Working with people outside of the system – Ton Vink, Chicago sept. 2014.

Ladies & Gentlemen, It is a pleasure to be here as delegate of probably the world's smallest but no less effective 'right to die'- society, Stichting de Einder.

I hope you will excuse me for not giving you the story of my life or the history of De Einder (The Horizon).
I am a philosopher in the empirical and sceptical tradition of David Hume and work as end-of-life-counsellor. I do this work in close collaboration with six colleagues and supported by De Einder.(Slide 1) It may be relevant to know I was prosecuted in 2005 for assistance with suicide and acquitted in 2007. Recent police interrogations took place in December 2013 and January 2014. Just so you know the criminal mind your listening to.

Also, I hope my English will be good enough for you to get the gist of what I want to say. On the other hand, I trust my English will be better than your Dutch.
For convenience sake my power point will visually present some material such as definitions, which otherwise you would find it difficult to keep in mind.

My time is limited and there is a lot I have to ignore.

As indicated, I will focus on working *outside* of the system in The Netherlands.

First of all, you should know that in the Netherlands we have a 'system' for everything. Even a system for working *outside* the system.

I will first present some details of a theoretical nature. But as dying is not a theoretical matter, I will next present cases that I have been directly involved with and that will illustrate the work of an end-of-life counsellor. After that I will try to bring both lines (theory and practice) together.

Two clarifications are needed to begin with:
What is this primary 'system'?
And second, what is this 'system outside this system'?

First, the primary 'system' refers to what is known as the 'euthanasia law' and I will say a few words about it. (I won't repeat Petra de Jong's information).
Second, the 'system outside this system' does *not* exist 'in conflict with' the primary system. It is a supplement or complement to the primary 'system'.

The law on euthanasia.
In the present company my country will probably be best known because of its 'law on euthanasia'. Curiously enough, this law isn't about 'euthanasia' at all. In the total body of the text of the law, the word 'euthanasia' isn't mentioned even once.

So, you might want to know, what is this law about? It states the requirements that have to be met *by the physician* who wants to respond positively to his patient, requesting the physician either (1) to end the patient's life, or (2) assist the patient in ending his life. All this – important – under the final supervision and ultimate responsibility of the physician.

In several thousands of cases a year, the physician does in fact respond positively. Almost always *the physician* ends the patient's life by administering lethal medication. Only in a very small number of cases does the physician assist the patient in ending his life.

It is tacitly assumed that when this happens, the patient dies 'a good death' or 'eu thanatos'.
This is *assumed*. It is not investigated and since recently we know for certain that it is not always the case. On occasion, we now know, the patient dies 'a bad death'. Nevertheless, even in those cases the legal requirements of due care are met by the physician, at least according to the review committees. The review committees do *not* assess whether the patient died a good death. (Slide 2)

So, actually, we ought not to refer to the 'euthanasia-law' but to 'the termination of life law' (TLL). However, the habit of speaking in terms of 'euthanasia-law' is ineradicable. (Slide 2)

The System: physicians-euthanasia.
This 'euthanasia' is what I will refer to as 'doctors-euthanasia' or 'physicians-euthanasia'. This is the form of 'euthanasia' that represents the 'system'.

In The Netherlands, euthanasia was (1984) officially defined as "the deliberate termination of the life of a person on his request by another person." (Slide 3,2) Needless to say, this definition is seriously at fault, covering far too much, in fact covering *every* case of one person deliberately ending the life of another person at his or her request.

However, this can be easily remedied, as I did by defining physicians-euthanasia as: "the deliberate termination of the life of a person on his request by another person, in accordance with the demands of the termination of life law (TLL)." (Slide 3,3)

Outside the system: self-euthanasia.
In the years after the Dutch 'euthanasia-law' became operative, it became clear that there was ample space *outside* of this system. This space is covered by the notion of 'self-euthanasia'. This notion was re-introduced in the debate by Boudewijn Chabot. It has a somewhat longer history, but that pre-dates the current debate.

In my writings I have defined this 'self-euthanasia' as: "the deliberate termination of his or her own life by the person himself, under his own control, after clear and careful consideration, and carried out with due care."

These two forms of 'euthanasia' complement each other and so to speak 'cover' the entire field of dying a self-requested 'good death'. (Slide 3,4)

Of course, looking at my definition, I am obliged to do what the Dutch euthanasia-law does *not* do: stipulate what I mean by a 'good death'. I will do so next and will also indicate where the difference lies between a 'good death' of a person by the hands of the physician and a 'good death' of a person by his own hands.

A good death.
In sum, a 'good death' (Slide 4,5) means a death:
- decided to after clear and careful consideration
- in which the individual's role is as large as possible
- that is carried out with the utmost care
- that is not executed in forced loneliness
- if at all possible, in contact with loved-ones
- without adding pain or suffering
- considered (given the circumstances) as dignified
- and accepted by the individual in peace and quiet.

Obviously (I would say), these conditions will not be met in every case to the same extend. This makes this 'good death' an ideal that you might strife for.

This 'good death' or 'eu thanatos' is what is looked for in both physicians-euthanasia and self-euthanasia.
In both cases death is 'self-requested' by the individual (not the physician, the patients family or any-one else).
However only self-euthanasia is also 'self-performed' and 'self-determined'. (Slide 5, 6-7)
Self-requested refers to the individual himself wanting, requesting, an end to his life.
Self-performed refers to the individual himself carrying out the act.
Self-determined refers to the individual having the decisive voice.

Self-euthanasia is distinguished from physicians-euthanasia by these last two qualities, being also self-performed and self-determined. (Slide 6,8)

By way of good-by to the theoretical part of my contribution, I will define 'self-determination' (or 'autonomy') in this context of self-euthanasia as: "The attaining and keeping of control and authority over the process of preparing, deciding and bringing about the termination of one's own life with due care and concern." (Slide 6,9)

To exert this self-determination, the individual must be mentally and physically competent to do so (some physical help may be necessary and allowed).

The practice of self-euthanasia.
There's a lot more theory to discuss, but as dying is not primarily a theoretical matter, so is self-euthanasia.
I will now turn to some examples of self-euthanasia in which I have been involved as counsellor. I will confine myself to the use of lethal medication. I leave out the voluntary refusal of food and drink as this is attended to by the physician, local nurses and family. And also the helium method, as this is taken to only rarely.

The case of Anton.
Anton was a marine-biologist of international standing. When we met he was 86 and he died at 86. He approached me as counsellor because his physical problems had reached a level he no longer wanted to tolerate. He had a good relationship with his physician but loathed the idea of not being his own man in this most vital decision. His physical problems centred around his backbone or spine, for many years now. He had led an eventful, fruitful and rewarding life, a life he could easily consider to be complete. He had nothing much to add and he saw no problem what so-ever in saying his good-by. He only wanted to do this with the utmost care.
He had remained a bachelor all his life but his work and travels had brought him some good friends world-wide. He kept in touch with them, but had informed them recently that at some point in the near future this contact might fail. If so, they ought not to worry. He was grateful for their friendship over the years, but all things on earth must come to an end. Surely as a biologist he was well aware of that.

It is very much an exception, but when he asked me if I were prepared to sit next to him in his last moments, I agreed, after having given his request some thought. His lethal medication consisted of 1,2 grams of oxycodon, taken together with 120 milligrams of flunitrazepam, which he obtained through a reliable Dutch source I could inform him about. He had carefully taken his anti-emetic in the preceding 24 hours. He left several envelopes with information for his physician, the coroner, the notary and other relevant persons. As he donated his remains to science, measures were taken in that respect as well.

After ingesting his medication, sitting upright in bed, he next laid down.
We talked a bit, for just a few minutes, but his speech was becoming slurry in about 7 minutes.
He slipped into a deepening sleep and as far as I could tell – I am not a physician – he died in about forty minutes.
I then left, as agreed. Measures had been taken for his physician to find him in time.

The case of Carol
Carol was well over fifty when she contacted me. Her history of psychiatric problems and treatment covered a period of over thirty years. She lived alone, no children, no partner, no real friends. Her parents had died. She wasn't an easy person to make contact and in fact, the necessity of visiting me caused her some serious sleepless nights. She first informed me extensively in writing about her condition and its history. At the end she wrote: some people consider their lives being over when they are well

over eighty. I am well over fifty, but I do consider my life as being over. And I would want to be able to end it on my own terms, dignified, well-prepared, without causing pain or trouble to any-one, not to myself and not to any-one else. And so she did, six months later, using two bottles of Nembutal, obtained from a well-known address in Mexico I informed her about. A few days before the event she informed me of the date she had set for herself. And we said our good-by.

The case of Thomas
Thomas, who was 83 when we met, was suffering from the onset of dementia. It was an illness he had seen progressing in both his parents for years. Already a long time ago he, therefore, had himself decided that, should he be diagnosed with the same disease, he would put an end to his life in time, on his own conditions.

This was his reason for contacting me. Other than Anton and Carol, Thomas had a wife who supported him, children who did the same (in fact I was at first called in by one of his children) and a number of grandchildren who were also aware of the state their grandfather was in and the plans he had made for himself.

In this respect, Thomas was well off. And more. His physician who felt he could not answer the terms for physicians-euthanasia, nevertheless continued to give his support to Thomas and his family. He (the physician) contacted me as counsellor because he wanted to assure himself of the reliability of the process, including the medication Thomas was going to use. (These were the same as Anton had been using, oxycodone plus flunitrazepam, obtained from the same source, though the road to contacting this source changes at random for reasons of safety.)

And there is more. This is probably The Netherlands at their best. The local pastor – obviously of a free-thinking kind – was also aware of what was going to happen and he offered his spiritual support to the family.
So, the evening before Thomas was going to take his lethal dose of medication, the pastor held an intimate service at their home. Present were Thomas, his wife, their children and grandchildren, to celebrate Thomas his life. Next morning, surrounded by his family, he said his final good-by.

The beginning of 2014 the family published a small booklet telling the story of the self-euthanasia of their beloved Thomas. They openly told their story, including the contributions by the physician, the pastor and the counsellor, who were all mentioned by their real names.

Other stories
The story of Thomas is very similar in several respects to story of another client of mine, Jan-Ru. His story you know by now, as it is told, with equal frankness, by his wife, Nel, in the film *Eyewitnesses.* (Produced by Boudewijn Chabot.) Jan-Ru ended his life by taking liquid pentobarbital (as did Carol).

I could tell you other stories I wrote about, also about elderly couples deciding to end their lives together, in the same harmony that they lived it together.
Just these days I was informed by the children of an elderly couple. They had peacefully died together in their own home, with their children present. She was 83, he was 84 and had recently been forced to move to a nursing home, much to his annoyance and to her great pain. The family brought father home for the weekend, which turned out – as carefully planned – to be the couple's last weekend. They ended their lives together, using pentobarbital-powder (12,5 gr. each), obtained from a well-known address in China.

All in all, I suppose, by now you get the picture of this so-called 'system outside of the system', illustrated by the use of lethal medication. (Slide 7, 10-12)

Theory and practice.
In conclusion I would like to try to bring together the bit of theory and practice I presented to you.

As stated: the notion of 'self-euthanasia' is a normative one. It isn't just 'self-thanasia' but 'self-e*u*-thanasia'. (Slide 8, 13) We noticed this 'good death' is an ideal you might strife for. We therefore have to ask, how far this ideal has been realised in the examples I gave.

So: how about Anton, Carol, Thomas, Jan-Ru and the couples I referred to. Did they die a 'good death'? And what problems did they face and had to conquer? And what about their family and loved-ones?

Looking at my definition of a 'good death' I think I can say that, given the possibilities and limitations of each case, their death was indeed a 'good' death.

Maybe *Carol*, who died as she had lived: in loneliness had deserved some final company. But this was her choice, and it fitted the way she had lived.
Anton also died the way he had lived and there is no doubt that he was at peace with it.
Thomas and *Jan-Ru*, I am tempted to say, represents the 'best practice' of self-euthanasia, as does the couple a referred to in a few lines. But let me add at once that this does not mean that there is no grief, no pain, no sorrow, in having to say good-by to life and the ones you love. Especially in the case of Thomas, who had a rich life in material and immaterial respects, the decision wasn't an easy one. And as a matter of fact I have been far more in touch with his widowed wife *after* his death, than *before* his death. The same goes for Jan-Ru's widow, Nel. People need time to come to grips with an event as large and impressive as this one.

The law and other dangers such as failure.
In the aftermath of a case of self-euthanasia, in The Netherlands the attending physician and coroner aren't the real problem. But there is the Law: the police, the public prosecutor, the forensic experts. How trigger-happy are they? This remains as yet one

of the difficulties the family and loved-ones have to face, as they turn from relatives into surviving relatives.

At this moment the 'unproblematic' standard procedure is an investigation that takes about two hours or more. It means control of your home is taken over by a force of six to fifteen officials, mostly uniformed.
For some-one who has just suffered an important loss, being questioned as a would-be criminal is highly unpleasant. Not to mention when your taken down to the station for further questioning and (an exception) autopsy being announced. (Slide 8, 14)
It is part of our job as counsellors to prepare our clients for events like these. Just as we have to inform them of other legal issues, for instance in connection with the obtaining of the lethal medication of their choice.

However, even taking this aftermath into account, my story sounds like an uncomplicated happy one. And that raises my last question: do things ever seriously go wrong? (Slide 8, 14) The individual failing to die, awaking, or threatening to awake, after a long deep sleep?

There is a well-known case in which I was involved as counsellor where it looked as though my client indeed would not die and re-awake. This situation lasted for some 48 hours. A film has been made of this case (it seems the Dutch are in the habit of making films of this nature), with a happy end as Paul, suffering from dementia, did after all die. The film was aptly named *Before I forget…* This all happened in 2008. (It happens that Paul's daughter is now one of my colleagues.)

Another case that pops up in the press now and then is the case of a male psychiatric patient who did indeed take is lethal medication as he should, but did not die. Hospital nor psychiatric clinic were prepared to consider physicians-euthanasia and the man tragically jumped in front of a train and died. This happened in 2009.

Nowadays (2014) in both cases better lethal medication would undoubtedly be used. Failures are very rare indeed. As far as we can establish they result from being found too soon by the wrong people, or not correctly following the procedure of self-euthanasia. For instance: not taking your medication securely seated in bed, but downstairs, thinking you can still go upstairs to your bedroom and never reaching the stairs or falling off it, vomiting as a result. Or not taking an anti-emetic at all. Or pausing for a moment when taking the medication and thus falling asleep before finishing it.

And there is 'Murphy's Law': recently a client of mine very carefully followed the procedure. Nothing was left out. But she did leave something on: a lamp that was never on during the night and now alarmed her neighbours, who, etc. etc.

Ultimately, it is definitely only the client's responsibility to take this most important decision. (Slide 8, 15)

But notwithstanding these exceptional circumstances that are really exceptions, I can safely say that self-euthanasia has reached a stage where it is available as a reliable possibility next to physicians-euthanasia.

For moral reasons – I am a philosopher, after all – self-euthanasia may even be the option to be preferred. The difference between ending another person's life or your own, is of course significant. But I will have to let this issue rest today.

Thank you for your attention. The remaining time I am of course willing to try to answer questions, if there are any.