100 years. If, after very careful reflection, a mentally competent individual of a great age feels that he or she has lived enough, in the sense of “it’s been a long and good life but now I would like to rest, thank you”, on what grounds could we reject this person’s rational wish for a safe and accompanied end in life?

This is, again, a legal question which sooner or later will be clarified through legal further development, that is, court cases brought to the European Court of Human Rights. The issue was part of the case of Gross v. Switzerland which led to interesting court findings. Alda Gross was a woman born in 1931 with some ailments due to her age, but neither severely nor terminally ill. However, the case did not become effective because she passed away before the Court took a final decision.

Due to the significant increase in life expectancy, this issue will come up more often and quite certainly need further attention in our society.

4) Distorted and biased press coverage

“The world’s foremost euthanasia clinic” ... “deadly cocktail of drugs” ... “poison” ... “suicide tourism” ... “active euthanasia” ... “on the waiting list for self-murder”... These phrases are not only found in tabloids.

Truncating, falsifying, scandalising, a “me-too” attitude as well as an incapacity and unwillingness to research and read: a large part of the

media uses any opportunity to create hype in order to sell their TV, online and print products. Far too often, the media is not about giving the public balanced and in-depth information but just about bolting out “news” to make money. Misleading media coverage not only leads to a distorted picture in the public’s imagination, but also to a lot of suffering for which the media ignorantly denies responsibility: more than once DIGNITAS has had people from abroad, some of them in a quite deplorable state of health, showing up without prior notice because they believed the nonsense of a “clinic” where one can “check in and one’s suffering can be ended”. How distressing for them (and for DIGNITAS too) when they have to be told that they have been misled by incompetent journalists. Those people have to go back home and then, of course, they must follow the normal preparation proceedings before an accompanied suicide could possibly take place for them.

What is far worse is that the public is not being appropriately and fully informed about suicide attempt prevention as well as their health care and end-of-life options.

5) The theocrats, moralist-ethicists and pseudo-pro-lifers

On 28th September 2012, a one-day congress entitled “Dying, whoever wants? Assisted dying and organised assistance in suicide as an ethical question and a challenge for society” was organised in Zürich by a group called “Forum Health and Medicine”. An investigation into the “who is who” of the speakers revealed interesting details: one of the announced speakers was the previously mentioned General Prosecutor Andreas Brunner, a long-standing opponent of the work of DIGNITAS. Another was Prof Andreas Kruse, disciple of Georg Ratzinger (the former Pope’s brother) and a well-known opponent of assisted dying and supporting the long-disproved slippery-slope argument. One speaker was Brigitte Tag, a German professor of law lecturing at Zürich University, who has tried to edge into the Swiss government a German proposal for a law on assisted dying which had already been rejected in Germany due to its conflict with basic rights. Then there was Dr Markus Zimmermann(-Acklin), a German Catholic moral theologian lecturing at the University of Fribourg, Switzerland. He is a long-standing opponent of assisted dying who published his opinion in his dissertation and who is now – together with the aforementioned Brigitte Tag – one of the leaders of the NRP 67 “End of Life”, a Swiss national research programme investigating end-of-life

issues and disposing of 15 million Swiss Francs of government (tax) money. The organiser of the conference was Markus Mettner, a German Catholic theologian... To summarise, it was an interesting ‘bouquet’ of opponents of freedom of choice in life and life’s end.

In the meantime, most studies of the NRP 67 have been finalised and a final report published. In August 2014, a publication “Suicide tourism: a pilot study on the Swiss phenomenon” was presented. An analysis of this work showed how the “researchers” had selectively and incompletely chosen data in order to claim a doubling of “suicide tourists”, how they gave incomplete and false information in respect of the legal situations in Switzerland, Germany and the UK (even quoting a British tabloid newspaper), and – to little surprise – out of all this they presented misleading conclusions. Such “studies” cannot be considered scientific. The NRP 67 has been criticised for lacking seriousness in its research, for its bias and for its lack of transparency. Additionally, through Swiss Federal Supreme Court discussion on a case seeking to obtain more transparency in the NRP 67, it has become known that the steering committee of the NRP 67, for research projects which in the evaluation phase had been rejected due to a negative expertise, simply sought new suitable expertise... The Swiss National Science Foundation (SNSF), which conducts the NRP 67, damages the reputation and good image of Swiss research.

It can readily be seen that a rising number of self-styled “experts” and “scientists” (in connection with some politicians) raise their voices and try to undermine existing freedoms as well as the achievements of liberal democracies. They have several things in common: they edge on to ethics boards and research projects without ever having done any comprehensive and open-outcome advisory work or true suicide attempt prevention, and without having accompanied an individual on their long journey to an accompanied suicide. They usually hide their religious-conservative background and views, they mislead the public and they are often buddy-buddy with certain politicians.

They spread their authoritative and paternalistic values, camouflaged by the image of “expert committees”, “bioethics” and “scientific research”, with the aim of forcing their personal, narrow-minded views upon other people and undermining a range of hard-won progressive-liberal ideas which were fought for and gained through enlightenment.

All of this gives rise to the suspicion that, for these people, freedom of choice in “last matters” is a nuisance because they make money out of people having to be treated after failed suicide attempts and out of life-prolonging measures – certainly much more money than if liberal access to end-of-life options was available. How many medical professionals are sponsored by the pharmaceutical industry? How many politicians hold shares in clinics and pharma businesses? The Swiss Academy of Medical Science (SAMS) has enjoyed the financial support of the pharmaceutical industry for many years. Quite likely, this is only the tip of the iceberg.

Power, money, religion and politics: for centuries this has been a problematic and dangerous mix which deprives others of freedoms in order to draw benefits for just a few.

Conclusion

DIGNITAS and similar organisations are actually protection-of-life and protection-of-freedom groups: their work is about enabling people’s options and choices through providing information. This is about empowering, chances and perspectives, about respect for the individual, about preventing unprepared, risky attempts at suicide (of which the vast majority fails).

For many mature, thoughtful and self-aware people, the feeling of not being noticed or taken seriously, of being controlled by others in a given situation of suffering, is unbearable.

An overall approach is necessary, one which puts centre-stage what the individual feels to be quality of life, which respects his feeling and which gives him advice in a comprehensive and open-outcome manner. This does not mean that nets at bridges are useless or that palliative care should not be further improved and enforced; quite the contrary. But it takes more than this: the ice-layer of taboo which covers the topic of suffering, dying and suicide has to be broken. These are part of life. All of us, for whatever reason, could come to a point at which we feel that our quality of life is not sufficient anymore, attempt suicide and we are *all* going to die one day. Rejecting or trying to forget about these facts will not dispose of them.

Once again: the right to life does not mean a *duty* to live. Furthermore, one cannot and should not withdraw from one’s professional and human responsibility by simply delegating thinking and deciding to an “ethics” (or other) commission. And, after all, it is still up to the individual to

decide what treatment he or she does or does not want. No one can step entirely into the shoes of another person and thus judge the quality of their life.

Human rights are minority rights: they have to be fought for and defended again and again, for the benefit of the citizens. There are several examples of how such defence is required if we look at the developments in Hungary, Poland, Turkey and Russia, and even in Germany as well as Switzerland, not to mention worldwide the big countries. In a democracy, parliament and government have not received their power for their self-serving or by grace of God. They have, only temporarily, been given such power by the citizens. This distinction should be kept in mind by elected politicians just as much as by citizens.

The ability to know about life's limitation allows us to deal with our future and with the end of our life. To have that perspective and to shape one's life according to those perspectives, because we *do* have that freedom, is a fundamental part of our existence. It may be due to the loss of perspective, it may be due to exhaustion resulting from suffering, or it may be due to realising that life has been lived long enough: the possibility of deciding to step away from life and towards death at a moment of one's choosing is the expression of a freedom which takes human beings seriously from the beginning until the end. It is inhumane that *anybody* should be left to attempt to end their life alone, employing horrible methods and with the high risk of failure which can have such dire consequences.

In its publication "National Strategy Palliative Care 2013-2015", referring to the Federal Council report "Palliative Care, Suicide prevention and organised assistance with suicide" of June 2011, the Swiss Federal Office of Public Health FOPH states that [in Switzerland] "*nowadays, in society primarily suicide assistance organisations are seen to be a possibility to ensure self-determination at the end of life*".

Is this a surprise?

The publication goes on: "*Other options which may also add to strengthen self-determination at the end of life – such as palliative care, patient's advance directives, identifying and treating depressions – are little known in public*"

How come?

And it concludes: *”However, knowing about these options is an important prerequisite to make a self-determined decision. Therefore, it takes more efforts in this field. Need for action is primarily on the two axes ‘informing the public’ and ‘informing the professionals’”.*

Indeed. And even more, implementing an approach which includes comprehensive and open-outcome advisory work in medical education would be a big step forward.

What can *you* do? Use your senses, critically question spoon-fed views, news and catch-phrases, and form your own opinion. On the one hand, this is about nothing less than people who turn to you in trust, and on the other hand about your own freedom of choice, self-determination and self-responsibility today and moreover in the future.

Ideally, as to freedom of choice in ‘last matters’ you would not reduce your engagement to your own planning ahead, but widen the scope to implement it in your daily work and further social areas. Even if you might not benefit from such freedom yourself – your successors, the next generation, will be grateful for your efforts.

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