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How DIGNITAS safeguards quality of life through comprehensive and open-outcome advisory work

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 April 29th 2002, at the end of paragraph 61. It highlights one of the difficulties 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. Consequently, people who have decided not to carry on living but rather to self-determinedly put an end to their suffering started looking for ways to do so. This development has gone hand in hand with tighter controls on the supply of barbiturates and progress in the composition of pharmaceuticals, which led to the situation that those wishing to put an end to their life could not use this particular option anymore for their purpose and started to choose more violent methods. A further, parallel, development was the rise of associations focusing on patient's rights, the right to a self-determined end of suffering and life, the negative effects resulting from the narrowing of options, and suicide attempt prevention.

Quality of life, the subjective judgement of well-being, is influenced by several factors. Health is one of them. Quite likely it is the most important. The World Health Organization WHO says in its Constitution:

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

and right thereafter:

«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»

Every day, we make quite some efforts for our own social, physical and mental well-being. We consume nutritional supplement products, caress our skin with lotions, do sports, eat bio and vegan, book consultations with a therapist, have our looks beautified by a plastic surgeon, take a wellness-holiday in a spa, etc.

But, no matter how well we are feeling and how we make efforts to live healthier and longer: some day, life's end will come. Even in the last phase of life its quality is very important.

Medically trained professionals – physicians, carers, therapists, etc. – accompany us from birth to death. They hold a special position in regard of maintaining quality of life, because they have not only expert know-how, but those who turn to them bring to them considerable trust in advance.

Quality of life and self-determination, even in “last issues”, are being discussed widely in public. However, medical professionals often invoke the picture of a deep ditch between different approaches of help, as if there was only *one* solution for a specific life- and ailment-situation. This unnecessary and senseless ditch has to be overcome, for the benefit of people who seek help.

Who or what is DIGNITAS?

DIGNITAS is a help-to-live and right-to-die not-for-profit member's 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 allowing 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 are not possible, the option of a dignified death must also be looked at.

Today, DIGNITAS, together with its sister association DIGNITAS-Germany in Hannover, which was founded on September 26th 2005, has some 7300 members in 70 different countries around the world, also in Czechia. DIGNITAS has an office in Forch and a house in Pfäffikon-Zürich where accompanied suicides for members from abroad may take place, if they cannot be helped at their home. There are 20 people working for DIGNITAS, almost all of them part-time, comprising board members, an office-team doing a lot of advisory work, and a team of companions/befrienders who visit patients and assist with accompanied suicides.

Contrary to the nonsense spread by incompetent journalists, DIGNITAS is neither a clinic nor a business, DIGNITAS does not offer euthanasia, DIGNITAS does not simply give poison or a cocktail of drugs to those wishing to end their life, and DIGNITAS is not about “check in and drop out”.

One third of DIGNITAS’ daily ‘telephone-work’ is counselling individuals who are not members of the association. DIGNITAS runs a free-of-charge online-forum with more than 3,000 registered users. It is set up as a self-help-community, taken care of by a professional mediator and two IT-technicians.

Furthermore, DIGNITAS assesses requests for the preparation of an accompanied suicide of those people, who send the relevant documents, such as a medical file, and tries to obtain a “provisional green light” from an independent Swiss physician for such an accompaniment with DIGNITAS. The latter is the “emergency exit door” which allows people to regain control over their destiny and prevents them having to resort to a lonely and risky suicide attempt. Besides all this, DIGNITAS works on further legal development and is involved in law-making proceedings and leading court cases, especially the ones aiming at a judgment by the European Court of Human Rights.

DIGNITAS is connected internationally with other organisations and does not restrict its services to Swiss residents. What is the difference between a metastasising pancreatic cancer in Switzerland and one in Czechia? Could we seriously tell the Swiss person “we’ll help you” and the Czech “sorry, you live in the wrong country”? The Good Samaritan did not request to see a passport before he helped the suffering man on the road. DIGNITAS ignores borders as far as possible.

The core goal of DIGNITAS is to disappear, to get obsolete. When freedom of choice in “last matters”, the freedom of talking openly about end-of-life-issues, the respect of the right to self-determination in life and suffer-

ing situations and a sensible suicide attempt prevention concept have been implemented, then an association like DIGNITAS will not be necessary anymore. In other words: if what DIGNITAS does is being done by the health care and social system, no one will need to turn to DIGNITAS. However, as long as most countries' governments and legal systems disgracefully disrespect their citizen's basic human right to choice and self-determination, and force them either to turn to risky suicide attempts or to travel abroad instead, DIGNITAS will serve as an "emergency exit".

DIGNITAS' philosophy

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

- Respect for the freedom and autonomy of the individual as an enlightened citizen
- Defending this freedom and autonomy against third parties who try to restrict those rights for some reason, whether ideological, religious, political 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

The people who inhabit a country 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. It is therefore unacceptable for a state or its individual authorities or courts to choose the fate of its citizens. Very much like 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, whether or not it still complies with one's own measure of value. To personally shape one's own end in life is included in this freedom. To choose the time and manner of one's own end in life is a basic human right, acknowledged by the European Court of Human Rights on January 20th 2011, judgment HAAS v. Switzerland, 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.

But, why should we discuss safeguarding quality of life hand in hand with end-of-life-issues?

The Pros and Cons of striving for more quality of life

According to statistics, between 1920 and 2013 life expectancy (from birth) in Czechia has increased from 49,6 to 81,3 for women and from 47 to 75,2 years for men. This is not much different in other industrialised ‘western world’ countries.

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

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

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.

So, if we feel good, then we could feel even a bit better? As stated in the introduction: we do a lot for increasing our quality of life. Medical science, pharma and the cosmetics industry help us in this. Research and advertising show us again and again further possibilities of what we can do good for our mind, our body and our soul.

Every day we are confronted with the ideal of the slim, omnipotent, sun-

tanned and fit-as-a-fiddle individual. 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 skin fold smoothed.

We are led to believe that good looks and being healthy are the norm – an ideal which we gladly follow suit. We act as if we could live forever young and fit. „Heroes don't die - they just fade away“. Suffering and death have faded from our perception. Dying is later and somewhere else. Life's end takes place in clinics, hospices, homes for the elderly and palliative wards. We have “outsourced” suffering to care homes and rehab clinics. Neatly filed away, sealed off from the pulsating life, so that the well-oiled performance-orientated society is not impaired.

Some day, reality catches up with us, often unprepared: we have an accident, we fall ill, we get old, frail, we die. It seems that we have forgotten how suffering and death, just as much as joy and birth, are a part of life, that there are life-crisis, consequences of an accident, isolation, severe illness and ailments due to old age. Suddenly, we are affected personally and become dependent on help.

Again, the individual looks for ways to re-install his own quality of life or to improve it at least, in the frame of the possibilities.

For this, the person concerned turns to medical professionals.

Blinkers and ditches

One can only define for oneself whether one's life still holds quality of life, 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 even whether it makes sense to continue this life or not.

The human being wants to be noticed and taken seriously and strives for self-realisation. Humans are not machines whose parts can simply be replaced and oiled, but they are much more complex: they have emotions.

To gauge one's own quality of life is a matter of feelings. Feelings constantly guide and accompany human life. The feeling of shame belongs to them.

Talking generally with other people about personal views on quality of life and the value of one's own life is one issue – yet it is another issue to say that, in a given situation, one's *own* life is not worth living anymore. And it is again a different issue to express the wish to end one's life. Additionally, there is the shame of being dependent on help.

Those who seek help are in a roller coaster of feelings: Support conveys safety and social reassurance, yet also the feeling of dependency. They wish for maximum possible independence, yet feel helpless due to not being able to act and they are afraid of being a burden to others. Often, anger, grief and frustration are growing, due to the abilities lost or possibilities unavailable. One is ashamed for not-being-able, or not being capable anymore.

In this situation, those seeking help look for information in order to weigh up their options and to gain safety.

Are they met at this point? Hopefully yes, but the reality can be quite different.

In the fields of medicine, nursing, psychological and psychiatric therapy as well as social care we see again and again that awareness for the individuality and complexity of the single case is missing or blinded out. The person is not seen as an individual subject but as an object, as a case. “Personalised medicine” does not mean that a doctor would take care of a patient in an especially empathic way, but, according to a publication of TA-Swiss (Technology Assessment, a centre of the Swiss Academies of Arts and Sciences) it refers to *“specific applications and research projects, as well as to the utopian concept for medicine to be able to identify the medications best suited to each individual person on the basis of diagnostic tests”*.

A further problem is expertise: specialists are so fixed to their field of know-how that they possibly do not recognise anymore certain aspects which are a side-line for them. The known therapy is the only right one!

In certain circumstances very personal elements may stand in the way: ego, striving for power, difficulties to accept the possibility of being rejected as a therapist and an understanding of providing help which subconsciously puts one’s own needs over those of the patient. However, what is it that the individual really wants?

There are palliative care specialists who emphasise that with sufficient palliative care any suffering could be soothed and therefore further options are not necessary, certainly not assisted dying made possible by organisations. The president of the German Medical Association even went a step further and successfully lobbied for implementing a prohibition on physician-assisted-suicide in the Model Professional Code for Physicians.

Such exponents like to refer to the “protection of life”, derived from the right to life, also 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 such experts digging ditches between different options to choose from in the field of help with severe suffering?

Their motives are multi-layered and may include monetary, ideological and power-seeking backgrounds. What these experts have in common is that they all wear blinkers whilst grooming 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:

“At the time of being admitted as a member of the medical profession I solemnly pledge to consecrate 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”.

They have also forgotten that there is neither *the* typical patient nor the *one* correct solution.

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. Possibly, the developments in medical science offer a new approach to a solution. Certainly, in many cases things will get off lightly.

But if not? 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 plunges into a downward spiral of failure and dwindling hope for improvement? What if the condition further deteriorates until he sits at the bottom of a deep hole and only sees the sky up above – and that's exactly where he wants to go then?

On January 9th 2002, the Swiss government explained that according to experts as well as research, for each actually “successful” and therefore officially registered committed suicide there are as many as up to fifty attempted suicides. Therefore, the risk of failure of an individual suicide

attempt is up to 49:1. In 2014, in Czechia, 1'488 people died due to suicide, according to data by the Czech Statistical Office. This signifies that in 2014 in Czechia up to 74'400 (!) suicides have been attempted. Not to forget that this number bases "only" on the officially registered 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 14'880 people of whom 13'392 have to bear the consequences of having failed. However, third parties also have to bear consequences: relatives and friends, police, emergency doctors, firefighters, train drivers... The World Health Organisation WHO estimates that worldwide 800'000 people die by suicide every year. The number of suicide attempts is therefore up to 40 million in a single year.

The consequences expressed in costs, which society has to bear, particularly due to failed suicide attempts, is enormous: The study „The price of despair – About the effects on the costs to be borne due to suicide 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, apart from 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, support care due to possibly lifelong invalidity, therapies, etc., which create 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 then resulted approximate costs of 2,369 million Swiss Francs.

Obviously, suicide attempts are a big problem in our society. What is being done in this regard?

In Switzerland, the Federal Council decided on June 29th 2011 not to prohibit organised assisted dying or to regulate it specifically by law, but to support palliative care and suicide prophylaxis.

A step in the right direction, however, still with blinkers: Why not promote palliative care and suicide *attempt* prevention?

Suicide Attempt Prevention – The counselling concept of DIGNITAS

The main work of DIGNITAS is not assistance in dying in cases of severe

and/or terminal illness. DIGNITAS is not simply a “right-to-die-organisation”. In the first place, DIGNITAS is help-to-live and suicide-attempt-prevention-organisation. A large part of DIGNITAS’ work is practical and legal advice for the healthy, the sick, relatives and friends of suffering individuals, medical professionals, etc. – and, of course, counselling of suicidal individuals who turn to DIGNITAS. In this, the primary question is not “how to die” but much more the question “how to continue living”. This is reflected in the logo of DIGNITAS: First, it is about dignity – the meaning of the Latin “dignitas”, then about how to live in dignity and only in the last instance about dying in dignity.

Anyone may get in touch with DIGNITAS, no matter for what reason. And in the frame of DIGNITAS’ resources, everyone receives advice and support. This includes advice regarding health care advance directives (advance decision) just as much as directions towards crisis intervention centres for people in a life-crisis with acute suicidal risk, directions towards palliative care for terminally ill, hints to helping organisations and expert physicians, etc.

In all cases, DIGNITAS tries to give advice adapted to the individual situation. Common denominator is that we 1) listen to people and take them seriously; 2) talk openly and honestly with them; 3) do not shunt them into the “mentally-ill-corner” or stigmatise them in any other way; 4) talk in a fact-orientated way about suicide and the high risks of ‘clandestine’ suicide attempts and 5) counsel in a comprehensive and open-outcome manner, that is in all directions.

What does this mean?

Regarding 1): The most incredible stories come from life itself. Even if the explanation about the suffering of the person who seeks help sounds absurd, it is essential to notice and take him seriously. It is his reality and he should be met there.

Regarding 2): Quite obviously, the person seeking help makes contact with a professional because he wants and needs expert know-how. Making light of the problem and attempting to diminish its seriousness, a ‘verbal dilution’, are counterproductive. The disappointment of not having been informed honestly by a professional to whom one has given trust in advance, hurts even more when reality catches up and it lastingly undermines the ability to trust.

Regarding 3): 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 “psychiatryisation” in medicine, such as can be seen from the latest expansion of the Diagnostic and Statistical Manual of Mental

Disorders DSM-5. Unnecessarily, the person seeking help is “classified”, “labelled”, declared to be sick. However, the person should be met at eyes level!

Regarding 4): The taboo surrounding suicide leads to a lot of suffering. Concealing, trivialising or scandalising are out of place because suicide and suicide attempts have been and still are a reality, a possible human act.

Regarding 5): “Informed consent” includes “informed”. In talking with the person who seeks help about all possible options in a specific situation of suffering, without intending to make a choice in advance, one empowers this person to think about all these options and one respects this person as an individual.

This approach can be applied to perfectly healthy people just as much as to those seeking help no matter whether suffering from a physical or an emotional problem.

Suicide attempt prevention is the roof over this comprehensive counselling concept. It reaches further than suicide prevention. The usual approach of suicide prevention includes:

- Restricting access to means of suicide by deliberate decisions or by developing improved technological processes
- Sometimes rather hesitant safety measures in places where many suicide attempts have taken place
- Limiting public awareness of suicides in the media and pushing the issue of suicide to be kept private.

Provocatively said, suicide prevention mainly deals with the reduction of deaths due to suicide, which is, aiming at one death less in the statistics. For this, it suffices if the suicide attempt fails. Obviously, this is a rather limited, statistical approach which – to little surprise – has not reduced the number of suicide attempts significantly. 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, who reject the idea of suicide, nothing will change in this regard.

The starting point of successful counselling to safeguard and improve quality of life is a liberal approach, respect for the individual and accepting a paradox: if risky suicide attempts with their dire consequences should be prevented, suicide as such has to be basically accepted. The ta-

boo surrounding the issue, the wall of fear of embarrassment, rejection and losing one's independence have to be lifted.

As already mentioned before: people whose quality of life has deteriorated to the point that by own judgment they do not see a chance for improvement anymore, sit at the bottom of a deep hole and only see the sky up above – and that's where they want to go.

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

This leads to a conversation atmosphere in which the patient can discuss the reasons why they do not see sufficient quality of life anymore and why they do not want to continue living as before. In general, everyone wants to go on living and enjoy sufficient quality of life. People wish to die because they cannot see how to go on living in the specific situation which they feel to be unbearable and unacceptable.

DIGNITAS' experience is that – paradoxically – the option of an accompanied suicide without having to face the severe risks inherent in “clandestine” suicide attempts is one of the best methods of preventing suicide attempts. It may sound paradoxical again: in order to prevent suicide attempts, one needs to say ‘yes’ to suicide. Only if suicide as a fact is acknowledged, accepting it generally as a means given to all humans to withdraw from suffering and life whilst also accepting and respecting the individual's request for an end in life, the door be opened to “talk about it” and to tackle the root of the problem which made the individual feel suicidal in the first place. Knowing about a real option, “a real way out”, will deter many from attempting/committing suicide through insufficient, risky, even dangerous means.

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

Only then may one call it comprehensive and open-outcome counselling. And the fact that at DIGNITAS we do not only talk about “it” but, under certain circumstances really enable the option of an accompanied suicide, is an important element of authenticity, the value of which should not be underestimated.

Further activities of DIGNITAS

Suicide attempt prevention is the roof over the daily work of DIGNITAS. Additionally, there are further fields in which DIGNITAS works with engagement. Two of them are described hereafter.

1) Further legal development

Legal work is an important part of DIGNITAS' work. Presenting legal questions in proceedings in order for Courts to deal with them, allows to further develop the right to live and die with dignity.

Twelve years ago, a man called DIGNITAS and explained that he was suffering from bipolar – manic-depressive – disorder, that he had attempted suicide twice and obviously failed, that he had been an in-patient in psychiatric clinics nine times and that he wanted the help of DIGNITAS to end his suffering. Knowing how difficult it was to obtain consent from a Swiss physician 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 not accessible, to recourse to the courts.

This was the starting point of legal proceedings at several levels of jurisdiction which led to the earlier mentioned judgment on January 20th 2011 of the European Court of Human Rights' decision in the case of HAAS vs. Switzerland, the judgment which acknowledges the right of a competent individual to decide about the manner and time of his or her own end in life as a right protected by article 8 of the Convention.

Many opponents of the “freedom of choice in last issues” will claim that there is no right to die. They are wrong; certainly within the jurisdiction of the European Convention on Human Rights – which covers all of Europe except for the Vatican and Belarus.

Since their founding, both DIGNITAS-associations have led or been involved in dozens of legal cases, of which one led to the Court statement mentioned. More will follow.

Another important line of DIGNITAS' legal work is the engaging in legislative proceedings. DIGNITAS wrote in-depth submissions in consultations of the Swiss Federal Council, the Crown Prosecution Service of England and Wales, the Scottish, Australian and New Zealand Parliament, etc. This list is to be completed by a comprehensive law proposal to regulate accompanied suicide by associations (Accompanied Suicide Act – ASA).

2) Accompanied self-deliverance

“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.

In the case of medically diagnosed severe or terminal illnesses, unbearable pain or unendurable disabilities, DIGNITAS can arrange the option of an accompanied suicide upon the 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 ending of life:

- the person has to be a member of the DIGNITAS-association
- the DIGNITAS patient’s instructions (health care advance directive) 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 3) most importantly, comprehensive historical and up-to-date medical reports showing diagnosis, treatments tried, medication, development of the illness, etc.
- based on this formal request DIGNITAS can 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.
- after the person receives the “provisional green light” there are details to be discussed with DIGNITAS such as about possible dates, how to travel, where to stay, further paperwork, etc.
- the person will have at least two face-to-face consultations with the Swiss physician who initially provided the “provisional green light”
- the person has to provide several official documents such as a birth certificate, etc. – Swiss laws states that these have to be newly issued papers

It is important to remember that, even at this stage and 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 their full consent could no longer be met.

Gathering information, reflecting, writing the request, obtaining all relevant documents, arranging the journey, talking it all over with loved ones: it all takes time. The preparation of an accompanied suicide for people from outside Switzerland takes at least 3 to 4 months.

In the course of the preparation proceedings, DIGNITAS and Swiss doctors will establish 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.

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's 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.

DIGNITAS' experience shows that only very few 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 some 30 years of such assisted dying practice being in place in Switzerland, only around 1,5 % of all deaths take place by accompanied suicide.

Allowing self-determined ending of suffering and life by a safe means within a carefully-arranged and safe framework, plays an important role in preventing lonely, risky suicide-attempts and a lot of suffering. Making possible this kind of arranged self-deliverance *is* suicide attempt prevention. In the words of British conductor Sir Edward Downes who – during his consultation with the Swiss physician granting him the "green light" in 2009 – said: "*This is a form of evolution, of humanity.*"

Old and new challenges

Most of the difficulties that DIGNITAS deals with have their origin in the fact that we have always been convinced that the right to die is in fact the very last human right and thus there could not be any discrimination just because of the place of the residence of a person. "*Why do you import such foreigners?*" was the main question which the General Prosecutor of the Canton of Zurich, now-retired Andreas Brunner, asked DIGNITAS'

founder in a meeting back in the year 2000. At least, this was an unmistakable announcement with an open visor. Often, attempts to narrow freedom of choice in “last matters” come across hidden under the cover/disguise of ethics, religion as well as research and science.

The opponents of freedom of choice in last matters are numerous and the obstacles to regain quality of life, have one’s rights and freedoms respected, and reach a self-determined, dignified, accompanied and peaceful end in life are many. There is a lot of work ahead:

1) Legal and political

The right to decide on the manner and time of one’s own end of life is a human right. However, human rights are minority rights. They have to be fought for and defended, again and again.

DIGNITAS is the spearhead of internationally further developing the legal situation in regard of freedom of choice and self-determination in health care and end of life matters due to its many years involvement in court cases. These range from the European Court of Human Rights case *PRETTY v United Kingdom* in 2002 to the Canadian Supreme Court decision *CARTER v. Canada* overturning the Canadian criminal code provisions which prohibited physician-supported assisted dying.

The core goal of Dignitas is to disappear. For this, freedom of choice needs to be implemented in other countries than Switzerland too.

2) Mentally competent individuals suffering from psychiatric ailments

Here is a quote from an e-mail that a young woman sent DIGNITAS:

“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 a widely-held opinion, people suffering from mental health problems normally have sufficient capacity of discernment to decide whether they would like to continue living or 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. Access to such option needs to be

possible also in order to avoid the high risk of a clandestine suicide attempt.

But there is a difficulty in Switzerland: it always takes a prescription written by a Swiss physician to obtain the Sodium Pentobarbital, and furthermore, if an assisted suicide is intended by a person who is suffering from a psychiatric ailment, it always takes a special in-depth medical appraisal by a psychiatrist indicating that the person's wish to end life is not a symptom of a treatable psychiatric ailment, but is based upon a self-determined, carefully reflected and stable decision of a competent person.

In practice this signifies that DIGNITAS is only able to arrange for an accompanied suicide for someone suffering from a psychiatric ailment if the patient presents a formal request with a medical file including such appraisal *and* a Swiss psychiatrist assesses the request and grants a "green light". Unfortunately, liberal psychiatrists accepting the concept of suicide are very rare. The Swiss organisation of psychiatrists and psychotherapists has proclaimed that their members will not write such psychiatric appraisals. The appellant in the earlier mentioned case decided by the European Court of Human Rights in 2011, contacted 170 psychiatrists in Switzerland, asking each of them to examine him and write an appraisal – without success.

3) Mentally competent old-agers

Going back to the increase in life expectancy mentioned earlier: According to the Swiss Federal Statistical Office, between 1900 and 2012 life expectancy in Switzerland has almost doubled from 48,9 to 84,7 for women and from 46,2 to 80,5 years for men.

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 dignified end in life?

This is, again, a legal question which sooner or later will be clarified through legal further development with the European Court of Human Rights. The issue was part of the case of ALDA GROSS, a woman born in 1931 with some ailments due to her age, but neither severely nor terminally ill. However, she passed away before the Court took a final decision.

4) Incompetent and biased media

"The world's foremost euthanasia clinic" ... "cocktail of drugs" ... "poi-

son” ... “suicide tourism” ... “active euthanasia” ... “on the waiting list for self-murder”... These words are not only found in tabloids.

Truncating, falsifying, scandalising, a “me-too”-attitude as well as the 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. They are almost only about money – not about accurately and profoundly informing the public anymore. Such misleading media coverage not only leads to a distorted picture in the public, 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 be put down”. How distressing for them and for DIGNITAS too when we have to tell them that they have been misled by incompetent journalists and that they have to go back home because they could not be helped right away but would have to go through the usual preparation proceedings first.

However, what is worst is that the public is not being appropriately informed about suicide attempt prevention and health care and end-of-life options.

5) The pseudo-ethicists, pseudo-religious and pseudo-pro-lifers

On September 28th 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. One was Prof. Dr. Andreas Kruse, disciple of the former pope’s brother Georg Ratzinger, and known as opponent of assisted dying and arguing with the long-disproved slippery-slope-argument. One speaker was Prof. Dr. Brigitte Tag: a German professor for law lecturing at the 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: a long-standing opponent of assisted dying who published this opinion in his dissertation and who is now – together with the afore-mentioned 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 tax money. Organiser of the conference was Markus Mettner – a German catholic theologian...

What are the aims of such groups and “experts”?

Through edging into ethic boards and research projects, they spread their authoritative and paternalistic values, camouflaged by the image of “expert committees” and “scientific research”, with an aim to force their personal views upon other people and undermining liberal ideas fought for and gained through enlightenment.

Indirectly or directly, they quite likely work hand in hand with medical professional organisations, the hospice-movement and the pharmaceutical industry. In 2013, the Swiss pharmaceutical companies Roche and Novartis increased its profit/turnover ratio to 24 % and 19 % respectively. The latest trend of the pharma industry is called “human enhancement” which is optimising medicine, considering normality as an illness and intending to sell as much performance-enhancing medication as possible...

For such groups, freedom of choice in “last matters” is a nuisance. Why should they bother to deal honestly and in an open-minded approach with the problem of suicide attempts, when they can make a lot of money out of providing goods and services thank to failed suicide attempts? How many politicians and top-notch physicians hold shares of clinics and pharmaceutical companies and receive further benefits, especially out of medication sold? The Swiss Academy of Medical Science has enjoyed the financial support of the pharmaceutical industry for many years . . .

Power, money, religion and politics: for centuries this has been a problematic mix. And this mix profits from the previously mentioned incompetence of journalists who do not critically research the background and motivation of such exponents.

Conclusion

Groups like DIGNITAS and others more are actually protection-of-life organisations because their work is about options and choices, about chances and perspective, about respect for humans, about prevention of unprepared, risky suicide attempts. For many mature, thoughtful and self-reflected people the feeling of not being taken seriously and to be controlled by others in a given suffering situation, is unbearable.

It is not single measures, but an overall approach that 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 suggests that the ice-layer of taboo surrounding the topic of dying and suicide has to be broken up. Suicide and death are reality, they are part of life. All of us, for whatever reason, could attempt suicide and we are all going to die one day. Rejecting or trying to forget about these facts will not dispose of them.

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 Federal Office of Public Health FOPH states that *”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 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’”.*

I hope that I was able to contribute something in this regard – even though, surely, it was only a brief glimpse of a task facing society as a whole.

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