DIGNITAS
To live with dignity
To die with dignity

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An essay by DIGNITAS – To live with dignity – To die with dignity

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Can Freedom Create Pressure?

Options strengthen freedom of choice and never create an obligation. The right to assisted dying should therefore always be understood as one option among others, never as an obligation. This makes it all the more important to take the concerns of those potentially affected seriously and to provide information about self-determination at the end of life.

*by Susanne**

For several months now, I have been working for DIGNITAS – To live with dignity – To die with dignity. When I tell people around me about my work, I am met with many questions, but hardly any rejection. There is a great deal of interest; many people want to know more – about the organisation and about the issues DIGNITAS deals with: freedom of choice, self-determination, personal responsibility in life and at the end of life.

A few days ago, I spoke to my aunt Anne in Austria. She is 87, fit and healthy. She is a role model for me because she has always lived her life with a strong sense of self-determination. She never married, worked as an immunologist and held professorships all over the world. She lived for many years in Germany, the United States and Canada, still travels extensively today and keeps in close contact with former students. I admire her positive nature, her wide range of interests, her education and, above all, her clear opinions. She is someone I like to turn to for advice because she listens openly and without judgement.

I was therefore all the more surprised when she initially reacted rather sceptically to my work and to the subject of voluntary assisted dying. I asked her about it, precisely because I had expected her to have a different view.

Her answer was clear and honest: she sees the demographic development and, at the same time, a certain self-centredness in society. Her concern was that she could imagine older people feeling both internal and, above all, external pressure “to go” sooner than later, rather than “being a burden” to others. That this pressure could increase, and that liberal laws might encourage it. That older people might even feel “pressured” by others.

She told me that when she was young and studying in the United States she once overheard siblings talking on a train. They were discussing how much better it would have been if their mother had “gone” a few years earlier – then there would have been more money left over.

Anne was shocked by the conversation. It shaped her view. Was that where her scepticism came from?

I told her that the opposite is often observed among people who suffer severely and for a long time: children and those around them will often try to dissuade them from physician-supported assisted suicide, or another form of assisted dying. Some people then need time and space to help their loved ones understand that, because of their state of health, they no longer wish to go on living. They struggle to gain acceptance for a decision that is their own, carefully considered and often contemplated much earlier in life. It is an important and valuable process, although an emotionally challenging one, both for loved ones and for the person wishing to end their suffering. These are among the experiences reported by many bereaved relatives following an assisted death.

I explained to her that freedom surely means having different options. So, can freedom of choice create pressure? I wanted to look at the issue from different perspectives:

The perspective of freedom ethics

Options strengthen freedom and never create an obligation. The right to assisted dying creates an option, never an expectation.

The right to assisted dying means that the state does not prohibit it. At the same time, there is a clear procedure designed to safeguard voluntariness and rule out decisions imposed by others. It should never mean: “people should die when they are old.”

If societies devalue older or ill people, for example by regarding them as “no longer useful”, this is a problem of ageism and social ethics – not a legitimate reason to restrict self-determination. Otherwise, other rights that could also be sensitive to “pressure” would have to be restricted as well, such as the right to stop treatment or refuse medical interventions through an advance health care directive.

Freedom of choice means having several options: palliative care, care in a hospice, making provisions through an advance directive, and others. These options are important for dignity and freedom of choice. Paternalism would affect those most seriously who are in need of protection.

A ban on, or severe restriction of self-determination at the end of life does not protect “vulnerable people” – whether supposedly or genuinely vulnerable. Instead, it removes the option for everyone. In doing so, it can force people who are already under considerable strain towards secretive and riskier alternatives. A legal framework such as the one in Switzerland and Germany provides a safeguard through transparency, documentation and oversight.

The legal perspective

In Switzerland, self-determination at the end of life is constitutionally protected and has been confirmed by the highest court. The Federal Constitution protects personal freedom, from

which the right to self-determination in medical decisions is derived.[1] In 2006, the Swiss Federal Supreme Court confirmed the freedom of choice and right to determine the manner and time of one's own death.[2]

Nevertheless, this right has clear limits. With regard to assisted suicide, article 115 of the Swiss Criminal Code makes assisting in suicide punishable when done for "selfish motives"[3]. This does not refer only to financial motives, as is sometimes mistakenly assumed. The fact that assistance is not punishable in the absence of selfishness is a central legal safeguard. In addition, the person wishing to die must have capacity of judgement. Both are instruments designed to prevent external pressure and sanction potential misconduct. Coercion and manipulation are therefore not consequences of legalisation; they are already punishable under existing law. Further provisions, including those in the Medical Professions Act and others, as well as court judgments and the professional code governing doctors, complete the clear legal framework for professionally and medically assisted dying.

There are also legal safeguards beyond Switzerland's borders: wherever assisted dying is legal in the world, there are clear rules, documentation requirements, reporting procedures and sanctions for abuse.

The perspective of autonomy and dignity

Self-determination as an expression of personal dignity: if people are allowed to live a life that reflects their own values, they should also be allowed to shape the end of that life according to those values and to seek support in doing so.

Suffering is individual and subjective. Some people define an unbearable life not only in terms of pain, but also, for example, in terms of losing control, the ability to communicate or intimacy. There are also cases in which palliative care options reach their limits, or in which the person does not consider them acceptable: not everyone wants to be sedated into death. In such circumstances, assisted dying may, so to speak, be the last viable path for that person. Simply knowing that this "emergency exit" exists can help make suffering bearable and restore or improve quality of life.

Thus, rather than creating pressure, it can have the opposite effect: it can provide relief and, at best, prevent violent suicides and failed suicide attempts. This is also the view expressed by medical professionals[4]. A legal, professionally supported "way out" can therefore reduce risky suicide attempts and the negative consequences associated with them for everyone affected – and ultimately for the state as well.

The perspective of equality

Without legal possibilities for freedom of choice in life and at the end of life, people who are still able to may try to end their lives themselves – although even for them this is rarely

[1] Explore the "Legal Perspective": https://dignitas.ch/en/activities/development-of-law/ and https://dignitas.ch/en/knowledge/court-rulings/
[2] See Court Ruling BGE 133 I 58 (in German)
[3] https://www.fedlex.admin.ch/eli/cc/54/757_781_799/en#art_115
[4] https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0274597

possible without considerable risks, as outlined earlier. People with physical disabilities or serious illnesses, by contrast, would be treated unequally.

Neither old age nor the need for care should lead to a disenfranchisement of people. On the contrary: precisely then, a system is needed that enables possibilities, pathways and voluntariness, thereby preventing discrimination.

However, the reality is troubling, as can be observed in Austria for example. It has been reported "that many people who wish to draw up an advance directive for end-of-life decisions experience discrimination. It has been documented repeatedly, including by the Austrian Ombudsman Board, that those affected are subtly or openly deprived of their autonomy, pathologised, denied decision-making capacity, and confronted with resistance, moralising attitudes or covert unequal treatment in hospitals, care facilities and palliative care settings."[5]

Freedom, trust and pluralism of values

In enlightened democracies, people should not be forced through prohibitions to adopt a particular religious or philosophical understanding of what constitutes the "right way to die".

Trust is built through choice. A "duty to prolong life" at all costs, simply because there are no alternatives, can undermine trust in medicine and the state. In Switzerland, politics and medicine ignored the growing demand for greater self-determination "in the final matters of life", which ultimately led to the founding of the two EXIT organisations in the early 1980s and, later, of others such as DIGNITAS. Elsewhere, for example in the Benelux countries, Spain and Canada, the healthcare system assumes greater responsibility.

Pressure is real – but not because of liberal laws

Pressure on older and ill people can certainly arise, but it has nothing to do with a liberal legal framework for self-determined dying. Pressure can already be exerted today, for example when decisions suddenly have to be made quickly: entering a care home, stopping treatment, deciding "not to go to hospital" and so on.

However, the regulated procedure for physician-supported assisted dying requires explicitness: conversations, records, assessment by medical doctors, and oversight by prosecutors, police and the medical officer. All of this makes pressure more visible rather than creating it.

If procedures become too rigid however, then counter-pressure arises. Excessive bureaucracy, as can sometimes be observed, can drive people who are suffering to despair, leaving them once again at risk of turning to illegal and dangerous do-it-yourself suicide methods.

Whenever possible, all the instruments and options for a self-determined end of life should be presented. Assisted dying is always only one of several. Others include advance directives, palliative care, respite and family services, psychosocial support, and pain or symptom management.

[5] https://schoepfblog.at/gianluca-crepaldi-assistierter-suizid-als-epidemie-ein-einspruch/ (in German; translation by DIGNITAS)

There should be no "structural pressure": access to palliative care and social support should of course be no less quality than access to assisted dying. But it is also worth considering the point raised by Gianluca Crepaldi: "The narrative that good palliative care would lead almost everyone to abandon their wish for assisted suicide is simply wrong. Palliative care can, of course, alleviate suffering, make ambivalence easier to address and change a person's wish to die. But it does not follow – and there is no scientific evidence to support this – that assisted suicide is primarily a symptom of inadequate palliative care."[6]

At the same time, there are ongoing debates in many countries about "structural" factors such as social isolation and gaps in care. This however is not an argument against the right to self-determination at the end of life. It is an argument for a better support infrastructure.

DIGNITAS has been campaigning for freedom of self-determination for many years, while also supporting other choices. It is precisely because options and an "emergency exit" are possible and accessible, that suffering can be alleviated and people may turn back towards life. Even those who choose voluntary assisted dying with DIGNITAS do not actually want to die – they do not want to continue living in a state of suffering that conflicts with their personal values of quality of life and dignity. If their suffering can be alleviated, they turn towards life and postpone the planned end, or ultimately abandon the idea altogether. In this sense, practically available end-of-life options can have a life-prolonging effect.

Everything is self-determination – self-determination is everything

My aunt Anne and I touched on all these aspects. The arguments made sense to her. At the end of our conversation, she asked: "Can't anyone give people who are suffering so severely some hope? Isn't it that family members feel especially bad when a parent dies? Don't they feel that they could have given them more joy or more hope?"

"What a high expectation!" I exclaimed spontaneously. I immediately adjusted this by saying that, of course, it is a wonderful and enriching thing to be able to give someone else hope. But joy in life? Can that ever come from anywhere other than within ourselves?

It was precisely Anne, who had consciously lived her entire life independently, albeit surrounded by many friends and companions, who brought up the family issue once again. That surprised me greatly.

So, I asked her what gave her hope and joy in life. What gave her, at 87, the energy and discipline to go for a long walk every day and even go to the gym three times a week. Besides the demanding journeys she still undertakes.

"It is myself", she said. Her choice of surroundings, friends and social contacts, as well as taking part in a range of activities. All of it accompanied by gratitude that she is still relatively healthy given her age and lives in a safe place.

[6] https://schoepfblog.at/gianluca-crepaldi-assistierter-suizid-als-epidemie-ein-einspruch (in German; translation by DIGNITAS)

The latter is beyond many people's control. Health, too, can only be influenced to a limited extent. Everything else, she described as something she could shape herself.

So what remains?

Probably self-determination.

It should be protected also at the end of life – when there are things that can no longer be influenced; when nothing remains that brings joy to life, when there is only suffering. For this, DIGNITAS – To live with dignity – To die with dignity offers a structured "way out".

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