



Rob Jonquière

Diplomat in End-of-Life Affairs

Chronicled by Els Wiegant



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Rob has played a crucial role...

Rob Jonquière's announced date to step down as Executive Director of the World Federation of Right to Die Societies has arrived. We would have wanted him to stay on because his contribution has been essential in the development and performance of our Federation, to which he has given a significant boost in its organization and professionalization.

However, we fully understand Rob's decision to leave a position that he has carried out with such dedication and care, sharing his great experience and knowledge. He has played a crucial role in coordinating our member societies and implementing steps that have contributed in a meaningful way to advancing our cause: that more and more people around the world are free to live their lives, confident that they have the choice to die in a gentle way if, and when they choose to do so.

We recognize that Rob deserves to have more time to do whatever he wants to do, and we are happy for him. The WF will always be grateful for all he has given us, and this book is a gift as a token of that gratitude. We want Rob to leave with a book written by him about his life, his work, and his great contribution to the medically assisted dying movement, and to the WF.

As you read the book, you will realize that the ones who gain the most from it are the readers. Through its reading, they will have the opportunity to learn about different stages of Rob's life, his commitment to educate health professionals, policymakers, and society at large about better end of lives, and the history of the WF.

This is an enjoyable book to read; an honest account of how Rob became what he is, the various positions he has held, his challenges and achievements. In addition to all the learning that comes from reading it, one cannot, in the end, but admire and appreciate him more.

Thanks to all members who have contributed to the publication of this book.

I have nothing left but to wish all readers to enjoy this book!

Chapter 1

Musician? Teacher? No, doctor!

A liberal and intellectual family provides the fertile ground for Rob's later career. Music plays a big part in it. So big that Rob even considered going to the music academy. It eventually becomes studying medicine, but the cello continues to accompany him throughout his life.

Academic environment

'I was born on April 4, 1944, during the hunger winter. The environment I come from can be described as intellectual, academic. My father worked as a chemist for the BPM, the Bataafse Petroleum Maatschappij, in Beverwijk, North Holland. In addition to that job, he was also a reserve officer. In the last days of the war, he was approached by a fellow chemist. Together with him he founded the Chemical Laboratory of the National Defense Organization in Delft, part of TNO, in 1946. That lab mainly did research on protecting the population against chemical weapons. Because of his work, our family moved first to Leiden and when I was in the third grade of elementary school, to Delft.

My mother, born in the Dutch East Indies like my father, came to the Netherlands at eighteen to study medicine in Leiden. Not so common in those days. She herself also came from an academic environment: her father was a judge. After graduating, she never practiced as a doctor, but she did research for a while at Leiden University. In 1956, there was a polio epidemic in the Netherlands. All children had to be vaccinated. As a doctor, she was then asked to become part of the grafting community in Delft. My mother vaccinated a lot of my classmates. She was also socially active. For example, she was a member of the Association of Women with Academic Training and served on the Delft Women's Advisory Committee on Housing. Through that work, she later served on the Delft City Council for the PvdA (Dutch Labour party, ed.) for a number of years. My mother was quite activist. Very early on, almost from the beginning, she had become a principled member of the Dutch euthanasia society, NVVE. Given my later career, it is remarkable actually that we never discussed that subject much in the family context.'

Tuberculosis

'The fact that my mother had studied medicine, she said, contributed to my being diagnosed with tuberculosis when I was two. With high red cheeks, I was just standing quietly in the playpen and she didn't trust it. Her professional uneasiness feeling turned out to be correct. For two years I was admitted to Het Zeehospitium in Katwijk, an institution where "pale noses" from Leiden were cared for who were infected with tuberculosis. Rest, Regularity and Cleanliness, and especially good nutrition were the main ingredients of the treatment in those days: with my bed on the balcony in the fresh open air, milk with cream – a luxury just after the war. With my almost white curly head, I was undoubtedly the nurses' darling. I must have had a life like being in paradise. Apart from the panic that arose every time we were later tested for TB at school with a Mantoux shot – there were still TB antibodies in my blood – I never suffered from that tuberculosis again in the rest of my life. Fortunately.'

The gymnasium

'In our family, it made perfect sense to go to college. My oldest brother did architecture, the youngest brother did medicine, as did my mother and me. My choice of high school fell on the grammar school my brother attended, partly because the local lyceums were Christian or Catholic. I was not raised religiously. I did attend a Remonstrant catechism for a while, because my parents felt that knowledge was helpful. Christianity is so mixed with our western culture.

My high school days were not entirely smooth. I could learn, but I didn't do much, at least not enough

My high school days were not entirely smooth. I could learn, but I didn't do much, at least not enough. In the second grade I was held back, and in the third grade I was put back a grade. I was even threatened with a transfer to the hbs (a certain type of high school, ed.), which at the time was considered a demotion. I insisted on staying at the gymnasium, which was the "crowd" I belonged to. That's where my friends and contacts were. Eventually it dawned on me that I would have to do something. Then I started studying very seriously and never looked back.'

Proud as a peacock I came home with a cello. Something clicked between us

The cello

'What played into my lack of concentration on school-work was that I preferred doing other things, playing

the cello especially. My father played the violin but didn't do much with it anymore. My oldest brother was put into piano lessons, and by age eight the question was: which instrument should we choose for Rob? Since we could then form a trio within our family, it became the cello. A nice lady came to our house, looked at my left hand, spread my fingers and determined: that's fine.

With my father I went to his violin maker in The Hague. Proud as a peacock I came home with a cello, well, a little one. Something clicked between me and that instrument. In all those years of my youth, during my studies and even now, music has always been present.

At grammar school, I played the cello with great enthusiasm and love. I was in the school orchestra and participated in the semi-annual music evening. Not without success, for many years I participated in the annual music competition in Delft. When things weren't going so well at grammar school, I even considered a move to the music academy. People around me advised against it. One said: "Everyone wants to become a soloist, but that is only for the happy few. If you enjoy spending the rest of your life behind the last desk of a second-rate orchestra, teaching boys and girls who are sent to lessons by their parents, then you should go to the music academy."

Student Orchestra

'To this day, I'm glad I gave up that option. Playing the cello as a hobby is much more fun than as a means of livelihood. In my Leiden student days, I was a member of the Dutch Student Orchestra and later Sempre Crescendo.

I even had to become a member of the student body for it. I did not feel happy with that kind of life because I never drank alcohol. So a few months later, after the annual concert, I cancelled my membership.

Meanwhile in Leiden, I had joined the Collegium Musicum, a choir and orchestra at the university – it still exists. That's where I found my friends. It was the background of my student existence, so it made sense to me to get involved in it on an organizational level as well. The Collegium had 120 members, all kinds of things had to be arranged for it. Later I became its president, and on my retirement an honorary member. The presidency did cost me a year of my studies,

I think, but it was a year in which I was able to develop in a different way. I learned a lot there that proved valuable later in my life: governing, organizing larger events and participating in social activities.

Looking back, I can see that this is a constant in my life: if I became involved in something, I often also became a director, chairman or board member. Not because I want to be the first in line, but often because no one else wanted to take on the task.'

Studying medicine

'In addition to my interest in the music academy, I toyed with the thought of becoming a teacher, but ultimately followed the advice of a vocational counsellor during my high school years. "Something in the nursing or medical field" he had said. That brought about the turnaround in my choice of studies – and thus in the rest of my life – years later. At one point there was no more doubt: I'm going to Leiden, to study medicine. From the beginning of my studies, I knew I wanted to become a general practitioner. Back then it was assumed that you became a general practitioner if you "couldn't do anything else", because the profession was not a specialization then. But becoming a specialist in a hospital never attracted me. Nor did its status – status in general – ever play a role in my choices.

I did have some doubts during my fellowships in neurosurgery and surgery. I found that super-specialistic work fascinating and the manual dexterity of operating appealed to me. Later in my practice, I did a lot of minor surgical procedures.

But what I found interesting about general medicine was that personal, accessible and direct contact with your patients; being there for them. For that reason, I also wanted to become a village doctor. There you can take your time, relax and pay attention to your patients. In a big city, everything is much more hectic and busy. I came back from that ambition when I once heard family members who lived in a village, speak outrageously about the doctor's wife. She was wearing trousers! Your actions and behavior, and that of your family, as a village doctor were very much under a magnifying glass, I realized.'

Chapter 2

A quirky family doctor

After studying medicine, in 1972, Rob settled as a general practitioner in Hengelo, Overijssel. He worked there for thirteen years. With his different patient population, his idiosyncratic view of the profession and an unusual choice in his private life, he is a maverick. But also, a very active doctor, who maintains a good relationship with his patients.

Free establishment

'In the early 1970s, I was now married, I heard from my parents that there was room for a new general practice in Hengelo, Overijssel. By now they were living in Delden, not far from there. I decided to settle there freely, and less than a week later one of the other family doctors in town announced his departure. He had a relatively small practice and I was allowed to take over his eight hundred patients. These were mostly Turkish – what was then still called – “guest workers”, working in the metal industry. He also had many healthcare workers in his practice. With that, I was in the luxury of a, as it was called, super-supported free practice set up. My patient base grew steadily, and within a year I had eighteen hundred patients registered. For more than thirteen years I ran the practice in Hengelo. Initially I did so together with my wife. We had three children: two girls and a boy. In the early 1980s we divorced and not much later I met Kees. She also lived in Hengelo and had two young children. Kees and I are still happily together.

I consider the divorce to be the blackest period in my life, especially because it caused the loss of contact with my children. My ex-wife and I were both active in local clubs, especially in music. We had many mutual friends. To the outside world, we were the ideal picture: a healthy family with three children, a beautiful house, a thriving practice. With the collapse of that, many friends and acquaintances could not cope. Even some fellow family doctors distanced themselves from me. I was known as “that divorced doctor”, the only one in Hengelo and the surrounding area. The growth of my practice also decreased slightly, but fortunately the contact with most patients has always remained good.'

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Consultation hours for Turkish patients

'An "odd bird" I was somewhat anyway. I wasn't aiming for that, but I did what I felt comfortable with and what I thought was important. What others thought about that didn't interest me much. Perhaps you could say that the family and environment from which I came, formed a basis for a certain unshakeable self-confidence.

In addition to my work as a general practitioner, I was active in areas close to my profession. For example, I was a board member of the Green Cross (an association for the promotion of public health, prevention of diseases and the provision of information, ed.) and I was in a group that participated in the establishment of a health center in a new housing estate. I became chairman of that – of course,

I say with hindsight – and I put a lot of time into it. All those perks I really enjoyed.

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I also did things that other GPs didn't do. For example, I set up a special consultation hour for Turkish patients.

There were many from the

beginning, but their number increased over time. In fact, one of the large industries in Hengelo employed a foreman who spoke Dutch very well. He regularly came to my practice with one of his colleagues and acted as interpreter. The man had become half a doctor himself. Whenever new compatriots came to Holland, he had them registered with me as patients. That was easy for him. At one point I held a special consultation hour twice a week, at five in the afternoon, for this group of patients.'

Patient participation

'I was also one of the first in the Netherlands to start with a form of patient participation. At the Nederlands Huisartsen Genootschap (association of GPs, ed.), in which I was active, the idea had taken root that as a general practitioner you cannot solve everything yourself. In order to strengthen the first line of our care system, health centers were established all over the country at that time. Disciplines such as general practitioners, district nursing and social work worked together there. This also gave rise to the idea that it was better for general practitioners to refer people with mental or psychological problems to social workers.

During an evening when we were discussing this with fellow GPs, the wife of a colleague wondered what patients would actually think of such a referral. Gee, good question, I thought. Then I invited a group of seven, eight patients to talk about topics relevant to patients in our general practice. They even thought about choosing a new physician's assistant, and we put out a quarterly bulletin with general health and practice information for all patients. The group existed until I left Hengelo.

That kind of participation was so new that it was even picked up by the national press. There were fellow GPs who took offence at that. In those days it was already considered unauthorized advertising if you placed an

ad that you were going on vacation and three weeks later that you were back. I did not conform so much to those rules; I was not an average doctor.

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I had the strong impression that my form of patient participation also had an effect on my work as a general practitioner: that the way I treated my patients influenced the way they treated me. I felt that my colleagues'

patients were getting better thanks to the doctor's help and that I was guiding my patients to get or stay better themselves. I noticed that difference at least during evening and weekend shifts, for example, when I was deputizing for other family doctors. My attempt to support that assumption with scientific research – I spent a year trying to start a doctoral program – unfortunately failed on epidemiological grounds. It did leave me with a lifelong interest in research.'

Chapter 3

Manager between two fires

After his time as a general practitioner, Rob moves to the management side. Via the general practitioner training program at the Vrije Universiteit in Amsterdam and the Universiteit Leiden, he ends up at the Riagg, an institution for ambulant mental health care. When friction arises over tasks and responsibilities with his superior, just as with his previous employers, he has had enough. He is ready for a real management position and at the right moment he receives a surprising phone call.

Coordinator of general practitioner training at VU

'During my last years in Hengelo, I was also a GP trainer. From an early age, the idea of passing on your knowledge and experience to others appealed to me, and I was now putting that into practice. Through the trainee position I had contacts with the Vrije Universiteit in Amsterdam, where my GPs-in-training came from. I sometimes spoke with them about the content of their work and about scientific research at the university.

When a position as head of the family medicine school became available in 1985, I applied. That position brought together all the things I wanted to do. In order to remain recognized as a family doctor and be able to provide patient care, I was going to work a few day parts in a practice in Amstelveen. Unfortunately, I stopped doing that rather quickly. Patients preferred to visit their own doctor and wait a day, so they didn't come to me and I couldn't build a relationship with them. That didn't feel meaningful. Definitely quitting direct patient contact – which, of course, I had already done largely due to the departure from my own practice – was a bit of a swallow, but the loss was offset by everything else I could do at the Vrije Universiteit. Besides, I was busy with my profession all day, could think about it and speak about it.

It wasn't the reason for my career switch, but it certainly helped that some of the problems created by my divorce were solved by our leaving Hengelo. It also felt like a relief that I no longer had to be on call 24/7. I had done that for years with love and without grumbling, but when I no longer had to, I only noticed how hard that had been.'

Acting Chair of Department

'When I had just started at the family medicine school, the Ministry of Education made a substantial budget available for the further development of primary academic education. A discussion arose within the Vrije Universiteit about who exactly the money belonged to, the university or the family medicine department. That led ultimately to the departure of the then professor of family medicine. Because this left the department "leaderless", I became acting chairman.

I found that an instructive job. It was not only attractive in terms of content, but I also had contacts with all the other departments, with the whole university. There were some people who thought that this position would be difficult for me because I did not have a PhD, let alone a professorship, but I was not bothered by that. Our department had become a factor to be reckoned with within the Vrije Universiteit. Looking back, I think I did quite well.'

Training extended with a year

'In the years that I worked there, we – the eight heads of GP training together – extended the training from two to three years. We felt this was necessary for the status of the family medicine profession. Longer training underscores that it is a serious specialty. Other specialties also require at least three or more years of study.

With two years of training, we were also constantly coming up against the number of topics we wanted to cover and especially the depth of them. As head, I was regularly asked by fellow specialists whether we could pay more attention in training to a particular topic in their field. Or from patient groups who thought general practitioners should know more about Parkinson's disease, for example. They were often right, but you always ran out of training time.

We had intensive and fruitful discussions about this nationwide: what learning goals do you want to achieve, how do you go about it, what forms of work do you use? The extended training consisted of a theoretical part during a weekly return day at the institute and a practical part during the remaining four days in the training practice. Even in a three-year course you cannot put everything

Longer training underscores that a GP is a serious specialty. Other specialties also require at least three years of study

I made the mistake of wanting to please him and as a result I slowly but surely snapped

you would like into it, so the curriculum was partly aimed at teaching doctors how to learn: *an éducation permanente*. We were also going to teach the GP educators better how to educate, with a program called Teaching-the-Teachers. In it, a lot of attention was paid to the technique of teaching and learning conversations. Because, as an educator you're not there if you say to your physician assistant: "Here's your room, these are your patients and let me know if you want to ask something."

In my opinion, the extended training and better training of family physician educators certainly contributed to the recognition of family medicine as a specialty. Later I did such a similar exercise again, when I became responsible for setting up a new training program for nursing home physicians at the same Vrije Universiteit.'

Discussions about money

'My departure from the Amsterdam School of Medicine in 1993 was the result of two things. First, the eternal discussions at the university about money. The organization of GP training and the funding from the national government were a somewhat opaque whole. As a result, there was constant disagreement between some universities and the general medical schools located there about the question: whose budget was made available? In fact, our professional training programs received much more money than basic training and scientific research; we were the richer brother. And that created friction. Because of the games that were played about that, I became fed up with the university and academic world.

Second, after some time at the Vrije Universiteit, a new professor of family medicine had been appointed. Although he said he greatly appreciated all that I had accomplished during my interim period and we had made clear working agreements about my new role within the institute, with him I always felt "just" the coordinator of one of his departments.

I made the mistake of wanting to please him and as a result I slowly but surely snapped. Then my mother died and I sat at home for a few days, waiting for the funeral. I was supposed to go back to work the following Monday, but suddenly I couldn't anymore. I was finally spent. Very instructive, from a professional point of view, to see how

you get into such a situation and everyone around you has long since noticed that things are going wrong, except you. I sat at home completely paralyzed for a few months, with a great sense of failure.'

To a management position

'When I had recovered and wanted to return to my original job, it had since been filled. The Vrije Universiteit offered me an exit program: sifting through newspapers, cutting out ads, writing application letters. I was looking for a management job, but that wasn't easy because my experiences were all in the niche of the family medicine profession. Eventually, a former colleague, who in the meantime had become a professor at the University of Leiden, offered me the chance to become the deputy head of family medicine training there. Over time, discussions arose there as well about who had authority and responsibility over what, and I finally decided to seek my future outside academia. I thought I had found it at the Riagg (Regionale Instelling voor Ambulante Geestelijke Gezondheidszorg, ed.) in Leiden, where I became manager of the elderly care sector in 1995. I was given the specific task of converting the outpatient, intra- and extramural Mental Health Care for the Elderly in Leiden and its surroundings into one regional center for geriatric psychiatry. It had to become a central place where admissions, outpatient treatment and extramural care would be integrated. Setting up something new, I lovingly put my energy and time into it.

Unfortunately, the same pattern gradually emerged there as well. Again, I worked under a director who, although promising to give me a free hand with my department and assignment, started to interfere more and more with the content. There, too, I was in a middle management position, with a supervisor above me whom I had to keep happy and, below me, the people I managed. What came from above and what came from below were often difficult to reconcile.

I didn't want that anymore; I felt I had proved sufficiently that I could and wanted final responsibility. When the Riagg had hired a headhunter for another vacancy, I inquired with her about my chances on the job market. I was in my mid-fifties. Just a few weeks after I sent my resume, I received a call. "I have one question for you", the headhunter said, "how do you feel about euthanasia?" "Positive, I've done it myself," I replied. "Good, then I have a nice job for you: director of the NVVE." That's where my Right-to-Die career began.'

Chapter 4

Encounters with death

Death and dying become a common thread in Rob's later career. It is y during his residency that he is first confronted with it. He learns to think about what being sick and dying mean to people. More and more, he becomes aware that talking about it is part of his profession. Counseling the dying does not mean that he acts, but much more that he is there for the patient.

Balint Group

'During my first internships, I joined a what was called a Balint Group, a kind of precursor to today's peer review groups. We met regularly with a number of like-minded fellow students to exchange experiences, opinions and doubts. It was mainly about the doctor-patient relationship.

Until then I had only dealt with the purely medical content of our profession, the physical part. At university you learned that this is how the body works, that this is what happens when you get sick and that this is what you have to do to cure the illness. During my internships I became aware that the contact with the patient goes far beyond the purely medical. I became aware that behind every disease there is a sick man, woman or child. I learned that working with the sick is above all about people. That sounds like an open door now, but at that time, as students, we were not concerned with that at all. Participation in the Balint group was the start for me to consciously think about what it means for people to be sick. And dying is part of that.'

The 'white tide'

'One event still stands strongly in my mind in that regard. It was during my internship in internal medicine at the university hospital in Leiden. As a resident, you were, certainly at that time, the lowest in rank. You walked at the back of what was called the "white tide": the professor who, with his entourage of highest to lowest (residents) – all dressed in white coats – made a tour of the patients in the ward.

I also walked in it, with a friend from the Balint Group. It was our responsibility to monitor some patients in the

ward. Among them was a woman who was terminal; her death was imminent. I had regular conversations with her. When the white tide arrived at her bedside, the professor glanced at her patient chart and said: "The blood values look good ma'am, good day." And he walked on, the white tide following behind. But my friend and I saw that at that moment she was dying. So we sat down by her bedside, held her hand and stayed there until she died.

Somewhere during that period, the conviction arose that I did not want to work in a hospital, especially a teaching hospital. It repulsed me so much

When we rejoined the white tide, the professor asked where we had been. We told him we were with a dying patient, to which he said: "That's okay, but you're here to be educated, so you're supposed to follow me." That experience made me think: this is not how I want to practice my profession. Somewhere during that period, the conviction arose that I did not want to work in a hospital, especially a teaching hospital. It repulsed me so much.

No fear of death

'The experience with that lady was, in retrospect, a moment when I became very consciously acquainted with dying and what it entails. In my youth I had only experienced one death closely: that of my beloved grandmother, on my father's side. I remember there was discussion about whether I wanted to go to her, I was about ten years old and had never seen a dead person before. Somehow, I didn't think that was a problem; I had no fear or aversion to death.

Later, in other internships, I was more often given responsibility for a part of the ward and found it important to pay particular attention to the seriously ill: sitting down with them and having a chat. In those days, these were never conversations about euthanasia, by the way; it was much more what you would now call "support in dying".

Especially talking about how you are dying, what you are afraid of, how your loved ones are coping, what you want to leave behind. I wanted to give people the space to speak freely about all those kinds of things.

During and after my fellowship in surgery, this continued. My supervisor was an excellent surgeon, a gifted specialist. As a (co)assistant I was responsible for the patients on the

ward. Two or three times a week I made a visit with the surgeon. Before we walked into the ward or went into a room, we reviewed – with the patient’s notes in hand – what was going on. Usually, the surgeon would walk in afterwards; after all, he was the practitioner. Something similar happened then: we came to the room of a lady who was also terminal and with whom I had had many conversations. When the surgeon had gone over the status, he said: “Well, that looks all right.” He did not enter the room; he left that to me. That incident typified the big difference between the specialist and the general practitioner that prevailed at the time: specialists are good at their skills, but they often didn’t have the time or inclination or the qualities to talk at length with patients about their feelings. And that’s exactly what I wanted.’

‘The disease K’

‘During that time, I became increasingly aware that conversations with patients about dying, about the road to death, are part of our medical profession. It is part of bereavement counseling and for me that does not mean that I do a lot, but that I am there. That I listen carefully, that I let the dying person set the pace. The initiative lies with the patient, I am subservient to that.

I also learned what *nó*t to do, at least not with everyone. At that time, the word “cancer” was often avoided, people spoke somewhat smugly about “the K disease.” In my ward was a lady with pancreatic cancer. I had already had many sincere, good and pleasant conversations with her, also – or especially – about the seriousness of her illness. All this time I had carefully avoided the word “cancer”. But somewhere, in an unguarded moment, I accidentally dropped it. Also thinking that she would know by now how things stood, after all the conversations we had had. She collapsed. All this time she had realized that she was very sick and probably wouldn’t get better, but she had never understood that she had cancer. From that experience I learned how alert you must be in your communication with the patient, how carefully you have to think. End-of-life conversations can be difficult, but it’s not a reason to avoid them.’

*It is part of bereavement counseling
and for me that does not mean that
I do a lot, but that I am there*

That deep, real contact

'Bereavement counseling is also an art. I once took a course on that in my GP days at the famous St. Christopher's Hospice in London, from Dame Cicely Saunders. She was a pioneer in the field of palliative care. A valuable lesson from her course for me was that, as a general practitioner, you must have a kind of filing cabinet in your head. If you are with someone who is dying, you open the drawer "palliative care". Then you are only concerned with that: with that conversation, with that patient, at that moment. Everything else is irrelevant. When the conversation is over, you leave with the promise to come back tomorrow. The drawer closes and another drawer, for the next visit, opens. This does not mean that the conversation is completely gone, but you do not focus on it again until you are with that patient again.

I've always taken that insight with me. I think that from very early on I went in that - what you call nowadays - "holistic" direction. All those experiences eventually led me to the realization that the contact with the patient, that deep, real contact, is so important to me. And I found that kind of contact in family medicine.'

Chapter 5

The final step: euthanasia

Twice in his life, Rob gives euthanasia to a patient. Although it is still illegal at the time, he does not hesitate when he receives the request. He knows early on that as a doctor you do everything you can to make your patient's suffering bearable and that the suffering has become hopeless when you can no longer do that. In that case, he firmly believes, euthanasia can be the last step in your medical action.

Something illegal

'In my medical career I have assisted two patients with their self-chosen end of life. The last time I would call a euthanasia, the first time I now consider more a form of ultimate pain relief. It was the early 1970s. Reports appeared in the press about the euthanasia that Frisian family doctor Truus Postma had given to her 78-year-old mother and the lawsuit that followed. Truus received a one-week suspended prison sentence. With that verdict, and later with others, the first standards of care for physician-assisted termination of life took shape. Euthanasia was not a forbidden topic of conversation, but little was yet written about it.

Because they themselves worked in healthcare, many of the patients in my Hengelo practice regularly met with seriously ill people themselves. They thought and talked about end-of-life issues more often than average. One of them was a nurse, in her mid-forties, with advanced colon cancer. Pretty soon the future looked very bleak for her; she had metastases everywhere. In the hospital she was under the care of a surgeon; as her primary care physician, I did the bereavement counseling at home. I had regular conversations with her; about dying, death, about what she still wanted in her life and what no longer.

At one point she presented me with the question of whether I would be willing to euthanize her if she could no longer bear the pain. We both knew, of course, that she was asking me to do something illegal, but strangely enough, I didn't have to think long about it. Also, because her boyfriend and family were behind her request. My answer was yes, because even then I considered euthanasia to be a final step in a dying process. That I would be doing something you could go to jail for, didn't stop me from pledging my cooperation.'

Large amounts of morphine

'But the question was: how does one do that, kill someone in a medically responsible way. From what I had heard here and there during my training, I knew that you had to be careful with the use of morphine as a painkiller. While theoretically you can kill someone with an overdose, if the patient has already had a lot of morphine in the previous period, high tolerance may have developed. Then the morphine – despite high doses – may no longer work. I had taken that into account with my patient, I had used other drugs for pain control.

When she was ready for euthanasia, weeks after her request, and had said goodbye to her family, it had to happen.

I picked up a dozen ampules of morphine at the practice and administered that huge amount – a large overdose, in other words. She fell into a deep sleep, but she did not die. Her boyfriend and I sat by her bedside, and I was overcome by a kind of panic fear that she would wake up again, which seemed terrible to me and had to be averted with all means.

Twice I went to the pharmacy to get extra morphine, but even that was not enough. Since, of course, what I was doing was not entirely legal, I could not consult with anyone.

Eventually, I got the phone number of Piet Admiraal through word of mouth. He was a well-known anesthesiologist and had been advocating euthanasia since the late 1960s.

Admiraal knew how to perform a euthanasia medically responsibly; he once wrote a brochure for doctors about it on behalf of the NVVE.

I remember him saying: "There's another one of those doctors messing around with morphine." Or words to that effect.

Other painkillers sensitize just as much as morphine, he explained, so what I had done didn't work. "You'll have to administer a muscle relaxant," was his advice. But then again, as a general practitioner, you don't just have those on hand. So, I went to the pharmacist again. He had already understood what I was doing and obtained a muscle relaxant from a fellow pharmacist at the hospital. Together with a barbiturate I injected it into my patient so that I was finally able to give her euthanasia according to the rules of art – *lege artis*. She fortunately died peacefully.

I was not as brave as GP Piet Schoonheim in 1984 and psychiatrist Boudewijn Chabot ten years later, by the way. I did not report her death as euthanasia, but as natural death. My patient had even explicitly asked me to do so, if I remember correctly, because she did not want me to get into trouble. I may have been lucky that there was never any hassle about it.'

'Your life, your wish'

'My second dying aid was to another patient, in the late 1970s. Bep was her name, and she was a district nurse. Bep had been treated for Hodgkin's (lymphoma, ed.) and recovered from that. Then she had breast cancer, an amputation, chemotherapy and recovered from that too. Until she developed very severe abdominal pain and was found to have ovarian cancer. Supposedly, she was a carrier of the BRCA gene, but that was not checked at the time.

Despite having to undergo increasingly tough treatments and us talking regularly about the question how much sense it still makes, she wanted to keep going. She said: "I overcame that Hodgkin's and that breast cancer; I can make it through this too."

Her condition continued to deteriorate and at one point she asked me: "Where do you stand on euthanasia?" I was able to answer her that I was not against it, that I had already

You decide when the time comes. When it is no longer bearable for you, then I am ready

done it once and that I was willing to perform it on her as well. I said to her: "It's your life, it's your wish, you decide when the time comes. When it is no longer bearable for you, then I am ready."

Fresh snowdrops

'I began to make preparations and I agreed with Bep that we would continue to talk to each other. I asked her if she had a picture of the circumstances in which it would really be enough for her. She was able to describe them well. She had worked in health care all her life and dealt with dying people; she knew what to expect.

What she would not find acceptable was for her to be completely cared for by others, to be dependent on them. As time passed, I visited her regularly and later visited her almost daily. She could no longer do anything, lay in bed all day, and was washed and fed by the friend with whom she lived. I thought these are the circumstances she described. Yet she did not indicate that she was ready for euthanasia. After a week or two-three I brought it up anyway.

"Bep, I absolutely don't want to put any pressure on you, but I don't hear you talking about euthanasia anymore," I said. "You're right," she replied. "But it's all much less bad than I imagined. I love lying here and enjoying all the friends around me and the view. I can live like this for a while longer."

Several times she re-described when it would be enough for her, and each time she shifted that moment as well. The last time was in early spring; I will never forget it. She said she wanted to see a bunch of fresh snowdrops on her bedside table one more time. And that's how it happened.

One Tuesday morning, I received a call from the pastor, who had an active role in her counseling and – quite unusually – knew of her euthanasia request. “Rob, the time has come. Bep wants euthanasia now. Are you coming?” I said I would handle the few patients in my waiting room and then come right over. Moments later I got another call: where was I? Bep was a little worried, afraid I might change my mind at the last minute.

By now my waiting room was empty and I left immediately. Then I sat and talked with Bep for another hour and a half. When I asked her why she had repeatedly postponed the moment of euthanasia during those past five or six months, she replied: “Because I had the confidence that you would help me when I indicated that it was my time. That trust gave me the freedom to say: I want to wait a little longer.”

Bep taught me that just the confidence that you will give euthanasia when your patient is ready for it, makes people able to cope with suffering longer than they ever imagined.’

Euthanasia request denied

‘Bep died peacefully. I told her story many times at presentations. She was an example of how a good euthanasia process can be done and what euthanasia, just as a *possibility* at the end, can mean to someone.

I was not, certainly at that time, an active lobbyist for euthanasia. I never actively offered it to patients, always left it up to the patient to bring it up or ask for it themselves. That may have been three or four other patients in my practice. But it didn't come of a euthanasia with them because they died before the suffering had become unbearable for them.

Only once did I explicitly refuse a request for euthanasia that was legitimate in itself. This came from a patient of a fellow GP for whom I was acting as a substitute. I could not and would not give euthanasia to someone whom I did not know, or did not know sufficiently well, and with whom I had not had enough time to build a relationship of trust. All in all, I did a lot of bereavement counseling, helping people die well, in a way that was acceptable to them. Of all those cases, only twice did it lead to euthanasia.’

Chapter 6

On the breach for a dignified end of life

So looking back, it is not illogical that Rob, a physician, gets the job of director of the Dutch Society for a Voluntary End of Life (NVVE), then called the Dutch Society for Voluntary Euthanasia. He holds the position from 1999 to 2008. It is the beginning of his career as an advocate for euthanasia and a dignified end of life, not only in the Netherlands, but later in the rest of the world.

Strange duck in the crop

'When the lady from the headhunter's office asked me to apply for the vacancy of director at NVVE, I had no idea what the job entailed. It soon turned out to be an association with some 80,000 members, about twenty office staff and a large number of volunteers. That attracted me. I liked the fact that it was a euthanasia society because, of course, I had personal experiences with that subject. But I was also interested in it because I wanted to make NVVE and its office a well-run organization. It was somewhat chaotic there at the time, I thought, and it seemed like a nice challenge to be able to put my management skills to full use there.

During several job interviews with delegations from the agency, I told them about my ideas about end-of-life care in general and about my experiences with dying, assisted dying and euthanasia in particular. Each time the question also arose as to what I, as a doctor, thought I had to do with an advocacy organization for patients; I would be an odd duck among activists. Some regarded doctors as these nasty people who didn't dare to give euthanasia. There were also volunteers who thought it would be handy to have a doctor in the house. He could write a stack of prescriptions for barbiturate (a suicide drug, ed.) for members who wanted to end their own lives. Of course, that couldn't be done at all, and that really angered some volunteers. I was said to be too much doctor and not enough activist. The fact that I was a doctor was something I personally found to be an important plus in being able to form a good liaison between the medical world and that of the patients.'

NVVE-colleague Walburg de Jong:

‘We were looking for a director who inspired confidence’

During his NVVE tenure, Rob worked closely with Walburg de Jong, who was with NVVE from 1980 until her retirement in 2013. She was involved in Rob’s job interviews in 1999.

Not a bunch of activists

‘Before Rob came, we had had a couple of directors. People from the business world who didn’t know much about the subject of euthanasia, and certainly not from their own experience. Especially with the last two interim directors, we had noticed through trial and error that we needed someone who knew what he was talking about. So that we could not be put away as a bunch of activists.

We needed someone who could show that we were a decent club, a reliable interlocutor

We were looking for a director who could communicate a reasoned and expert position on euthanasia, someone who inspired confidence. Someone also who was credible to doctors. Because in principle, the KNMG *doctors’ organization* was not at all willing to enter into discussion with the NVVE *patients’ organization*. You had to be a doctor to get a seat at the table there. In their eyes, euthanasia was a doctor’s issue; patients didn’t have that much to do with it. Certainly, also to foreign countries it was more credible if a doctor who had experience of it himself, defended euthanasia and could explain how it worked in practice in the Netherlands. We needed someone who could show that we were a decent club, a reliable interlocutor. Even to our own staff and volunteers, it was better to have someone at the helm who knew what they were talking about. Who understood the questions our counselors were confronted with on the phone and in members’ homes. They had often felt misunderstood before.’

Sense of commonality

‘The agency I found, consisted of active, enthusiastic people. Idealists with a pragmatic streak, each had developed and picked up their own tasks over time. There was a psychologist, a member support service, a telephone service, administrative and financial staff and a facilities officer. Among other things, Walburg coordinated the volunteers.

There was little structure in the organization, and I saw it as my job to professionalize it: create an organizational chart, have a personnel manual and files created, hold performance reviews, set up an information process, things like that.

At the same time, it was like a club with a strong sense of community, especially when the euthanasia bill was proposed. For me, this was most symbolized by the daily ritual of cutting newspapers. Together we all started the day at the office kitchen table. We had subscriptions to all the daily and weekly newspapers and browsed through them, cup of coffee in hand, looking for relevant news for our cutting paper. At that table opinions were formed and exchanged; at that table the craziest ideas were born. Sometimes the cutting got a little out of hand and we were still sitting there at lunchtime. But the advantage was that no expensive team-building days had to be organized, because the mutual bond was maintained daily at the kitchen table. We also had a lot of fun; we laughed a lot. People sometimes asked me if I wasn't horrified by it: being preoccupied with death all day. But that wasn't us at all. Of course, if you talked to and about members with a death wish, you took it extremely seriously. But perhaps to put things into perspective, we also looked for some levity. For example, at that time we recruited Peter de Wit as a cartoonist for our membership magazine *Relevant*. He had a wonderful way of making fun of the subject. That sometimes led to angry letters or even an occasional cancellation, but that was never a reason for me to say: we are stopping these cartoons.'

Monthly regional meetings

'Completely new to me, of course, was working for an association with members. I noticed how big it was when I once proposed in all my innocence to inform the members "just" by letter about a program change for the general assembly. Did I realize that 80,000 letters, with 80,000 envelopes and 80,000 stamps would mean an expense of € 50,000? No, I hadn't realized that.

With members, I naturally had contact at the annual membership meeting. But we also started organizing monthly regional meetings around the country. We gave information to members and interested parties and each time about two or three hundred people attended. We went there with a regular club from the office. All of us and all the information material in my car: we were like a traveling theatre company.

**Pill of Drion: Huib Drion (1917-2004) was a legal scholar, professor and counselor. In 1991, he advocated making available a means by which the elderly could humanely end their lives. His advocacy of this, later named after him, "Drion's Pill", caused a lengthy public debate that remains unresolved to this day.*

Members really appreciated those meetings; they felt they were taken seriously. For us it was instructive because we heard what was on their minds and what they needed. For example, we started offering more support in filling out forms, making treatment orders and living wills, and we developed a non-resuscitation token.

During a series of these regional meetings, at the time of the discussions about Drion's Pill*, as an experiment, without any scientific basis of course, we split the room into two groups. One group had to imagine that they could legally dispense the pill, the other that they wanted it. It was remarkable to see that even the biggest proponents of Drion's Pill, in the role of dispenser, started making strict demands on the applicants. While the applicants said: just give me the pill. People turned out not to be as autonomous as they thought of themselves.'

Member participation

'Member participation in the policies of the NVVE was not really a topic of discussion in my time. Because of my experiences in my general practice, I was quite open to it, but I never had the impression that there was a great need for it. In my view, the volunteers were the representatives of the members; my door was always open to them as well. The only one in which I involved the members more actively was because of an issue raised by an active member. In order for a member to bring a counterproposal to the general membership meeting, you had to collect a minimum of twenty signatures. The only time you could do that was right before the General Assembly started. Impractical, of course, because that often attracted a few hundred people. Then I came up with the solution of a preliminary consultation. There, members could discuss their own proposals and motions, and that consultation should take place a few weeks before the General Assembly. That seemed like a neat way to arrange better participation. I felt that the board should not be present there, otherwise it would not be a real member consultation. The board members found that extraordinarily complicated. Even more so because, as director, I was there to explain the board's proposals when necessary. In the beginning there was a lot of interest in the members' meetings, but later they dwindled to a steady, small club of people.'

Sitting on your hands

'Working with volunteers was also new to me. Once the euthanasia law was passed, we as NVVE wanted to stay

The Dying Dutchman

'One of the wild ideas at the NVVE at that time arose from a suggestion made by Philip Nitschke. He is the Australian doctor who had been the first in the world to legally perform euthanasia. He had emigrated to the Netherlands, where euthanasia had now become legal. We had a lot of contact with him. To make euthanasia possible throughout the world, he suggested, you would have to have a

Dutch boat sailing outside of territorial waters, a boat where people could receive euthanasia. After all, Dutch law would apply on board, just as happened later with the abortion boat. At the kitchen table, we were joking about what the name of such a ship should be. The suggestion was "The Dying Dutchman", by analogy with The Flying Dutchman. It was cause for hilarity for a long time.'

absolutely within the boundaries of the law with our activities. We could not afford to lose or tarnish our image as a reliable interlocutor and advocate of a dignified end of life. Assisting suicide was therefore expressly forbidden to our staff, and we were on top of it. The member support service, LOD, often came to members' homes and of course knew how to end your own life if you wanted to. We had even made a Dutch translation of the "Scottish booklet", in which a Scottish Right-to-Die society had collected information on all kinds of ways of suicide. Members could order that.

But giving more than basic information was "not done" for volunteers, we urged everyone. Sometimes someone would ask an LOD staff member to be present at the suicide, so he or she wouldn't have to die alone. Know what that means, I warned repeatedly. "Imagine an old lady with trembling hands taking her pills and one falls to the floor. What do you do? You pick it up and reach for it, it's automatic. Know that in such a case you are legally assisting in suicide and are therefore punishable. Being present at a suicide is not prohibited, but you will have to sit on your hands." The problem was that, certainly in those early days, it was "terra incognita" for all concerned as to exactly where the boundary lay. The public prosecutor had to define that boundary. We discussed this tension with the volunteers many times. In a few cases I had to break the volunteer contract because people did not keep to the agreements.'

The NVVE board taken hostage

'In 2003 the then board of the NVVE was once taken hostage by the police. The reason was the suicide of a woman with psychiatric problems who had been counseled long and intensively by the psychologist who worked for us. Just before she carried out her suicide, on the evening itself, she had spent an hour on the phone with her. Our psychologist operated on the edge of what was and was not allowed in such a case, but she was very competent, and we had full confidence that she remained within the boundaries of the law.

After the woman's death, one of her relatives nevertheless got the feeling that something was not "kosher". What had this NVVE woman discussed with her relative? Had she assisted her in her suicide? After the Public Prosecutor's Office initially declared the complaint inadmissible, a special proceeding was nevertheless initiated. For its investigation, the prosecution demanded the file that the psychologist had kept of the conversations with this woman. She refused to give that, because it fell under her professional secrecy and under the woman's privacy, she felt. As her employer, I completely agreed.

One afternoon the board was meeting in the office when the doorbell rang. Three policemen at the door, from Bureau

Lijnbaansgracht, around the corner from us. By order of the Prosecutor's Office, they came to pick up the file; they had to "freeze" the situation until the file was obtained. As director and employer, I refused.

No one was allowed into their computers or closets then, no one could make phone calls, and no one was allowed to leave the premises. Not even the board, which included the then Alkmaar Chief Public Prosecutor Adelbert Josephus Jitta. I was only given permission for a phone call with our lawyer.

While waiting for the prosecutor on duty, who had to come all the way from Almelo, some 150 kilometers from Amsterdam, we sat and waited for hours. The police officers were somewhat concerned about the situation; it was also a very unusual situation for them. By now it had become evening and one of the officers went to get food for us at the Thai restaurant. Of course, at our expense, he even handed in the receipt neatly.

After consulting with the officer and our lawyer, we finally had to hand over the file in a closed and sealed envelope; we couldn't get out of that. No case was ever made of it. It was an extraordinary, and in retrospect, somewhat comical experience.'

Chapter 7

A euthanasia law

In his new position as director of the NVVE, Rob becomes involved – from his very first working week – in the creation of the Dutch euthanasia law, for which the late Minister Els Borst has then just submitted a proposal. Solicited and unsolicited, he gives advice, comments on changes to the proposal and follows the many deliberations. The law will always play an important role in his career.

Reliable interlocutor

‘My motivation to fight for proper euthanasia legislation arose when Els Borst, then Minister of Health for the D66-party, had submitted her proposal for the Act on the Assessment of Termination of Life on Request and Assisted Suicide. The euthanasia law, as it is popularly known. In the previous decade, legalization had been increasingly emphatically discussed and the subject was increasingly on the social agenda.

Now there was a concrete bill, of which I – together with Walburg, the board and others of the society – was able to closely follow the whole process up to the moment of approval in 2001 and to which we contributed as much as we could. A strong sense of commonality had grown in the office and in the society: after years of just proposals, this law had to be passed and we were going to do our best for it.

I now dare say that I have succeeded in making NVVE a reliable and serious interlocutor on the subject. Before my time, the society had a rather negative image. If something happened and they were asked for a reaction, the answer was invariably: yes, but... Always a negative angle. Earlier draft bills were interpreted by the board as a way to protect the physician, whereas the board was more concerned with the autonomy of the individual. The individual should be able to have euthanasia if he wanted it. Els’ bill did not give the patient a right to euthanasia, they thought. And that was true, but I thought: better a slightly lesser law than no law at all.

In consultation with the board and the office, I decided at one point: we are going to communicate in a different way. I worked hard to ensure that we would participate in the discussion as representatives of the patient, as the one who will make use of the law. We did not have to be discussed about us, we had to be discussed with us, but from a positive point of view. We actively did that – and later at

WFRtDS I continued that line. You always must talk with everyone. I agreed with Walburg: no matter who asks for an interview, we always say yes. Doesn't matter from which medium, pro or con, domestic or foreign.'

Hopeless and unbearable suffering

'Together with Walburg, I attended many discussions in working groups, House Committees and later deliberations in the House and Senate, sometimes as an invitee. We felt we had to be there, even if we were often only a handful of people in the public gallery.

I have always defended our euthanasia law with heart and soul. I feel I am an heir to Els' ideas, even when I spoke about them abroad. She herself sometimes told me that she had confidence in the way I explained the law.

Her bill was particularly clever. It is, in my view, a model for the approach to legalization in other countries. For she ensured that not "terminal suffering" or "a terminal illness" was included in the law as a condition for euthanasia, as has often been done elsewhere in the world, but "hopeless and unbearable suffering". That has been essential.

Els' reasoning was: why does someone want euthanasia?

Her answer: not because you want to end your life, but because you want to end your misery. That is central.

That is why she chose that terminology: "hopeless and unbearable".

At length and intensely, I discussed, among other things, with Adelbert Jitta, the aforementioned chief prosecutor who was closely involved in this issue, that one word "and" in the legal text. Shouldn't that have been "or?" Adelbert was in favor of that. He was for patient autonomy and felt that the patient's wishes should always prevail. On the contrary, I am very happy with that word "and." It brings patient and doctor together in that difficult end-of-life decision. The patient indicates that he finds the suffering unbearable. The doctor makes every effort to change unbearable in bearable, and if that is no longer possible, that suffering has become hopeless and he can give euthanasia. After all, unbearable is not necessarily hopeless. By way of

illustration, if you have a bruise under a toenail due to trauma, it can cause truly excruciating pain. But a doctor can make that bearable with tiny surgery. So, such suffering is not hopeless.

No matter who asks for an interview, we always say yes. Doesn't matter from which medium, pro or con

NVVE-colleague Walburg de Jong:

‘We received journalists from all over the world’

After the presentation of Els Borst’s euthanasia bill, Walburg de Jong becomes head of communications. Together with Rob, she maintains press contacts. There were many in those turbulent times.

Hundreds of interview requests

‘Especially after the euthanasia law was passed, we received dozens, hundreds of interview requests, including from abroad. From Australia to Japan and from the Vatican to the United States. The general tenor was: what on earth are you doing in the Netherlands!’

Many journalists had seen little or nothing of our twenty-year run-up to the law. They did not know that the practice of careful euthanasia had already grown, that there had already been several court cases leading to the establishment of criteria of care. They had not experienced that maturation process; legalization came as a bolt from the blue for them.

It was a hectic, but often fun time. I remember Rob and I once walking through The Hague and I was talking to two journalists at the same time, a Nokia to each ear. We also received journalists from all over the world at the office. Making them understand exactly how things worked in the Netherlands and what the law meant was sometimes bewilderingly complicated. Japanese journalists wanted a tour around our office because they were convinced that we had beds with infusions somewhere where we were killing people. When they understood that we didn’t, they were sometimes almost disappointed. They had expected something much more spectacular and dramatic: a father or mother who had been euthanized because the children had to go on vacation and no longer wanted to take care of them, weird stories like that.’

Japanese journalists were convinced that we had beds with infusions somewhere where we were killing people

Unbearable and hopeless are two aspects, two sides of the coin called “suffering”.

By the way, I am somewhat different from people who think that when a right-thinking person asks, the doctor should just have to carry out that wish. That doesn’t suit me. It would make me feel like letting someone down. If someone wants to die, you should have a conversation with them, explore whether you can help. So, I have a problem with making a last-will pill available to anyone over the age of eighteen, which the Last Will Cooperative is fighting for. I cannot instinctively embrace that idea.’

Talking with everyone

‘Understanding and giving understanding to dissenters has always been my mission. For example, I strengthened ties with doctors’ organization KNMG and I remember intensive discussions with faithful Catholics and Christian politicians.

Understanding and giving understanding to dissenters has always been my mission

A brutal murder

‘On Feb. 8, 2014, former Minister Els Borst was murdered. She was 81 years old. I did not maintain personal contact with her, but of course had witnessed her up close during her years as a minister. Her death was an incredible shock. For me, and for all of the Netherlands. It is and remains, even ten years later, indigestible that such a beloved and respected politician was stabbed to death right in front of her house, on her return from a party meeting she had attended that day. A most senseless and brutal murder.

That she was killed because of her views and her efforts for a euthanasia law makes it even worse, if possible. The man who killed her

said at his trial that he had done so because he was “divinely instructed to kill the one responsible for the euthanasia policy”. The newspaper quoted him as saying: “I had a dream as a child in which God, the devil and Jesus stood before me and told me to kill the person responsible for euthanasia.” He was a psychiatric patient and also killed his sister a few months later.

In all the years that I have championed euthanasia legislation, I have never felt unsafe. I never thought, I have to be careful. The murder of Els made me realize that the same thing could have happened to me or others involved in this issue. It made me feel even more determined to defend Els’ law.’

At the invitation of party chairman Bas van der Vlies, I once participated in a discussion with the heavily Christian SGP (political) party, in a small room populated exclusively by men in severe, black suits. Of course, they did not like euthanasia at all and were uncompromisingly against the new law. I was under no illusion that I could change the minds of my opponents. But I did want to create mutual respect, to show that we were not an organization that took death lightly. Despite their anti-attitude, that also succeeded.

Els Borst not only brought about a euthanasia law during her reign, but she also made millions available to improve palliative care

The same goes for discussions with palliative care people. This then began to emerge, unfortunately mostly supported by faith groups. The first hospices were almost all Christian. Els Borst not only brought about a euthanasia law during her reign, but she also made millions available to improve palliative care.

Termination of life on demand and palliative care belong together, I have always felt, and I had many discussions with people from that angle. With Ben Zilic, among others, at the time one of the leading representatives of palliative care in the Netherlands. He ran a large hospice in Nijmegen, Rozenheuvel. Zilic, he said, had never received a request for euthanasia in all his years at the hospice, proof to him that you didn't need euthanasia. But that didn't surprise me at all, because people all over the country knew you should never go to his Rozenheuvel if you ever wanted to ask for euthanasia. No matter how good his palliative care was. And I would tell him that, after which we would have beautiful conversations together.'

Intensive lobbying

'Our involvement in the creation of the law included providing a lot of information and lobbying intensively. For example, we once invited all the political party spokespersons to the NVVE office for an information afternoon. At some point you then start counting "heads": how many people will vote for it and are there enough of them. It was obvious that CDA, SGP and ChristenUnie would be against it because of their religious beliefs. SP (the Socialist Party, ed.) and especially GroenLinks (GreenLeft, ed.) were concerned that a euthanasia law would reduce the urgency to improve

care. After all, there was then an “easier” solution at hand: euthanasia.

It was to my advantage that as a doctor I could refute such a misconception. For doctors, the patient’s choice always comes first, and end-of-life considerations are by definition very personal. Therefore, you can never say: ah, now I know what unbearable suffering is. No, every time you must re-enter that conversation, have the willingness to invest time and energy in it again and again.

There are still many doctors who refuse to give euthanasia for reasons other than religious ones. For the NVVE, that was the reason in 2012, when I had already left, to establish an End-of-Life Clinic: to help people who were not helped by their own doctors – for whatever reason. I was initially opposed to this, because they claimed they wanted to eliminate a waiting list of three thousand people, and I thought doctors would not be able to perform euthanasia more often than a few times a year. In practice, the staff of this Levensindekliniek, later called Expertise Centrum Euthanasie, proved to be very careful. I adjusted my opinion.

At the time, then GreenLeft party chairwoman Femke Halsema did the same thing. Adelbert Jitta and I spent an entire afternoon talking with her, sometime in the period leading up to the vote in the Tweede Kamer (House of Representatives, ed.). I have always strongly suspected – but perhaps that is wishful thinking – that we were able to persuade her to vote for the bill, a crucial vote.’

The ‘slippery slope’

‘I do still regret what happened after the trial of Flip Sutorius, general practitioner in Haarlem. In 1998 he gave assisted suicide to former Dutch Labour Party senator Edward Brongersma. The man was 86, his health was poor, he lost many family members and friends, and he had become lonely and socially isolated. Brongersma was tired of life; he suffered unbearably from the experienced isolation and rather wanted to die.

After many, long conversations, Flip became convinced of

the urgency and authenticity of his wish and gave Brongersma help with his suicide. There had been more such cases, they had even been described in detail in scientific journals, but

There are still many doctors who refuse to give euthanasia for reasons other than religious ones

they had had no legal consequences. Apparently, the Public Prosecutor wanted to create case law. Sutorius was prosecuted, all the way to the Supreme Court.

Somewhere in the parliamentary process of a law, a so-called legislative consultation always takes place, as is the case with the euthanasia law. In such a consultation, party spokespersons and officials go through all the proposals and amendments again, letter by letter. Is everything correct?

Walburg and I were following that from the public gallery when we received the news – hooray for Nokia – that the Haarlem court had ruled in the Brongersma case: Flip had been acquitted. Down in the hall we saw murmurs. There, everyone – including the ministers – had also received the message.

With some – as I understood it also with VVD Minister of Justice Benk Korthals, with whom Els had introduced the

Opponents of a euthanasia law often fear that euthanasia will become far too easy once it is legalized

law – the news led to the well-known fear of the “slippery slope”. Opponents of a euthanasia law often fear that euthanasia will become far too easy once it is legalized. That there will be carelessness, that you can get euthanasia for just a little thing, so to speak.

The court ruling would have been reason for Korthals to put on the brakes; he would have even threatened to repeal the law. We later learned that Els had called him in the car on the way home at night, and that as a result, the law stated that suffering must have a “medical basis”.

The Supreme Court’s ruling later echoed this. It ruled that “life fatigue” is not a legally valid reason for assisted suicide, but neither did it impose a penalty on Sutorius. For that reason, mere suffering from life, which later came to be called “completed life”, is not sufficient reason for a doctor to be allowed to grant euthanasia. There is still debate about that after all these years.’

Dear Members of Parliament

‘After the bill passed the House of Representatives, it was the senators’ turn. Although the government had a small majority in the Senate, here too there would be a vote without group discipline. The differences were so marginal that we decided to pull out all the stops to convince the

senators. All the more so because, as usual, the opponents were very well organized. Near the Senate building, black-clad people walked around the Court Pond praying. That made quite an impression.

NVVE then called on members to send a card to The Hague with a personal story of why one was in favor of the euthanasia law. "Dear Members of Parliament" was the name of the action and in no time the mailroom of the Binnenhof (where the government is seated, ed.) was flooded with postcards, 70,000 in all. Each incoming document had to be numbered, filed and credited as an agenda item, a huge job. The head of the mailroom was not happy with us.

In response to our postcard campaign, Schreeuw om Leven, a Christian group opposed to abortion and euthanasia, held a march in the Binnenhof on the day of the vote in the Senate. As many as 10,000 people participated in that. That experience taught me again that opponents are often better organized than the proponents. Those think they are making a reasonable proposal, that no further action is required. I also saw this often later on abroad.'

Netherlands-Belgium

'On April 10, 2001, the *Act on the Assessment of Termination of Life on Request and Assisted Suicide* was passed in the Senate. For a while it was exciting which country would be the first in the world to have a euthanasia law: The Netherlands or Belgium, because there they were also very far along with it.

After the official parliamentary approval, the minister still had to approve all kinds of regulations and forms, so-called General Measures of Administration. We, as NVVE, even had to exert some pressure by telephone to avoid losing to our "rival" at the last minute. In the Netherlands, the euthanasia law came into force on April 2, 2002, in Belgium a few months later.

By the way, it is very Dutch that for years we tolerated an illegal practice, as we did with gay marriage, soft drugs and prostitution. For more than thirty years, actually as early as 1973, after the court ruling in the Postma case, doctors in the Netherlands had been doing something that was not allowed, but was being turned a blind eye. Judges played a pioneering role in creating useful case law, and the Public Prosecutor's Office made generous use of the expediency principle: its right not to prosecute.'

SCEN Advisory Council

'Part of our euthanasia law is that a doctor must consult at least one independent physician before giving someone

euthanasia, almost always a SCEN doctor. As director of NVVE, I became part of what later came to be called the SCEN Advisory Council. SCEN had evolved from Support and Consultation for Euthanasia in Amsterdam. The SCEA began in 1997. Some twenty family doctors were trained as consultants, a specialist circle was established, and doctors could call a central phone number 24/7 with their questions. Together with Amsterdam family doctors, a protocol was also established.

From scientific research and others, this form proved to work so well that after the passage of the euthanasia law, it was decided to set up a nationwide structure along the lines of SCEA. Els Borst's ministry allocated funds for it and doctors' organization KNMG put a lot of energy into it. Over time, SCEN became an increasingly professional institution. It got an Advisory Board, which I thus became a member of as a patient advocate. Later there came a Committee on Education and Registration SCEN Physician and I chaired that. We turned the course that was there, into a more professional training. A day and a half of theoretical knowledge, including the law and how to write a correct report, then you were registered as an SCEN doctor for six months. During that time, you had to do a minimum of two euthanasia consultations, make reports and discuss the cases in your regional SCEN intervention group. Providing you passed both theory and practice with good results, your registration was continued.'

The Dutch law: exclusion from punishment

To say that euthanasia is legal in the Netherlands is legally incorrect. Active termination of life (euthanasia) and assisted suicide by a doctor is indeed punishable under articles 293 and 294 of the Penal Code. However, thanks to the Euthanasia Act, officially called the Act on the Assessment of Termination of Life on Request and Assisted Suicide, the doctor can invoke a special ground for exclusion from punishment.

The doctor will not face punishment provided he meets six standards of care and reports the euthanasia or assisted suicide to the municipal coroner. All reports are submitted to Regional Euthanasia Review Committees. They assess whether the doctor performed the euthanasia according to the law. If they reach a negative verdict (in jargon: "not in accordance with due care"), the case is referred to the Public Prosecutor's Office and the Health Care Inspectorate. The Board of Procurators General can then decide whether or not to institute criminal proceedings. Since the law went into effect, this has only happened in a very few cases.

A doctor will not face punishment provided he meets six standards of care and reports the euthanasia to the municipal coroner

In 2023, 9068 reports of euthanasia or assisted suicide were made to the Euthanasie Review Committees. Of these, five were labeled “careless” (not in accordance with standards of care). The majority of reports came from general practitioners: 79.9 percent, and were performed at the patient’s home: 78.9 percent. Euthanasia means that the physician administers a lethal drug to the patient. Assisted suicide involves the doctor prescribing and handing the patient the lethal drug, and the patient taking it himself.

The six standards of care are:

1. Voluntary and well thought out

The doctor must be convinced that the patient’s request for euthanasia is voluntary and that he has given it careful thought (deliberate).

2. Hopeless and unbearable suffering

The physician must be convinced that the patient is suffering hopelessly and unbearably. In assessing hopelessness, the diagnosis and outlook are central. There is hopelessness if the patient cannot be cured, he suffers unnecessarily and this cannot be alleviated. Unbearable suffering is mainly about how the patient experiences the suffering. This is different for everyone. The physician must be able to empathize with the patient and his suffering.

3. Inform about the situation and prospects

The doctor must give the patient information about his medical situation and what it will look like in the future. He must verify that the patient knows enough and that he has understood the information well.

4. No reasonable other solution

The doctor must decide with the patient that there is no reasonable other solution to his situation. This does not mean, by the way, that the patient is obliged to try all possible treatments.

5. Consulting independent physician

The patient’s physician must consult at least one independent physician. This physician-consultant must see the patient and assess whether the physician has complied with the required standard of care. The physician-consultant must not be involved in the treatment. This task is almost always performed by SCEN doctors, of which the Netherlands has about 600 to 700. SCEN stands for Support and Consultation in Euthanasia in the Netherlands.

6. Medically careful execution

Finally, the doctor must perform the euthanasia (or assisted suicide) in a medically careful manner.

Different role for SCEN doctor

'What I personally learned in my training is that you have to be aware that the work of a SCEN-doctor is totally different from that of a general practitioner. It is not the job of the SCEN doctor to judge whether patient X should or should not be euthanized, or whether he would have done the same as a doctor himself. You must judge whether patient X's doctor was able to come to his decision in a good way and followed the procedure properly. How do you train? That was the question for us. SCEN physicians are always experienced in providing euthanasia assistance, which is a requirement for taking the training at all. It can then be tempting to watch along with the euthanizing doctor, to interfere with the case. You may think: I would have done that differently. Or: why didn't the doctor try this or that?

There was some debate at the time about whether a physician providing euthanasia should have extensive knowledge of palliative care. Some felt that a doctor should not grant euthanasia if he had not sufficiently exhausted palliative options. But in principle, the doctor does not have to use those options – or at least not all of them. He may have good reasons for not doing so, for example, because the patient explicitly rejects them. The question a SCEN doctor should ask the doctor requesting the consultation is: "Have you considered palliative care, and if not, why not?"

There has also been a similar discussion about euthanasia requests from people with psychiatric problems. Shouldn't the SCEN doctor in those cases actually be a psychiatrist? I have always argued that a SCEN doctor should do no more than see to it that the procedure is done properly and that the criteria are met. If that procedure means that a second psychiatrist must be involved in these cases, then the SCEN doctor should only check whether that has happened. Nothing more. You don't have to be a psychiatrist to do that. The same goes for patients with rare diseases, in that the SCEN doctor does not have to be a super specialist either.

It is not the job of the SCEN doctor to judge whether patient X should or should not be euthanized

Percentage of euthanasia on total number of deaths slightly increased in twenty years

Every five years since 1990, twelve years before the euthanasia law went into effect, research has been conducted in the Netherlands on the frequency of euthanasia, assisted suicide and other end-of-life medical decisions. The fourth evaluation of the Euthanasia Law, in 2023, shows that the number of euthanasia cases increased from 2,700 in 1990 to 9,275 in 2021. The percentage of these that were officially reported by the physician rose from 18 to 83 percent during that period.

The percentage of euthanasia of total deaths increased slightly since the last review. In 2015 it was still at 4.5 percent, in 2021 at 5.3. That of assisted suicide remained stably low: at 0.1 per-

cent in both years. The number of euthanasia requests granted (as a percentage of the number of requests made) increased from 55 percent in 2015 to 67 in 2021. In 2005, it was 37 percent. Termination of life on demand has largely involved people with cancer since the very first death survey in 1990. Their share is declining, though. In 2022, it was still 58 percent of the total number of reports. The share of people with heart or vascular disease that year was 4.1 percent, with lung disease 3.2 percent, nervous system disease (such as ALS or MS) 7 percent and people with other conditions 28 percent. By 2023, 90 percent of euthanasia reports involved people aged sixty and older.

All this does not alter the fact that an SCEN doctor is also there for “Support and Consultation”. So, you do have to keep a doctor from making mistakes if you identify them. That function is important and valuable. But getting involved in or taking over the treatment is explicitly not the intention. Then you can no longer be a SCEN doctor.’

Chapter 8

Out into the wide world

Rob took his first steps on the international stage as early as 1992. He likes the experience so much that later, soon after starting his directorship at NVVE, he becomes secretary of Right-to-Die Europe. Despite the first disappointing meeting he attends, he is convinced of the usefulness of international cooperation, including at the European level.

GP training in Poland

'My first international experience dates back to my time as head of the family physician training program in Leiden. In 1992, I was asked to participate in the European Consortium for Primary Care on behalf of my employer. The ECPC is a group of five European, university GP institutes – from Denmark, Germany, France, England and the Netherlands – supported by the British Council. Through the council, a request had come from Poland to help establish there a nonexistent specialty of family medicine, including training.

As president of the consortium, I was actively involved in this for a number of years. We set up general practitioner training programs at eight different institutes spread across Poland. After that, I also investigated for the ECPC in Russia, the then Czechoslovakia and Bulgaria whether we could do the same thing, but in the end it all fell through.'

First meeting RtD Europe

'The international work in Poland had grabbed me: bringing all these different countries and cultures together, I found it fascinating. So when I became director of NVVE and heard that there was a European association of Right-to-Die societies, it appealed to my desire to be able to do something internationally as well.

My first RtD Europe meeting, in Paris, I remember well. RtD Europe, founded in the early 1990s from the WFRtDS by the late Aycke Smook, a Dutch surgeon-oncologist, consisted at the time of some twelve European RtD societies. I came away from it somewhat disappointed. Exchanging photos and stories about the grandchildren seemed to be the main topic of conversation at the meeting. The content might as well have been dealt with over the phone in ten minutes, I thought at the time. Later I understood that

after the umpteenth fruitless conversation with doctors or politicians, the members chatted about private matters. Sometimes they had known each other for years.

I also realized after that first time that it was indeed a gathering of people all over Europe and the world, fighting for the same thing that NVVE and I stood for. They were people with passion, stamina and a lot of knowledge. So, unlike my then chairman of the board, I was convinced that it was important for us as NVVE to be part of the international bodies. If only because we were the first country in the world to have a euthanasia law. I felt a moral duty to spread our thinking; the Netherlands could be a guiding country.'

RtD Europe secretariat to the Netherlands

'In 2000, on behalf of NVVE, I also went to a World Federation congress for the first time, in Boston. Because the Netherlands, Belgium and Luxembourg had just become the first countries in the world to obtain a euthanasia law, we jointly organized the next world congress in 2002 in Brussels. At some point, I suggested that a meeting of RtD Europe be held there at the same time; after all, most of the members were together anyway.

That's pretty much where my substantive and organizational involvement with RtD Europe began. I became secretary and we brought the secretariat to the Netherlands. My secretary, Kitty Jager, did secretarial support for RtD Europe in addition to her work for me and NVVE. Together, sometimes with another person from NVVE, we went to the meetings and conferences. Kitty handled most of the administrative and organizational matters: booking hotel rooms for member organizations, preparing and sending the newsletter, taking minutes, collecting membership fees. Almost all communication went through her, so over time everyone in the RtD community knew Kitty. When she quit, she was greatly missed.'

Council of Europe

'In those early years of 2000, I also went a few times to Strasbourg, to the magnificent headquarters of the Council of Europe. While the Dutch House of Representatives and later the Senate were debating Els Borst's euthanasia

I felt a moral duty to spread our thinking; the Netherlands could be a guiding country

Kitty Jager, secretary for Rob in his capacity as secretary of RtD Europe

‘The feeling that we did something worth fighting for’

Kitty Jager worked at NVVE from 2003 to 2013. The first six years she was Rob’s secretary, also in his capacity as secretary of RtD Europe. After his retirement in 2009, Kitty becomes project officer at NVVE. Four years later, she transfers to the Kidney Patients Association Netherlands, where she becomes policy officer for Theme Days and Webinars.

‘Of all the RtD societies, the NVVE was the largest. That of Japan, the JSDD, has been the largest for a few years from 2004. During the Tokyo congress, the NVVE symbolically offered an old Dutch painting as “proof” of that. Later the NVVE passed the JSDD again, it is still one of the largest RtD societies in the world.

At that time, we had the most professional organization and the most money. Societies often had only a handful of volunteers in the office, sometimes a single paid employee, we had a whole office. So we were an example to other countries, they sometimes looked at us with some envy.

The RtD Europe meetings were a bit like a family event. Of course, there was the official part, but the joint lunch and dinner were at least as important. People knew each other personally; it was often cozy. I have always found the international part of my job to be very enjoyable and educational. My English has improved a lot because of it. What I remember most from that time is that we really felt we were doing something innovative, something worth fighting for. And what was necessary. In America, for example, opposition to euthanasia and assisted suicide was strong and fierce. Later, surveillance was sometimes even needed at the hotels where we held our conferences. We didn’t experience those kinds of extreme things in the RtD Europe era, but the activism of our work then was exciting.’

We had the most professional organization and the most money. So we were an example to other countries, they sometimes looked at us with envy

Not dead yet

During the 2014 World Federation Congress in Chicago, dozens of disabled opponents of euthanasia held a noisy protest. With their wheelchairs, they blocked all the entrances and exits of the hotel where the congress is taking place; no one could get in or out. Under the slogan "Not dead yet" they strongly objected to the meeting of RtD societies invited by, what they called "the Suicide Fundamentalists" of host Final Exit Network. In a pamphlet they handed out, they called it not a meeting of the World Federation of Right to Die Societies, but of the World Federation of "Right to Be Killed and the Duty to Die-Societies. According to the protesters, those attending the congress were not at all concerned with the right to die. As they said in the pamphlet, the congress was all about doctors who euthanized deaf twins in Belgium because the two were afraid of losing their sight. And

about doctors in the same country who euthanized a transgender man who was unhappy with his sex surgery. They accused doctors in the Netherlands of "killing" babies with spina bifida, and they claimed that the congress had the aim to introduce bills in more than 25 countries that would allow disabled people to qualify for lethal injection and assisted death, rather than life.

They ended their protest manifesto with the dramatic text:

We are not better dead than disabled.

We don't need to die to have dignity.

We deserve the same suicide prevention as everybody else.

We want assistance to live, not die.

We are strong and proud, and we are

NOT DEAD YET!!!

proposal, a Christian Democrat delegate to the Council, Austrian Edeltraud Gatterer, argued that our law violated Article 2 of the European Convention on Human Rights. This states that the right to life of every human being is protected by law and that no one may be deliberately deprived of life.

Some time before, she had made a recommendation to the Committee of Ministers, the Council's decision-making body, on the protection of the human rights and dignity of the terminally ill and dying. It was mainly a plea for good palliative care available to all in Europe, but it also came down to the fact that euthanasia was prohibited in all member states – including the Netherlands. According to

our Council of State, which tests bills against international treaties, this was not true, by the way, Minister Korthals said during the discussion in the Senate.

I had good contacts with VVD Senator Dick Dees, who was also a member of the Council of Europe. He always warned me when something was about to happen. Then I would grab a plane and travel to Strasbourg to provide the council members with correct information, solicited and unsolicited.'

Silvio Berlusconi

'I also did that, along with Dees and the Labour Party member Erik Jurgens, to support Swiss Dick Marty. Like Dees, he was a parliamentarian for the Council and the special rapporteur on euthanasia. In 2003 he had made a proposal, in response to Gatterer's opinion, calling on member states to collect and analyze data on the state of assisted dying in their countries, just as had previously been done in the Netherlands. In addition, members were advised to encourage a debate on assisted dying at home and to explore the

Then I would grab a plane and travel to Strasbourg to provide correct information

possibility of introducing legislation that would exempt doctors, under strict conditions, from criminal prosecution if they assisted someone in their suicide. Legislation, in other words, more or less like the one that had just been passed in the Netherlands.

That met with a lot of resistance, especially from Catholics on the Council and from Eastern European members. Kevin McNamara, a member of the British delegation and a conservative Roman Catholic, came up with a counterproposal. In it, he claimed – wrongly – that Dutch doctors had given euthanasia in a disturbing number of cases without the patient's explicit request. RtD Europe provided Dick Marty with ammunition to refute that and I, as RtD Europe secretary and representing the Netherlands, was able to contribute to that.

In the end, more than two hundred amendments to Marty's proposal were submitted. These had to be dealt with piece by piece, causing a huge delay. The story goes that Silvio Berlusconi provided a plane to transport all the conservative Italian councilors to Strasbourg so that they could stop Marty's proposal at the vote. The amended proposal finally voted on was so far from Marty's, that he himself voted against it. For this kind of development in Europe, I was instrumental by helping with correct information.'

Chapter 9

The person in charge

From his position as secretary of Right-to-Die Europe, after his retirement from NVVE Rob makes the transition to the World Federation, which he would like to professionalize. Rob gradually developed in its ranks from Communications Director, first briefly called Webmaster, to Executive Director. He owes this last title to then Board Chairman Ron Plummer. He sees Rob as “the person in charge” at the World Federation.

New laptop

‘Quite soon after I started doing work for RtD Europe, I also felt the urge to take the World Federation to the next level. The federation – with then just under forty members – was literally and figuratively run from behind the kitchen table. The board consisted of ten or twelve unpaid volunteers, often enormously motivated and passionate people. Some were also not shy about paying a plane ticket or other expenses out of their own pockets.

Because I was a paid employee of NVVE, by statute I was not allowed to serve on the board of the World Federation. That was reserved for the directors of member organizations. I could, however, do other things. One example: at that time, in early 2000, the board of the World Federation, in an attempt to expand its financial scope, had commissioned an American to raise funds. This did not get off the ground sufficiently, also because it turned out he was working on a laptop that kept failing. The federation had no money for a new one so then, in consultation with then WF president Mary Galnor, I purchased it from NVVE’s automation budget and donated it to the WF. A practical solution that stemmed from the fact that I – and our board was behind me – thought the federation was valuable.’

Professionalization WF

‘Professionalization of the World Federation was the subject of a study I conducted at the end of my NVVE directorship, in 2008-2009. Because it was considered undesirable for both Eugène Sutorius, NVVE Board Chairman, and I to retire simultaneously, NVVE loaned me to the World Federation for six months for that assignment.

The reason for the study was an impending separation of RtD Europe from the World Federation. There was a disagree-

ment over money. The board of RtD Europe felt that it received too little budget from the World Federation's cof-fers, while the European societies did contribute a substan-tial part of the WF membership fees. It has become a con-flict that at times flared up, about which – now that the main protagonist in that discussion has passed away and this is my story, without hearing from others involved – I only want to say that I have always been sympathetic to the existence of RtD Europe.

The fact is that the threat of that split-off led the World Federation to want to explore the possibilities of restructur-ing and professionalizing the club. I had already made a concrete proposal for that at the 2008 conference, but for the board this went too fast. It didn't want to overwhelm the members and asked me to identify their wants and needs first.'

Another outcome was that the federation should employ someone part-time who could assist members in terms of content and politics

Research outcomes

'I prepared a survey for com-pletion by members. It was completed by a majority of the members. Among other things, I had asked them what they thought about the vision and mission of the

federation, about solidarity as a guiding principle and how far it extended, about the desirability of joint lobbying and fundraising, about the website and about whether the World Federation and RtD Europe should continue to exist along-side each other. There was fairly broad support for the latter, by the way.

One of the other questions was whether members needed administrative support. There was a large majority in favour of that. Members wanted someone who could provide active support for them, basically someone like Kitty: someone to answer emails and questions, arrange things, a desk function.

Another outcome was that the federation should employ someone part-time who could assist the members in terms of content and politics. Someone of an academic level who could support them in their efforts to achieve more freedom of choice around the end of life in their own country.

Someone who – paid by the federation – could think and work with them for a period of time. A kind of consultant. Occasionally I have been able to fulfill that role myself, but then my travel and accommodation expenses were paid by

the member organization that invited me. So unfortunately, only the larger or richer member organizations can afford something like that.'

Discussion regional structure

'Professionalization in my view meant, among other things: financial compensation for this kind of support work. That increases the quality and continuity of the work, my experience at NVVE had taught me. My estimate of the cost of an administrative assistant and a consultant amounted to an annual budget of around \$250,000; that of the World Federation was only \$30,000 at the time.

We did some brainstorming to increase the financial space – for the federation and for RtD Europe. We came up with all kinds of ideas. One was this: I had calculated that all member societies together had about 500,000 individual members. Were each society to contribute 50 cents per member annually, you would already have the desired budget. For a small society like the Northern Territory in Australia, that meant an annual contribution of \$9; for a large one like NVVE, it would run into the tens of thousands of dollars annually.

NVVE had expressed its willingness in principle to consider such a contribution, but only if other members would do the same, for at least five years, and on condition that some firm organizational changes would be made.

Unfortunately, it never came to that, because it would be too great a budgetary burden for most member organizations. To set a good example, NVVE did make that amount of 50 cents per member available to the World Federation on a one-time basis. Among other things, this amount was used to pay for my research and my compensation for it. Later we had another complex discussion about our organizational structure. I had designed a plan in which the federation acted as an umbrella over regional structures, which in turn hung like an umbrella over the national member organizations: a RtD Europe, RtD Americas, RtD South America, RtD Asia, RtD Africa and RtD Australia. That, too, did not get off the ground, because only Europe had such a regional organization, which was still functioning reason-

Professionalization means: financial compensation for this kind of support work. That increases the quality and continuity of the work

ably at the time. The other continents unfortunately never succeeded in establishing a regional umbrella. Only much later did something similar arise in Australia: Go Gentle Australia. Not so long ago, the first steps were taken in Colombia to form a Latin American umbrella.'

Communications Director

'After my retirement in 2009, I stealthily started doing more and more for the World Federation. The results of my research were discussed at the WF board meeting in October of that year. Improving the provision of information via the website was seen as an important first step towards the necessary professionalization.

I had already started a little bit of that during my research. I had taken a course and was then asked by the board to become webmaster. Thanks to the then editor of the WF newsletter, Faye Girsh, my position was given the title "Communications Director." She thought the designation "webmaster" was too derogatory. The board established a job description and compensation for my work and asked me to report over a year what I had done and how much time it took.

In one of those quarterly reports, I suggested that, in addition to my job as webmaster, I should also take charge of communications on behalf of the board and between the board and member organizations, for example. I simply wanted the World Federation to operate more professionally and effectively. I also liked it and I had the time, after all, I was officially retired. The board gladly accepted my offer. One of the things I changed was that all communication from the board would go through one central address. That was not the case until then. By using that central e-mail address, mine, the World Federation was recognized as the sender immediately and by everyone.

I simply wanted the World Federation to operate more professionally and effectively. I also liked it and I had the time, after all, I was officially retired

‘Have you never read history?’

In a 2010 blog on the website First Things, a publication of the U.S. Institute on Religion and Public Life, Wesley J. Smith compares Groningen neonatologists who worked in close consultation with parents to end the lives of very severely disabled babies on the one hand with the case of a 25-year-old Frisian mother who killed four of her young children on the other.

Smith asks the questions in his blog: “So, what’s the difference between the accused woman and doctors who kill babies? An MD license? The use of a lethal injection? Or is it bigotry against babies who will have disabilities or have terminal diseases?”

Rob responds with: ‘What a foul headline is made by Wesley Smith. I respect him for his

ideology, but making this parallel between the well reasoned termination of life of a handicapped newborn by a doctor after extensive consultation of experts and lengthy consideration with the parents (OK to disagree on the argument, but...) on the one side, and the killing of four (!) seemingly healthy babies by a possibly desolate mother on the other, is beyond what I expected of a well educated person. Nothing but putting the Groningen protocol in a bad lighting could have been the reason for this. A shame!’

Smith’s answer reads: ‘It’s murder. It is deciding that another’s life is not worth living. It violates human rights, as set forth at Nuremberg. Have you never read history?’

Of my own accord, in my capacity as Communications Director, I had already responded a few times to news I had come across on the Internet. I explained the meaning of the terms related to our topic, because they were often used completely incorrectly in the public debate. The different definitions always led to confusing discussions. I also explained how the legislation in the Netherlands and other countries worked. There was a lot of misinformation about that, and I felt I had to refute it. Of course, you never know to what extent that influenced the debate, but I felt it was worth my time. For example, I had spirited discussions with Wesley J. Smith, a well-known American lawyer and author and one of the most outspoken opponents of suicide and euthanasia.’

Former president of the WFRtDS Ron Plummer:

‘Rob was the backbone of the organization’

Ron Plummer served as president of the World Federation from 2014 to 2016. After a poignant encounter with an MS patient in a hospital near London, where he visits for his work as an accountant, he joins the Voluntary Euthanasia Society (VES). Almost immediately after, he becomes a board member of this oldest Right-to-Die society in the world, founded in 1935. The VES is no longer a member of the World Federation because it does not want to get involved with an organization who has some members operating on the edge of the law, or just over it. After Ron opposes a proposed bylaws change within the VES and the majority of members vote for it anyway, he resigns his membership. Not much later, the VES is renamed Dignity in Dying, also not a member of the WFRtDS. Ron does become president of Right- to-Die Europe and later of the World Federation.

Wise people

‘When I got involved with the World Federation, Rob was webmaster and sort of secretary of the board. He did everything, was the backbone of the organization. He didn’t really need a board; he could do it all on his own. But the board, of course, was the formal representation of the members, elected and appointed by them. It contained wise, sophisticated people who had a lot of experience and offered good ideas in discussions about the direction and activities of the federation. Board members were mostly active in their own organizations and countries; at the federation,

Rob was “the person in charge”. That is why, as chairman, with the support of the rest of the board, I made the decision at the time to appoint him Executive Director, because that was just what he was in practice. Rob was happy with that.’

Quite professional

‘The stage of exchanging family photos was well past when I joined the World Federation. Representatives who came to the conferences were really interested in right-to-die issues and in the movement. I thought the federation was already quite professional at the time.’

In my business career – I held a senior position with an English firm – I went from meeting to meeting, so I had seen a few things. Of Rob’s management skills, I was immediately impressed. Let me give you an example of the way he handled things. At one point we had to move our legal headquarters from the U.S. to Switzerland. That had to do with new American legislation around not-for-profit organizations. That required the federation to deliver all kinds of information within tight deadlines. An almost impossible task for an organization that was not American, but global.

I anticipated that we would run into huge fines if decisions on the move were not made quickly enough at our General Assembly. Rob suggested dividing the process into three simple resolutions and having them voted on. That worked like a charm. Rob has a natural talent for making something so complicated manageable and keeping progress on it. He is a diplomat, good at dealing with people who have opposing views.

As chairman, I had a stabilizing influence on him, I think. Because I think Rob is a very capable man who did a good job. I could rely 100 percent on what he said. He may have missed something he didn’t think was that important as I did, that can happen, but I never caught him in a falsehood. I encouraged him. If he suggested something, we as a board almost always went along with it. I think the World Federation has certainly contributed to the creation of assisted-dying legislation around the world. Each member is a grass-roots organization in its own country and has to deal with a constituency, politicians and policymakers there. The members do most of the work, but the fact that they could show that they were part of a global organization whose members helped each other with information and knowledge certainly had a positive impact.’

Rob has a natural talent for making something so complicated manageable and keeping progress on it

When I look back, I think the World Federation has become a lot more professional in the last ten, fifteen years, and I am immodest enough to think that I have contributed to that

Executive Director

'The board was fine with me taking charge of communications. It allowed me into its meetings, initially only as an observer and note-taker – for a while I was even given the title Reorganization Advisor. I was not allowed to get involved in Federation's political or policy matters. Gradually, however, my duties began to look more and more like those of the director position as I had held for eight years at NVVE. From that time, I was used to facilitating a board: preparing meetings, implementing policy decisions, and leading a membership association.

Managing an agency was also part of my duties at NVVE, but of course the federation did not have an agency, just me. I began by making some practical, sometimes very simple changes to make the organization more efficient. For example, board members were in the habit of always using the "reply-all" button when replying to an email. The result: an endless number of emails in response to a congratulations or something else trivial. I put a stop to that.

More radical was my suggestion to reduce the size of the board. It consisted of ten to twelve members. A number chosen in part because the board and members wanted to see global representation reflected on the board. The size has been reduced to five: a chairman, treasurer, secretary and two members. This works better for the relatively small organization that the WFRtDS is, with – by 2024 – just under sixty members.

We also got the bylaws in order and streamlined financial accountability. That expansion of my duties led me to change my title in 2015-2016 under the chairmanship of Ron Plummer, with whom I worked well, to Executive Director.'

Limit to professionalization

'When I look back, I think the World Federation has become a lot more professional in the last ten, fifteen years, and I am immodest enough to think that I have contributed to that. The last few years have seen the addition of two staff members: Laura De Vito, who took over my job as webmaster and, as a lawyer, also deals with legal and regulatory matters, and Jane Barrett, who does media and events. But as long as you don't have money to pay such people more

than an expense allowance, there is a limit to that professionalization. As a small agency, the three of us developed ideas and plans, to which, unfortunately, there was little response from the members and the board. Sometimes we had the feeling: who are we doing this for? The World Federation does not belong to us, it belongs to the members!

But then again, the member societies are often already up to their ears in work at home, short-staffed and all struggling with tight budgets. The World Federation comes second, after all. It is inherent in how such a voluntary umbrella organization works.

The board is an exponent of the community that the World Federation actually is. It includes people who are very knowledgeable on the subject of assisted dying. If you want to take professionalization a step further, you must have

someone who is an administrator as president and someone who has a career in finance as treasurer. By the way, in general I do see an upward trend, even among members. Especially the large societies are more often developing their own professional support.'

Member societies are up to their ears in work at home, short-staffed and struggling with tight budgets.

The World Federation comes second, after all.

It is inherent in how such a voluntary umbrella organization works

Chapter 10

Refuting nonsense stories

First in his position as NVVE Director, and later as Executive Director of the World Federation, Rob gives lectures and presentations on euthanasia and assisted suicide all over the world. Often the interest of his audience focuses on Dutch law. Each time, Rob then has to first debunk an endless series of ghost stories. In about four countries, he offers advice and support in the creation of an end-of-life law.

Lecturing

'The role of consultant, which I had seen in my research as part of the professionalization for the World Federation, I started to feel more and more as my own. In fact, I was already doing that during my NVVE time. I was invited numerous times for lectures abroad, explaining to doctors, politicians, judges, lawyers and so on. I have addressed the Scottish, English, French, Belgian, Danish, German and Austrian parliaments, and the Council of Europe. I have participated in many debates and given dozens of interviews for national and international newspapers, for radio and television.

It was often not so clear whether I was asked as a representative of the World Federation or of the first country in the world with a euthanasia law; that got mixed up. It was clear, however, that there was a great need for substantive information about exactly how the Dutch law was put together. Because wherever I went, through the media, the idea had been created that we Dutch had gone crazy. Doctors who were allowed to kill people legally. How dare we!'

Ghost stories

'Groups that were vehemently opposed to euthanasia, often out of religious conviction, came up with the wildest ghost stories. These groups were more emphatic abroad than at home. They constantly hammered at the risk of the slippery slope and did not hesitate to hurl the craziest rumors into the world. For example, in 2012, during his bid for the presidency, American Republican Rick Santorum claimed that Dutch people wore wristbands that read "No euthanasia please" and that elderly people no longer dared to go to the hospital for fear of being euthanized.

23 countries, 74 cities

During his time at RtD Europe and the World Federation, Rob visits numerous countries and cities for lectures and debates:

United Kingdom: London, Edinburgh, Glasgow, Manchester, Oxford
Ireland: Dublin
France: Paris
Switzerland: Zurich, Basel, Geneva, Bern
Portugal: Lisbon
Spain: Seville, Malaga, Barcelona, Madrid
Germany: Munich, Frankfurt, Berlin, Fulda, Trier, Potsdam, Erfurt, Cologne, Duisburg, Munster, Hamburg
Denmark: Copenhagen
Norway: Oslo
Sweden: Stockholm, Malmö
Finland: Helsinki, Turku
Iceland: Reykjavik, Akureyri
Belgium: Brussels, Ghent, Antwerp, Liege, Leuven
Luxembourg: Luxembourg
Austria: Innsbruck
Czech Republic: Prague, Brno
Italy: Milan, Rome, Turin, Bari
Canada: Vancouver, Calgary, Toronto
United States: New York, Los Angeles, San Francisco, San Diego, Washington, Chicago, Boston
Mexico: Mexico City
Japan: Tokyo
New Zealand: Auckland, Wellington, New Plymouth, Christchurch, Dunedin, Queenstown, Hamilton, Wanganui, Napier, Collingwood
Australia: Adelaide, Melbourne, Canberra, Sydney

In Germany already in 2001, immediately after our law was passed, the fable was spread that Dutch ambulances were waiting in a traffic jam in front of the border to Germany because seriously ill people preferred to be taken to a German rather than a Dutch hospital. For fear of euthanasia. There was even said to be a village in Hungary where many Dutch people had settled who wanted to avoid euthanasia in our country. Virtually every lecture, every interview, every debate I had to begin by refuting this kind of nonsense.

Incidentally, I must say that our role as a guiding country, so by 2008-2009, turned somewhat against us when in the Netherlands the discussions about euthanasia in psychiatry, dementia and completed life began to play more emphatically. For us, those discussions were a perfectly logical next step in the further development in the implementation of the law, just as Els Borst had envisioned. But abroad it was seen as evidence of the slippery slope: you see, first only the terminally ill and now the genie is out of the bottle. I did have moments when it was difficult to explain that this development was precisely because of the extremely careful way Dutch doctors handled euthanasia.'

Tricky task

'From my lectures on the Dutch euthanasia law came a number of times the request if I wanted to cooperate in the creation of a bill abroad. That in itself is a difficult task, because nowhere in the world is the jurisdiction the same. In England, for example, a bill must be approved by two very different Houses: the House of Commons and the House of Lords. In the former are representa-

tives elected by the people, in the latter people who are entitled to membership because of their position or origin. That dynamic is very different from ours.

On top of that, it is culturally determined how one can view life termination as the ultimate act of a doctor when there is nothing more he or she can do to relieve a patient's suffering. Nor does the concept of "unbearable and hopeless suffering" fit every culture. Although I very cautiously believe that it does increasingly come to be considered a universal starting point for laws and dealing with a dignified end of life, and I'm glad of that.

This kind of thing shows that in the world you cannot establish one route towards a law or a blueprint for a law. That's why, as a World Federation, we never included that as an objective: it's just not possible. You can't do much more as a community, as members together, than exchange experiences, support each other, learn from each other, and see how you can perhaps achieve the desired solution through an alternative route. The common thing – this is also in our mission statement – is that we fight for every individual in the world to have the right to make their own choices around the end of life, and to have the legal opportunities to do so.'

Fierce opponents

'In four countries – New Zealand, South Australia, Finland and Iceland – I visited at the invitation of the local RtD organizations for longer or more frequent visits, partly to set up a program that would enable them to influence public opinion favorably. In New Zealand, the national RtD society drove me all over the country to inform the local "chapters," as they are called there, about the structure and content of the Dutch law. So that they could spread that story further, as an example of how things could be done in New Zealand. There was press interest in that, but sometimes fierce opponents. In New Zealand you had Ken Orr of the notorious Right-to-Life organization: Christian, against abortion, against euthanasia. He continuously published sharp articles against legalization of euthanasia, always full of deliberate disinformation. Through the mail I had often had fruitless discussions with him. So, during my trip I tried to get into conversation with him, also invited him to attend one of my lectures. He had never responded to that. Until one day in the lobby of the hotel where I was to give a lecture, at the entrance to the hall, I noticed a man behind a small table handing out leaflets about Jesus. I immediately

Ingrid Kuhlman, President and co-founder of the Icelandic Right-to-Die society:

‘It is partly thanks to Rob that we have made such good progress’

Ingrid Kuhlman is the Dutch president and co-founder of the Icelandic Right-to-Die society *Lífsvirðing*. She came to Reykjavik in 1991 to study Icelandic, got into a relationship, became a mother of two children and has been running a business in training and consultancy with her husband since 2002. Ingrid has written books and articles on communication and time management, among other subjects. *Lífsvirðing* is a member of the World Federation, has about 320 members and 4,500 followers on Facebook. Compared to other countries, that is little, but Iceland, with its 380,000 inhabitants, is a very small country.

Father Ton Kuhlman

‘In 2002, eleven days after the euthanasia law went into effect in the Netherlands, my father Ton Kuhlman was euthanized. Just after I had settled in Iceland in 1999, he was diagnosed with an inoperable brain tumor. His suffering had become

inhumane, undignified, and unbearable, and when that is the case, you want death to be painless and dignified. My father asked his family doctor for euthanasia. He met the criteria and died peacefully with us, his family, around him. We all supported his decision.

That experience led me to believe that Iceland, too, should have such a law. It took a year or two before I had processed his death to the point where I could talk about it publicly. Through my work and that of my husband, and through my publications, I had become somewhat of a Known Icelander. The reason I started speaking out on the subject was also because the public debate used a very negative term for euthanasia and voluntary termination of life: murder. I thought we have to make sure that this discussion is conducted in a positive and considered way.’

Appropriate name

‘Year after year the discussion flared up briefly and then subsided. Legislatively, nothing changed; euthanasia was and is prohibited here. In 2015, the humanist association conducted survey that showed 74 percent of Iceland’s population was in favor of euthanasia. It was time to establish our own national Right-to-Die society, I thought, and I did so – along with four other people – in 2017.

There are no foreign words in the Icelandic language, and Rob pressed us to choose a good appropriate name

One of the first things I did was to contact the World Federation, with Rob. There are no foreign words in the Icelandic language, and Rob pressed us to choose a good appropriate name, for both the society and the subject. *Lífsvirðing*, the name of our society, means “respect for life,” and the name “*dánaraðstoð*” is Icelandic for the word chosen five years later, at the 2022 Congress, by the World Federation as a general, neutral term: assisted dying. For that advice, we are grateful to him to this day. Rob also immediately decided to come and help us set up. He gave two presentations here and we visited several associations, including those of disabled people, nurses, and doctors. The latter two were especially important. The opposition to euthanasia in Iceland came, and still comes, mainly from those medical professionals. In 2010, only 18 percent of doctors and 20 percent of nurses were in favor. That did increase to 56 percent and 86 percent, respectively, by 2023, which is quite an improvement.’

Status and credibility

‘The opposition comes from circles around palliative care. Doctors and nurses think that you don’t need euthanasia if you provide good palliative care; they see palliative care as an alternative to euthanasia. During Rob’s first visit, a doctor claimed that the Netherlands has a euthanasia law because its palliative care is so lousy. Rob was able to immediately refute that claim by

pointing out that the Netherlands and Belgium are in the top five countries with the best palliative care in the world. Later, during a second visit, Rob further explained to doctors his view: that euthanasia can be a good endpoint of a palliative care process and that one does not exclude the other, that they belong together. The fact that Rob was a doctor and gave euthanasia himself made a big impression. He was open about the fact that he had not succeeded immediately the first time, and he advised his colleagues not to tamper with morphine. Among his peers and nurses, that admission granted him status and credibility. His being a doctor was more important than his directorship of the World Federation.’

Good first step

‘Death is a taboo subject in Iceland. Actually, that is strange because this country is modern on many other subjects, such as abortion and gay marriage. Why this is not the case with life termination, I do not know exactly. It may have to do with the fact that Iceland is such a small country. Everyone knows everyone and then the situation can arise that patients don’t dare go to their family doctor if they know he or she has given euthanasia. Which is nonsense, of course: patients will always have to explicitly ask for it themselves and doctors will never be obliged to give it. Out of a small population like ours, you might get fifteen to twenty euthanasia requests a year, we’ve calculated. Then you only need a handful of doctors who

should be willing to perform euthanasia. By now that handful is there; the ball is rolling.

A draft bill was even presented in the spring of 2024. Each party in the Icelandic parliament has the right to introduce a bill twice a year. The Reform Party, which has pushed for legislation before, chose euthanasia as its topic. They asked us for the Dutch and Belgian legal texts and based their proposal on them. It contains the same criteria of care, retrospective review by regional review committees, freedom for the doctor to grant or withhold euthanasia and so on.

It's nice that in several countries it is Dutch people who are so committed to euthanasia: in Italy, Denmark, Iceland

As a society, we have always believed that there should be a proper public discussion about the end of life, a debate in which everyone participates: politicians, MPs, doctors, nurses, patients, the entire population. We want a dignified end of life to be a choice for everyone, but we have never taken a position on what form it should take.

The draft bill talks about an incurable disease as a condition for euthanasia and "unbearable and untreatable suffering." We do welcome that. Only it is unfortunate that there should be a one-month waiting period. We, as one of the civil society organizations asked for a response, criticized that. For my father, that waiting period

would have meant an undignified and inhumane end. Even though the proposal was suddenly there relatively quickly, it may still take years before it is addressed, let alone adopted. But it is a good first step.'

Inspiring

'Over the past few years, since our founding, Rob has provided us with much advice and guidance. His wisdom and knowledge have been crucial, for example in shaping our vision, mission, and goals. During the conferences in Iceland, I have seen how well he communicates. With his words Rob influences people, he is inspiring and has the unique ability to touch them. He explains the most complex issues so clearly that his listeners can easily reuse his message; how the legislation works, how palliative care is organized in the Netherlands, that there is no slippery slope. He was sometimes asked difficult questions about this during our conferences. These he answered with great knowledge and kindness, without hurting his opponent. It is nice that in several countries it is Dutch people who are so committed to euthanasia: in Italy, Denmark and here in Iceland, for example. Rob once said, "We export euthanasia", and there is some truth in that. It is partly thanks to Rob that we have made such progress in Iceland. He has meant a lot to the conversation about a dignified end of life in this country, for that we are grateful.'

thought that could only be Ken Orr. I spoke to him – yes, it was him – and invited him to come into the hall to listen and ask questions if he wanted to. He was dumbfounded, but he accepted my invitation, along with some supporters. They asked many questions, and I answered them as best I could. This was something unprecedented for our New Zealand colleagues. Like their opponents, they too often avoided dialogue.’

More impact

‘I feel that during that tour of nearly five weeks in New Zealand I was able to contribute something to what became their law a few years later. The premise of “unbearable and hopeless suffering” is thankfully central to that. All those weeks I had done nothing but focus on that and advocate that the law should not include such terms as “terminal illness.” My admiration for Els’ wisdom has only increased. Later, upon request, I conducted a similar week-long tour of South Australia. I have also twice supported the Finnish organization Oikeus in approaching the national parliament. As recently as 2023 in launching a citizens’ initiative that requires the Finnish parliament to consider a bill. This led to a success the following year, the required number of signatures were obtained.

In Iceland, I spent a week and later again. There I accompanied the local society in media appearances, talks with members of parliament, doctors’ organizations, and nursing homes. Although I was there as Executive Director of the World Federation, I often spoke about the Dutch law. This was also because it was used as a reference point in the Icelandic discussion. Apparently, such a story from me still had more impact than that of a local representative, despite the fact that they followed the same line. I think this “success”, if you can call it that, was partly due to the fact that I am a doctor and that I have performed euthanasia twice.’

Assisted dying or euthanasia

‘The terminology, the use of words, has been the subject of many a debate in the World Federation over the past twenty years. That discussion has always been there, but it flared up after our World Congress in 2002, when euthanasia laws had been passed in the Netherlands and later in Belgium and Luxembourg.

The word “euthanasia” does not help in the public discussion because it evokes in many people the association with Hitler and Nazi practices in World War II. Opponents use that unfortunate term to bolster their objections.

Different terms are used within the World Federation. Canada, for example, uses MAiD: Medical Assistance in Dying. Australia talks about Voluntary Assisted Dying, VAD. In the Netherlands it has long been called “voluntary euthanasia”, but that “voluntary” has been dropped because euthanasia, by definition, can never be involuntary, then it is murder.

Others sometimes add the word “dignity” or a derivation thereof: Dying in Dignity, Dignified Death, Dignified Methods. In many countries, the use of “(assisted) suicide” appears to be grist for the mill of opponents, who are only too happy to cite policies to actually reduce the number of suicides.

In the Netherlands it has long been called ‘voluntary euthanasia’, but that ‘voluntary’ has been dropped because euthanasia, by definition, can never be involuntary

We have tried several times to arrive at one common and accepted terminology for the act itself, but always failed. Not long ago, however, it was decided that we will use “assisted dying” in our World Federation communications. That is the term already used by the Americans at the 2000 World Congress in Boston. By the way, members have the autonomy to choose their own terms. We did advise: always explain

exactly what you mean by it before getting into a discussion. That way you can try to avoid misunderstandings. For us as the World Federation, the core lies further in the words: “choices” or “end-of-life choices.” What matters is that people have a choice, that they have the right to die in dignity and that the law gives them that opportunity. That’s what our mission statement says.’

Chapter 11

Increasing understanding

Through his decades of involvement in the subject, at home and then around the world, Rob watches from the sidelines as the discussion of assisted dying evolves. Acceptance has grown, is his tentative conclusion. Although there is still plenty of work to be done for the members of the World Federation.

Doctor Death

‘For almost 25 years I have attended the conferences of the World Federation. That alone has given me an idea of the developments in our subject. The number of countries with no legislation on assisted dying is, of course, still quite a majority, but I do see that there has been a gradual increase in international understanding.

At the first conference I attended, in Boston in 2000, the talk was still mostly about Jack Kevorkian, the American euthanasia advocate who, by his own admission, had helped more than 130 patients end their lives. He was convicted in 1999 of aiding the suicide of an ALS patient and spent eight years in prison for it, a kind of martyr. “Doctor Death” he was called, and that term – I have been called that myself at times – was typical of the atmosphere and tone of debate in many countries at the time.

That debate then became increasingly global and led to legislation in several countries. We always claim that the Netherlands is the first country in the world to get a euthanasia law, and in fact that is correct: we are also the first country with a euthanasia law. But actually, the Northern Territory of Australia legalized euthanasia before we did. After the law had been in effect for six months, it was torpedoed by the Federal Government. In fact, Northern Territory has limited self-government and was not allowed to make its own laws in this area at all. Philip Nitschke was the first doctor in the world to take advantage of the legal opportunity to give euthanasia. He was hugely disappointed when that was no longer allowed. Later he turned more and more to so-called “do-it-yourself methods”.

BeNeLux versus Oregon model

‘The Netherlands developed its law thanks to case law and in Belgium, meanwhile, the parliamentary debate on legalization had started along roughly the same lines in terms of content. Luxembourg then developed – using the pattern of the laws in Belgium and the Netherlands – its own law, but it did not enter into force until 2009.

A different kind of practice had grown in America. The state of Oregon legalized so-called assisted suicide in 1997. When extensive and strict conditions are met, doctors are allowed to write a prescription for a lethal drug. The person then takes it himself, without mandatory assistance or the presence of a doctor.

Since the Netherlands got its euthanasia law, you saw around the world that countries started to make a choice between the “BeNeLux model”, which was based on physician assistance, or the “Oregon model”, without that direct physician assistance. Which choice they made depended mainly on the jurisdiction and culture in that particular country. American states – in 2024 there were eleven – chose the Oregon model in subsequent years, and that number is still growing. However, the Oregon model is gradually being modified somewhat. For example, there is discussion about the requirement that the applicant be expected to have only six months to live.’

Medical Aid in Dying

‘In 2016, Canada surprised with a legal regulation for what they called Medical Aid in Dying, MAiD. The regulation leans towards the BeNeLux model, it also chooses suffering as the main criterion. The Canadian practice is followed with interest worldwide and the term “MAiD” has been widely

accepted alongside “assisted dying”.

New Zealand also eventually opted for a law more along the lines of the BeNeLux model. Unlike in Oregon, the guiding principle is not a terminal illness or an expected life span, but unbearable and hopeless suffering.

Meanwhile, even on the Australian continent, one state after another has

proceeded to legalization. The same can be said of Iceland, where serious steps toward a euthanasia law are now being taken.

In the Scandinavian countries, which are so like the Dutch in terms of culture and society, I would have expected more development. I have given several lectures in Norway and in Sweden, but to my surprise the debates there have still not resulted in legislation.

Spain, Portugal and even Germany, where there was always enormous reluctance to legislate because of the Nazis, have also passed legal regulations. Italy and France are as yet conspicuous by their absence from the list of countries with euthanasia laws. Our member organizations and other

I do see that there has been a gradual increase in international understanding

national RtD societies undertake many initiatives, generate much publicity, but bills always stumble in parliamentary debates. But one day a form of assisted dying will be legalized in those countries too, I foresee and hope. In the Netherlands, the conversation about euthanasia has never died down either. Talking about it in public has become commonplace: the other day I heard on the car radio an interview with someone who had asked for euthanasia. An open conversation, just during the day, in a program about human interest. The subject has really become socially acceptable.'

Toyota

'Yet there are also countries where little or nothing has changed in recent decades. Scotland is taking steps toward its own law, but the rest of the United Kingdom still has none, despite having the oldest Right-to-Die society in the world.

Another example is Japan. There the situation is the same as it was twenty years ago. A remarkable event during the 2004 World Conference in Tokyo illustrates this in my mind. At the beginning of the conference, to everyone's surprise, an official-looking delegation marched into the auditorium with security and all, a man in a tight gray business suit leading the way. A true spectacle it was. He entered the podium, delivered a speech in Japanese – simultaneously translated into poor English – and left again, his entourage following behind.

The man turned out to be the chief executive officer of Toyota. He did not come to present us with the latest car, no, he was there as a high-ranking Japanese, a member of the political elite. His story boiled down to his deep concern. Japan has a rapidly aging population and is therefore running up against the limits of health care affordability. As a 100-year-old there, you are still entitled to a new hip, and you get it. His fear was that euthanasia would be dismissed as a solution to the social problem of that large, expensive health care system. Japan also obstructed for a long time in the World Federation when it came to statements we issued; the word "euthanasia" was absolutely not allowed to be used in them.

Incidentally, the Japanese did always see the importance of an international federation. It was they who sowed the seeds of the World Federation when they invited a number of RtD organizations from America, England, France, Australia and the Netherlands to Tokyo in 1976. Four years later, the World Federation was then established at

The circle of people engaged in the subject has become larger and broader

a conference in Oxford, England. The Japanese Society, the JSDD, has always remained one of our most loyal members.'

Long breath

'The greater acceptance for assisted dying is reflected not only in the number of countries with a law or a law-in-development, but also in the circle of people engaged in the subject. It has become larger and broader. It used to be mostly activists, people who often fought for the cause thanks to negative experiences with the death of a loved one. Gradually, others became involved as well: doctors, psychiatrists, nurses, lawyers, ethicists, civil servants, and politicians.

Where you also see the progressive acceptance is in our connections with umbrella international organizations. Right-to-Die Europe had long held official status as a non-governmental organization, NGO, of the Council of Europe. Because the survival of RtD Europe is hanging by a thread, especially now that their president has passed away, we are investigating whether the World Federation can take over that status.

We also want to be recognized as an NGO by the United Nations. Such recognition gives the World Federation status and influence, and that is important for our pursuit of a more humane end of life for all world citizens. Whenever the subject of life termination or euthanasia comes up in such an international organization, as an NGO you are invited to participate in the discussions. You don't have that opportunity as an individual Right-to-Die society, or at least less. For example, as far as the United Nations is concerned, we would like to see the right to die and to a dignified end of life included in the Universal Declaration of Human Rights. While the right to life is protected in it, the right to die is not. The only question is what kind of investment such an NGO status of the federation is going to require. You might have to delegate someone to New York twice a year; that costs money, of course. These are considerations that will have to be made in the coming years.

By the way, it will be some time before we can move forward with this, because we have a practical problem: our formal place of business. The World Federation established itself as a not-for-profit organization in Switzerland in 2016. The Swiss government has no requirements for that at all, but it also doesn't give you formal branch registration in that country. You do need that when you want to be recognized at the United Nations as an NGO. The federation is working on that now. These are long-term processes.'

Chapter 12

Source of information and spokesperson

As a participant in no fewer than twelve World Federation conferences, Rob accumulated a great deal of (practical) knowledge about organizing such international meetings. He is an oracle, press spokesman and jack-of-all-trades all in one. Also in this last part of his career, fun and sociability are an important binding factor.

Business meeting

'From the moment I became director of NVVE through 2024, I attended twelve world conferences. There should have been thirteen, but covid threw a spanner in the works in 2020. As a result, the conference in Mexico unfortunately could not take place.

There have always been misunderstandings about exactly what the World Conference entails. Actually, it is a dressed-up general assembly of members. In fact, the only thing we are obliged to do as a federation is to hold a business meeting – the General Assembly – at least once every two even years. That's the way it is in our bylaws. There we deal with things like budget, adaptation of bylaws, the annual plan and annual review, appointment of new board members and so on.

Twelve WF conferences

2000	Boston (USA)
2002	Brussels (Belgium)
2004	Tokyo (Japan)
2006	Toronto (Canada)
2008	Paris (France)
2010	Melbourne (Australia)
2012	Zürich (Switzerland)
2014	Chicago (USA)
2016	Amsterdam (Netherlands)
2018	Cape Town (South Africa)
2020	Mexico City (conference canceled due to covid)
2022	Toronto (Canada)
2024	Dublin (Ireland)

From the very first conferences in the 1970s, one of the member organizations always acts as host. So it is a member that hosts the conference, not the World Federation. The latter is only responsible for the business meeting. Because there are so many countries and so many experts together at that business meeting, we have always advised the host country to exploit that unique asset. On the one hand to use that knowledge for the developments in their own country and surrounding countries, and on the other hand to let

the population learn about the experiences in other countries. Of course, such a meeting is also good PR for local developments. Because of the activities surrounding the general membership meeting, it has come to be called World Conference.

When the Netherlands co-organized the 2002 conference with Belgium and Luxembourg, we made a thematic division in the program: lectures and discussions on the medical, legal, ethical and advocacy aspects. Because as an international, umbrella club we cannot produce a blueprint for an end-of-life law or for a path toward it, our conferences have always focused on what it means to be a grassroots organization. How do you lobby effectively, who do you need to talk to in order to be influential and how do you get those people to do so? How do you get good experience stories

Our conferences have always focused on what it means to be a grassroots organization. So, how do you lobby effectively?

'An awful lot of laughter'

'Visiting countries and cities for lectures, conferences and the World Conferences I have always found a useful use of time. But of course, it was also fun and instructive and a wonderful opportunity – sometimes together with my wife Kees – to visit a country I would otherwise not easily visit. Sometimes I added a few days to my trip, at my own expense of course.

For an organization like ours, the social context of the conferences was at least as important as the content. After the formal program ended, we often ate or drank together in groups of different composition and there was an awful lot of laughter.

We experienced crazy things, like that time I was in Tokyo with NVVE board member Jacob Kohnstamm for the conference. After a long flight, we tried to overcome the time difference and associated jet lag by keeping ourselves awake. We boarded a bus for a sight seeing tour of the city. Upon entering, the guide shoved a photo of the imperial couple into the passengers' hands. That had to be passed around to the back so everyone could look at it. When the guide came to retrieve the photo at the end of the tour, Jacob had dozed off in the back of the bus with that photo in hand. How outraged she was. How could we be so disrespectful! We were able to laugh about it for years afterwards.'

Lifetime Achievement Award

For contributing so much, so long, so tirelessly, and so courageously to our right to a peaceful death

At Rob's second-to-last World Federation conference, in 2022 in Toronto, he received the World Federation of Right to Die Societies Lifetime Achievement Award. At the presentation, Committee President Asunción Alvarez pronounced the following:

'This award goes to the person who has contributed throughout his life in a tireless and deeply committed way with the objective of defending the right of people to have the freedom to decide the end of their life with the necessary help to die well.

The nomination was received, and it was easy for the committee to make the decision. Graduated as a physician, he worked as a family doctor and very soon became interested in and committed to the cause that defends the right of

people to die with dignity. He is familiar with the topic of assisted dying since a long time.

Involved in the debate on the legalization of euthanasia in his country, he led a Right-to-Die society there, after which he has been an essential contribution to our federation.

At the same time, he has been an indispensable voice for many groups throughout the world. He has traveled to innumerable places to support those who fight in their respective countries for the legalization of MAiD or those who ask for advice to find the most appropriate way to apply it once legalized.

That is why it was decided to honor with the 2022 Lifetime Achievement Award: Rob Jonquière.'

and how do you use them? The format has remained roughly the same, only the structure – including a formal agenda – has become somewhat more professional.'

Practical knowledge

'My role at the world conferences has changed over time. The first years, apart from 2002, I attended the conference as a representative of one of the members, the NVVE. Later I was there as secretary of RtD Europe and again later as a representative of the World Federation, in various capacities.

I have gained a lot of especially practical knowledge about organizing such a biennial conference. I know roughly how

Continues on page 86

Silvan Luley, representative of the Swiss federation member Dignitas:

'Rob's diplomatic nature has always impressed me'

In 2022, at the World Conference in Toronto, Canada, Rob will receive a special award: the WFRtDS Lifetime Achievement Award. This has been awarded once before: to American Derek Humphrey. The nomination to give Rob the award comes from Silvan Luley, the representative of Swiss federation member Dignitas. He has known him for some 20 years and explains why he thinks Rob deserves the award 'damn well'.

Robust structure

'The enemies of the freedom to make your own choices – whether abortion, gay marriage or a dignified end of life – never sleep. They are superbly organized, loud and highly visible in the debate. They have money and skillfully use social media to influence public opinion. All over the world you see new conservatism and new religious movements emerging. Maybe it is not more people, but there is more polarization. Therefore, it is essential that a professional

organization – we, the World Federation – is there in opposition to that. For us as a member organization, it is super important that we have an umbrella above us that stands like a house. I have always seen the World Federation as a signal to the public and politicians that we are not just little clubs doing some assisted-dying work. We are part of a robust structure and that helps us to be taken seriously.

Rob has always stressed that the World Federation itself doesn't do much: no campaigns, no lawsuits, no writing bills. It's the member organizations that take care of that. The World Federation, he says, is the shop window that makes all that visible in one place. The importance of that cannot be understated. Rob, later together with Laura and Jane, definitely made the World Federation more professional. Certainly in the last five years this has been noticeable. Like many other organizations, that process started with the professionalization of com-

After all, as an umbrella, you have to keep all the members and all these different types of leaders together

He is like a friend, but at the same time he keeps a proper, professional distance

munication: an informative website, clear explanations of the terms we use, a clear world map, the use of social media. Our working groups that address certain issues are also evidence of that professionalization. It creates knowledge and helps you to present yourself to the world as an organization with know-how. Of course, the board is responsible for this, but Rob is the one who has provided the impetus for it in the background.'

Taking everyone seriously

'What has always impressed me most is Rob's diplomatic nature. He is able to deal with the most diverse people: the angry, the quiet, the aggressive, the verbose, the unobtrusive. He makes them all feel that he is taking them seriously and I am convinced that he sincerely does.

I, too, have always felt taken seriously and respected, even when I provoked or claimed things you can't actually say. He is like a friend, but at the same time keeps a proper, professional distance. I have never heard anyone speak ill of him and never heard anything negative about others out of his mouth. He doesn't.

At the same time, he is honest and straightforward. You know where he stands, he makes that clear to you in a respectful, diplomatic way. He is not

paternalistic, gives everyone space and yet you know: he is the boss.

For an organization like the World Federation is, those qualities are invaluable. After all, as an umbrella, you have to keep all the members and all these different types of leaders together. Especially when they're live together, because that's when tensions can rise. Rob's diplomatic gift of always finding the balance, calming people down when there are conflicts, unleashing the best in them and encouraging them to find each other again on common interests; all that makes him the perfect CEO, the perfect board secretary. Moreover, the fact that he is so humble about it was the reason for me to nominate him for the Lifetime Achievement Award. I am extremely happy that he received it; he has more than earned it. I will miss him tremendously.'

many visitors you can count on, what conditions the hotel or conference hall must meet, how to put together a good program, how to keep the finances under control, that sort of thing. For the organizers in the host country, I have therefore become a source of information.

A World Federation conference also attracted press attention and media contacts usually went through me. Actually, I was always so busy with that during the conferences that I hardly got around to participating in the program.'

Knight of the Order of Oranje-Nassau

On April 26, 2016, the day before King's Day in the Netherlands, Rob was named a Knight of the Order of Oranje-Nassau. The Dutch royal house has been awarding these honors since 1892 to citizens who have shaped their work or activities in a special way, made a notable achievement or pursued a particular value for society.

Rob remembers the celebration well. 'As usual, I knew nothing about receiving the knighthood. I thought I was going to the festive presentation of a new project of my eldest son. It wasn't until I entered the Nieuwe Kerk in Amsterdam that it dawned on me. I was caught off guard, had not taken it into account for a moment and felt very honoured. The knighthood medal was presented by then Mayor Eberhard van der Laan, now deceased. Later I understood that attempts had been made to have the presentation take place during the opening of our World Conference in Amsterdam, a few weeks later. That was not possible, so my knighthood was included in the usual presentation to more Amsterdam citizens on the occasion of King's Day, the so-called Lintjesregen.'

About Rob, the mayor pronounced the following words:

'You were director of NVVE from 1999 to 2008. For some people, every day is one obstacle too many and illness terrible. A theme that calls for reflection. To make euthanasia discussable abroad as well, you have been director of communications of the WFRtDS since 2008. In this position, you support organizations worldwide to define their vision and position on this issue. And you show them how to have a decent debate about it.

You are also a member of the SCEN Advisory Council. You have always taken a constructive position, which is highly commendable in a subject like this, where emotions are easily lurking. This attitude has certainly helped you in your ambition to create wider support for a voluntary end of life. Rob Jonquière, it has pleased the King to appoint you Knight of the Order of Oranje-Nassau.'

Grassroots movement

'The question of the extent to which the World Federation has contributed to giving more people in the world the free choice of a dignified end of life, I find difficult to answer. I do not have the hubris to think that there would have been less legislation if the World Federation had not existed. We did achieve – and I personally achieved – success here and there, in the form of contributions to legislative development. But if I am honest, I think my experience as a

The personal contact during our world conferences is important and irreplaceable

physician and my knowledge of the Dutch situation and legislation carried at least as much or more weight as my representation of the World Federation.

What is certain is that

Right-to-Die societies around the world would have been more loose sand and lacked connection had it not been for the World Federation. We really are deeply a grassroots organization. That you can exchange experiences, enthuse and encourage each other is, in my view, the greatest asset of the World Federation's existence. And that personal contact during the conferences is important for that. That's irreplaceable, even with all the video calling capabilities that are there now and weren't there twenty years ago. Back then, of course, there was also much less information available. Now almost everything is on the worldwide web. I think it is absolutely a great gain that we have brought together all the relevant information on our website, wfrtds.org, including a world map with the legal situation in the various countries and the experts who are approachable on the subject. We are not only a grassroots movement but also a knowledge community.'

Enthusiasm and conviction

'With enthusiasm and conviction, I have worked these past more than fifteen years to increase the federation's visibility, among its members but also beyond. I have fought for a wider recognition of the right to a dignified end of life in the world, but I did not do this alone. I have always experienced great support from many representatives of our member organizations. People who actively helped and provided useful and constructive comments on the plans coming from me and the staff. People who were always willing to participate in working groups when asked and who supported initiatives in word and deed. I am enormously

grateful to those countless colleagues with whom I have been able to work to achieve the goals of the World Federation.

It has also been wonderful that all the boards and Committees that have had to deal with my interference in recent years have placed so much trust in me. I still feel sincerely flattered by that.

I am convinced that my successor, Peter Warren, will do an excellent job of supporting and facilitating the grassroots aspect of our federation. He will put his own stamp on it and that's the way it should be, that's fine. I hope that the path we have taken together in recent years towards better

visibility of the World Federation and wider recognition of the right to a dignified end of life will continue. That is what I wish from the bottom of my heart for the federation and the individual member organizations. I have done what was in my power, now it is time for new impetus.'

I hope that the path we have taken together in recent years will continue. I have done what was in my power, now it is time for new impetus

Chapter 13

A big thank you to Rob...

**Ted Goodwin,
President WFRtDS (2010-2012)**

Our movement, like all social justice movements, develops and progresses much as a tapestry takes shape over time. The leaders, activists, and supporters come into this effort and eventually leave the work, much as threads are woven into various parts of the pattern at various stages of the process.

Rob, you have truly been a constant 'golden thread' that has run the length of our effort for decades. Your work as Executive Director has provided a focal point and a consistency on which we have relied. You will, no doubt, be greatly missed.

Good luck, Rob, in all of your future endeavors.

**Erika Preisig,
President Lifecircle, Switzerland**

You are such an impressive personality; it is an honor to have had the opportunity to get to know you. You have campaigned for euthanasia for decades, investing a lot of time and energy in something that concerns us all, because we are all going to die. Thank you, Rob, for all your kind words and patient support. I will always appreciate you very much. May you yourself find a peaceful death at the end of a fulfilled life. Should you ever need my help, I will be there for you. All the best

**Cindy Merrill,
Co-Founder of Texas Death with
Dignity, USA**

Rob, although we are an ocean apart, I have always felt you were just a room away when I needed help or information. Texas Death with Dignity was founded in 2013 and in 2014 I attended the International World Federation Conference in Chicago. Two years later I first 'met' you online and we have chatted on and off since then. And we almost chatted in real life in Amsterdam. My bad luck in planning! You have been a saint in answering questions and helping this 'techie dinosaur'. You have brought hope to Texas with news of positive changes with aid in dying issues from across the world.

Thank you for all you have done in helping to articulate the mission and vision statements of the WF by guiding and inspiring your members and supporters in so many ways. We'll miss you! Take care

**Ingrid Kuhlman,
Chairwoman of Lífsvirðing, Iceland**

Rob Jonquière provided unwavering support and guidance when we founded Lífsvirðing, the Icelandic Right-to-Die Society. His willingness to share his expertise and devote his time and resources were extraordinary. Rob's profound wisdom and influence were instrumental in shaping our society's mission and objectives.

As time passed, Rob remained a pillar of support. In 2018, he was one of the speakers at our conference on assisted dying. Rob is very eloquent and has a unique ability to connect with people

through his words. His adept handling of sensitive questions about assisted dying and palliative care demonstrated his expertise and composure under pressure.

I want to express my heartfelt appreciation to Rob for his unwavering support and kindness. Though he now steps down from his role as Executive Director, his legacy will continue to inspire us.

Rob, may the next chapter in your life be bright and fulfilling!

Warm regards

**Helen Long,
Chief Executive Officer Dying with
Dignity, Canada**

Rob, you were one of the first people that I reached out to very early on after I joined Dying with Dignity Canada (DWDC) in early 2020. You were such a great source of history and information and helped to connect me to people across the world who felt the same way I did about assisted dying. Always warm, quick to make you laugh, and happy to share, every call was a pleasure.

When DWDC was fortunate enough to be selected as host of the WFRtDS Conference in 2022, you took the time to answer our many, many questions about past events and to tell us about some of the very successful events you'd attended.

On behalf of everyone at DWDC, our very grateful thanks to you for all your hard work over the years – Rob, you will be greatly missed by your friends and colleagues in Canada.

Thanks so much

**Miriam De Bontridder,
member Supervisory Board of the
NVVE, the Netherlands**

It is with boundless admiration that I look back on how you pulled the cart of WFRtDS for many years. Most of the time you were on the ball and looking for how to take the organization to the next level. We worked together on several files and always the energy you put into achieving results stood out. Your commitment to the right to die with dignity was not limited to the Netherlands, where you did pioneer work for NVVE, the Dutch right-to-die society. As CEO of WFRtDS, you closely followed developments around euthanasia worldwide and gave valuable input to local right to die societies all over the world.

With your farewell, WFRtDS loses an inspired director but I am sure you have made every effort to find a successor who will continue your work in the way you advocate.

Good luck and I am convinced that our paths will continue to cross.

**Pam Oliver,
Health Lawyer & End-of-Life
Researcher, New Zealand (Aotearoa)**

Rob made a major contribution to the campaign for legalization of assisted dying in New Zealand. His extraordinary generosity extended to not only being available over two to three years for discussions and interviews about the issues that commonly concern health professionals in a nation contemplating legalizing assisted dying; he also made a visit to New Zealand, undertaking an exhausting tour of medical and university groups around

our country. In those meetings, he answered questions from uncertain or outright oppositional people attending, tirelessly and with his trademark good humor, patiently repeating the evidence base on procedural and ethical safety from the Netherlands and other jurisdictions, without trying to be persuasive as such. His quiet, common-sense messages remained in New Zealanders' minds long after his visit, helping people to work their way through the myriad complex arguments for and against legalizing assisted dying in our country. New Zealand will be forever indebted to Rob for his contribution.

**Ann David,
President End-of-Life Choice Society,
New Zealand**

The End-of-Life Choice Society NZ wishes to record our members' warm appreciation of Dr Rob Jonquière's contribution towards New Zealand's successful quest for assisted dying legalisation.

Rob, your personal visits to our country, your public education talks, your willingness to submit your expert opinion to our Parliament's select committees helped us to accomplish important steps forward.

We have also been the beneficiaries of the many initiatives you have taken to create and sustain the World Federation of Right to Die Societies; it is a human rights organisation we are proud to belong to. Please accept our heartfelt thanks and our good wishes for the future.

**Janis Landis,
Past President Final Exit Network,
USA**

Final Exit Network (USA) extends its thanks and appreciation to Rob Jonquière on his retirement. Rob has done an amazing job of overseeing a complex organization of many different countries and languages as well as varied stages of right to die legislation. In particular, we want to mention Rob's outstanding efforts in responding to the assault on death with dignity when former WFRtDS President Sean Davidson was arrested. We are all indebted to Rob for his tireless work to raise funds for the legal defense and to keep all member organizations updated.

We join all others working for end-of-life autonomy in wishing Rob a happy and healthy retirement.

**Asunción Álvarez,
President WFRtDS, Mexico**

I feel very fortunate for my friendship with Rob, built over several years of collaboration. First, as someone who consulted him from Mexico to clarify all kinds of doubts about MAiD and the WFRtDS; then, from 2018, as part of the WF committee. During the time I have been president I have had a closer relationship with him and a more frequent communication which I appreciate.

Rob is a person who stands out for his kindness, organizational skills, and willingness to help. He is undoubtedly one of the most knowledgeable and experienced people in the right-to-die movement; he has championed and promoted it in his own country even

before it was a legal option and then around the world as Executive Director of the WF where he has been central to its functioning.

My admiration, thanks, and best wishes to Rob in the next stage of his life.

**Sten Niklasson,
Board Member of the Swedish Rätten
Till en Värdig Död and Board Member
of the WFRtDS**

The continuous debate on the benefits of global fora like the United Nations and its predecessor The League of Nations, frequently ends in the conclusion that if they did not exist, one would have to invent them, however difficult to manage, because the world simply cannot do without international mechanisms for cooperation and resolution open to all states.

Similar conclusions may be voiced as to the usefulness of the WFRtDS, a global non-profit organization, currently including some sixty members. Had it not been for its long-time Executive Director, Rob Jonquière, whose energy, and sense of conciliation have steered the Federation away from split and disharmony, its fate might have been less felicitous and local right-to-die societies deprived of its coordination and information services.

Best regards

**Peter Gowin,
Executive Director, Austrian Society
for a Humane End of Life**

Our interactions started in 2019, right after the establishment of the Austrian Society for a Humane End of Life (Österreichische Gesellschaft für ein humanes Lebensende, ÖGHL), when ÖGHL considered becoming a member of the World Federation. We had a very fruitful initial exchange of ideas and views, both at the personal and the professional level, which quickly led to ÖGHL becoming a member of the World Federation in 2019. One of the first entries of the News Section on ÖGHLs website is your welcoming message as Executive Director of the World Federation, dated 'Amsterdam/ Geneva 24 July 2019'*.

Membership in and interactions with the WF and several of its working groups were most helpful in the development of our society, but also, with your support, in gaining a global profile and recognition.

On behalf of the Austrian Society for a Humane End of Life and in my personal capacity I would like to express our gratitude and appreciation for work you have done for the World Federation and, in particular, in support of the Austrian Society.

With best personal regards

*accessible at <https://www.oeghl.at/news/grussbotschaft-der-wfrdts>

**Jean-Jacques Bise,
Co-President Exit A.D.M.D., Suisse
Romande**

Rob Jonquière has decided to retire. His extensive knowledge of end-of-life issues, his availability and his great commitment to the WFRtDS have made a major contribution to the development of legislations on dignified dying. EXIT A.D.M.D. (Association pour le Droit de Mourir dans la Dignité) Suisse Romande thanks him sincerely and wish him all the best in his retirement.

**Nathalie Andrews,
honorary Co-President,
and Annie Wallet, Co-President of
Association Le Choix, Citoyens pour
une mort choisie, France**

Rob Jonquière, a man we all know and appreciate for a long time! This retired generalist and long active at the NVVE is an essential reference within the World Federation. Always ready to answer questions and find solutions, his work throughout these years has been appreciated by WF member associations.

One day, he said: 'I gained my first experience with euthanasia as a GP in the 1970s.' It's our turn today to say that his commitment has never wavered. Thank you, Rob!

Last but not least, Rob is also passionate about the famous Citroën 2CV. He has been driving it for many years and with his oldest son takes part in historic car rallies.

Life is a book composed of several chapters, we wish him to write a new one just as successful as the previous ones.

Gosh, much of your life was dominated by death, Rob. As a GP you already performed euthanasia. Later, you became director of the NVVE and then secretary of Right-to-Die Europe and CEO of the World Federation.

What can I do for you?

Um, is there such a thing as assisted living?





Colophon

This is a publication of the World Federation of Right-to-Die societies (WFRtDS) on the occasion of the retirement of its Executive Director Rob Jonquière in September 2024. The text reflects his personal experiences and memories. Where possible and where necessary, these have been checked with stakeholders.

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Former general practitioner and manager Rob Jonquière becomes closely involved in the fight for a dignified end of life in 1999. He is director of the Dutch euthanasia association NVVE for less than a week when Minister Els Borst submits a bill, which will eventually become the world's first nationwide euthanasia law. During his directorship, Rob also takes on duties for RtD Europe, the European umbrella organization of sister associations. Later, when he retires from NVVE, he has a prominent role in the World Federation of Right-to-Die Societies (WFRtDS). Throughout his career, Rob has meant much not only to this struggle in the Netherlands, but also in countless other countries. On his retirement in September 2024, the WFRtDS donated this book to him, chronicling his life story.

Former WFRtDS President Ron Plummer:
'Rob was the backbone of the organization'

Silvan Luley, representative of the Swiss federation member Dignitas:
'Rob's diplomatic nature has always impressed me'

Ingrid Kuhlman, President and co-founder of the Icelandic Right-to-Die society:
'It is partly thanks to Rob that we have made such good progress'

