Twenty years

DIGNITAS – To live with dignity – To die with dignity

Progress and Challenges – Review and Outlook

World Federation of Right to Die Societies
Biannual Conference, Cape Town, South Africa
September 2018

booklet to complement the talk

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, including in South Africa. 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. What is the difference between a metastasising pancreatic cancer in Switzerland and one in another country? How can we seriously tell the Swiss resident "we will help you" and an outsider "sorry, you live in the wrong country"? It would be an unacceptable and inhumane discrimination against the person not living in Switzerland.

DIGNITAS' goal is not that people from abroad should travel to Switzerland for an accompanied suicide, but that everybody can make use of such an option at home.

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.

Why DIGNITAS was founded

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. However, departing on a "long final journey", which is making use of self-determination and freedom of choice, 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 goodbyes to loved ones and friends.

An international approach

DIGNITAS was founded two years after Swiss theologian Rolf Sigg, together with German Dr Julius Hackethal, had founded Ex International in Berne, a small member society conducting accompanied suicides for non-Swiss residents ever since. 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.

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.

The goal of DIGNITAS

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".

What's suicide attempt prevention got to do with assisted dying?

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.

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".

Many industrialised modern states show a high number of suicides and even higher counts of failed suicide attempts. 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!

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.

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. 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. However, 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.

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 trains 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: building a bridge

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.

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".

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.

DIGNITAS' further developing of the law: 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 and 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 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.

Further developing the law: 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.

What is the opinion of the public?

On 15th May 2011 DIGNITAS celebrated a double victory in a Zürich Cantonal people's vote: the people of Zürich supported by 85% and 78%

respectively the activities in the field of accompanied suicide as well as the efforts to grant this option to individuals from outside Switzerland.

The vote came about because two small conservative-Christian political groups had started two people's initiatives (referendums), one aimed at prohibiting assisted suicide entirely and another aimed at making it impossible for someone who has not lived for at least one year in the Canton of Zürich – where DIGNITAS has its seat – to access help with an assisted suicide. One cannot imagine a more inhumane, discriminatory and hypocritical goal, one which flies in the face of the Christian credo "love thy neighbour as thyself".

The challenge was to publicly campaign against the initiative prior to the vote. DIGNITAS arranged for a committee comprising several organisations, designed posters with a short and clear message and put a lot of manpower and funds into a campaign calling for safeguarding and defending freedoms. Some critics felt that these efforts were unnecessary and the initiatives would not stand a chance anyway. How short-sighted! To settle for second best is not good enough and, even if the prognosis seemed to be true, there is a big difference between winning a vote with 51% or 85% and 78% because one sends an important political signal. This is what DIGNITAS aimed for and invested in, and it's what we achieved: the overwhelming result was quite likely the key for the Swiss Federal Government dropping its plan of creating a specific law to regulate physician-supported accompanied suicide by non-profit organisations such as DIGNITAS. An earlier analysis of the government's plans clearly showed that this proposal was not just aimed at regulating the issue but, in fact, at narrowing access to end-of-life help.

In countries of the 'western hemisphere', public opinion is generally in favour of freedom of choice in end-of-life questions. There are many polls which show this, although one has to keep in mind that poll results will vary according to the wording of the question asked, the degree of understanding of those polled, what information they have recently been presented with, the sample of people polled, and how the poll has been conducted.

The degree of understanding of end-of-life matters in members of the public is a key factor, one which signifies that one needs to put efforts into educating the public. Over the years, DIGNITAS has given numerous

presentations to universities, nursing schools, groups of lawyers and doctors, youth parliamentary meetings, etc.

Only those who are informed have real freedom of choice!

Outlook: challenges for the next twenty years with DIGNITAS

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.

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 re- quest and (if appropriate) grant a "provisional green light". Unfortunately, progressive-libe- ral 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.

1) The press, film makers and beyond

"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.

Many documentary film projects just focus on the storyline of an old or terminally ill individual "going to Switzerland". This is a well-trodden path which adds nothing new to the debate. It is now time to shift the focus and to show the issue of assisted dying in its proper context with the main focus on those topics and questions which are *actually* important: the issue of the many (failed) lonely suicide attempts and how to prevent them, the palliative care issue, the 'power-money-dogma' wall of resistance against freedom of choice in life and life's end, which has to do with the problematic (usually hidden) connection between politics, pharmaceutical industry, medical boards and ethic committees under religious influence, etc.. All this and more is most relevantly connected with assisted dying and it needs to be thematised, unmasked and exposed to public debate.

5) The ethicists-moralists, pseudo-religious 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 the "last matters".

In the meantime, most studies of the NRP 67 have been finalised and 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. 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" 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.

Thank you, as we continue for another 20 years!

DIGNITAS looks back on twenty successful years, in which the member society achieved much more than what was dreamt of on 17th May 1998. Experts in politics, law and medicine, as well as students, researchers and others, call on the experience and expertise of DIGNITAS. DIGNITAS is connected worldwide with experts in the field of law and medicine and with organisations which have similar goals and which advocate for real quality of life until the end.

The board of DIGNITAS and the over twenty part-time employees, as well as supportive external experts from diverse fields, lead the member society into the future. Creativity, engagement and an immense socio-political, legal and medical know-how make DIGNITAS a unique organisation and allow it to achieve goals that other organisations can then benefit from.

Some politicians, religious-conservatives, pseudo-"researchers" and self-declared "experts", "ethics commission" members, interest groups of psychiatrists, and "health authorities" are against freedom of personal

choice and attack the legal status on political and legal level with the aim of narrowing and undermining an individual's right to a self-determined life and end-of-life.

To rebut their attacks, and also for its goal of "exporting" the "Swiss model" so that one day people will not need to turn to DIGNITAS and Switzerland anymore, DIGNITAS is spearheading Swiss and international "right-to-die" litigation. DIGNITAS will continue to engage with efforts to improve human rights and choices in life and at life's end, and will keep on working hard to bring about freedom of choice as well as compassion and care for individuals who wish to shape their life self-determinedly until the end. All these individuals deserve nothing less, and the public health care system can be improved to take better care of these people.

"DIGNITAS – To live with dignity – To die with dignity" says *Thank You* to all its members, supporters, employees and co-thinkers for their loyalty and for the power they give the organisation to implement, internationally, the idea of real freedom of choice and self-determination combined with self-responsibility in life and life's end. DIGNITAS also says *Thank You* to its critics and opponents who challenged the organisation again and again, even though they sometimes tried to paralyse it with dubious methods: through each of their attacks DIGNITAS grew bigger and stronger.

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