

# Derecho a Morir Dignamente (DMD)





Constelación  
de los Comunes

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Person interviewed  
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### **Who are you and what is your relationship with *Derecho a Morir Dignamente*?**

My name is Fernando Marín. I became a doctor in 1991. Then, I worked mainly in primary care in various social and health care settings and around the end of the 20th century, in 1998, I began to work more in at-home palliative care, attending to people who wanted to die at home but couldn't find assistance. And, around then, I also began my activism for the right to die with dignity, for voluntary death, for the recognition that being able to make decisions about one's own life is an important cultural element of our rights. And currently, I'm vice president of the association *Derecho a Morir Dignamente*. I work for the association, providing advice from a medical point of view on end-of-life decisions.

### **Where are we?**

We're in Madrid, Spain. The headquarters of the Federal Association is in Plaza Puerta del Sol, at kilometer zero. And then, there are several different organizations that make up this association of associations.

### **How did the idea of forming this group come about and who was it founded by?**

*Derecho a Morir Dignamente* was started in 1984 as the personal initiative of a mathematics professor who, a few years later, founded the group in Madrid. He wrote a letter to the editor and about twenty people replied to that letter. And from then on, they started meeting in cafeterias and the organization started to emerge. He attended an international congress because several similar associations already existed in other countries.

It took a while to get it legalized. There were some problems with the Interior Ministry when Felipe González was president, and then the association left, the professor went to live abroad, and in Barcelona they took up the fight. Salvador Pani, who gave a lot of support to the Catalan group, was fundamental in that intermediate stage. And then, somehow the association came back to Madrid. Madrid has been the most dynamic group ever since, and it's where the headquarters of the organization is currently located.

### **What legal form does the organization have and why?**

It's a non-profit association that is financed exclusively by membership fees. We do not ask for any public money, any subsidies, any outside help. Sometimes we use university infrastructure, educational infrastructure, local libraries, but no outside money. There are some federated



associations that correspond to the autonomous communities. The autonomous communities still haven't decided what to do, but well, that's our project.

### **Are there permanent employees that work for the association?**

Yes, there are six people that work full time here with a fixed contract that work in different areas with the technical team. So, there is a communication area, a press and media area, an area for activities with all the groups across Spain, activities with all the groups in Madrid, an administrative area, accounting, and so on. And then, there is a transversal work team, which is the personalized attention provided by the people hired in the technical team, which deals with living wills, end-of-life rights, a guide to voluntary death, euthanasia, etc.

### **How would you describe a typical member of the association?**

The typical member is a 60-year-old woman with higher education. Which makes sense because the people who are most concerned about end-of-life rights are those who have their basic needs covered. This is an association, so in that sense it doesn't reflect the socioeconomic diversity of society at large, right? It's like other associations that are political, religious, cultural, intellectual, or artistic. It reflects that other percentage of society. It's made up of people that come from a higher socioeconomic status. So, the typical member is a woman in her sixties, a professor, who has her own sense of freedom. So, very genuine, very authentic.

### **What other groups or associations exist in Spain that defend the right of a person to choose how and when to end his or her life?**

Well, in Spain, there are other associations that also argue that it is necessary to have a euthanasia law, which is a law that we have now had for a couple years. They also promote living wills that respect and defend the wishes of each person until the end. Not as their main goal, but as something they also support. That includes pretty much the entire social fabric that defends human rights, minority rights, family planning, that respects a pluralistic society, that defends the voluntary interruption of pregnancy and the bodily autonomy of women, that defends LGBTQ rights. Of course, there's some nuance, too. For example, there isn't unanimous agreement surrounding the trans law. And, it certainly doesn't have to be that everyone agrees. And, in the case of euthanasia, almost all associations share this ideology, except those that belong to the Catholic Church or very conservative religious movements. And that's why social surveys show that there is overwhelming public support for these rights because the majority of the population agrees.

### **What does it mean to die?**

Well, dying is the stopping of the clock. It's turning off your brain and your body. Your heart stops beating. Your lungs stop breathing. Your body cools down and your self disappears. That is dying. That's why there's an intermediate situation between life and death, which is called a vegetative state, in which there is very serious brain damage but the person is still alive. The person is still breathing but is no longer there. When an organism no longer functions, it dies. Because life begins with birth and ends with death. The opposite of death is not life; the opposite of death is birth. So, everything has a beginning and an end. And this is how the life of living beings is made. All living beings that are born at some point have to die and their biological life ends.

**You mentioned the vegetative state. From your perspective, is a person in that state alive or dead?**

For me, yes, that person is dead. It's a form of being dead. There's no human life. There's still a living being there, but it resembles something more like a snail, or a snake, or a lizard than a human being. If we think about what makes us different from other mammals, like apes, or even dolphins and whales, what really makes us different? Well, there's a gigantic leap in intelligence. It's the ability to manufacture objects, to create art, culture, to make something out of nothing. That is exclusively human. And when you lose that capacity, well, you lose your humanity.

That doesn't mean that you're nothing when you are in a vegetative state; I think you are still something. And also, because we recognize that you are one of us, we respect your existence, we respect your body, we treat it with certain care, because we believe that the concept of dignity also extends to that situation. But the capital-D Dignity that we speak of when we talk about dignified death, comes from the idea that everything you do with your life depends on your freedom. That's what gives it substance, isn't it? It's what makes you human, what differentiates you from those other living beings, which also deserve respect. For example, people who have pets love their animals very much and give them a lot of affection, but they're on a different level aren't they? I wouldn't say it's worse. It's just different. You're no longer human.

**Why do you think it is taboo to talk about death in our society?**

Well, death has always been a taboo. The thing is that death used to be much more commonplace – it still is in some parts of the world. I mean, it wasn't until around 1940 that antibiotics were discovered. And if your dog died, there was a good chance you would die, too. That still happens in some parts of the world, although less and less frequently. And there have always been old people, but there have never been so many people who have become as old as they are now. And women used to die all the time in childbirth. Every family would have a baby or child that died, usually from infections. There used to be deadly epidemics of disease.

But, so, we lived with death. Unfortunately, in some countries, death is still very present in many cases. Sometimes, it is avoidable. Even if it's not violent, it may be caused by humans somehow. And, in the developed world, what has emerged is a fantasy that, with the medical technology we are inventing today, we will be able to postpone death indefinitely. Well, really what's happened is that death is being made invisible. Because death is so final, so unavoidable, it seems better to live ignoring it. And so, it always seems that other people die, that it's their turn. In Madrid, 120 people die every day, but we don't see them. They're in morgues, hidden away in funeral homes. I believe that it's possible to incorporate death into our culture and talk about it from time to time. And that it's healthy to do that.

**Do you think that the Catholic tradition of Spain has something to do with this social taboo?**

Yes. Religions have used death in a very twisted way, as a sort of emotional blackmail. Just like they have done with other things like sex or freedom in general, right? It used to be that if you wanted eternal life, you had to behave according to their moral criteria. Sometimes, it was even sold economically, wasn't it? Popes sold a kind of passport to heaven. Now, you also have to take into account that, say,

100 years ago, the vast majority of the population was illiterate. That's why they needed those stained glass windows, those cathedrals, that nonverbal language to be able to demonstrate their power, that there was something there.

And then also, people suffered very much. They had to try to survive. There are movies like *The Name of the Rose* that are set in the Middle Ages. You get to the end of that movie and you see that life was very, very difficult. You see that life was essentially about making it to the night alive. And hoping that during the night you weren't eaten by a wild beast, or killed by a soldier, or raped, and so on. We think that life has always been like it is now, but no, life was very, very hard. And so, it was very comforting to be sold the promise of heaven in those days.

It is still comforting. I like the metaphor of heaven because we need stories, too. It doesn't matter that it's not true, it doesn't matter that heaven doesn't exist. What matters is that if a loved one dies, he or she no longer suffers. Whether or not they are "somewhere," they will be in your memory, or in the stars when you look up at them in the sky. As the poet said, "you are the eyes of dead friends who remember the earth." No matter what, you feel it, you feel the presence of a loved one, you have that love that is real even if it cannot be measured. And that does exist. And with that, you console yourself until death reaches you too, of course.

### **What does the concept of "dying with dignity" imply?**

To die with dignity is to be able to die as you wish. So, the first thing would be to realize that you are going to die, or that it is possible for you to die. Then, you have to have an idea of what you would like to avoid or what you would like to have around you when you die. There is still too much collective silence, where everybody knows that someone is nearing the end but nobody wants to talk about it. Of that elephant in the room. That's a problem because it leaves you very lonely, it leaves you much, much more lonely than you already are. When the grim reaper points at you and tells you, "I'm coming for you," you start to feel differently. You feel like you're part of a different world, the world of those who are going to die, don't you? Sometimes those people identify with each other and have their own language. As if, the world of the living, the world of the healthy, doesn't understand us. It is very hard to relate to a person who's only going to live for a few months and they know because you can't ignore them but you also don't have to be extremely accommodating. You have to talk about them and want to. And you have to endure the straining, the venting, the crying, the complaining, the anger, the rage. To get through all of that, to go through this process, and to get to the end.

And the challenge is that death is a liberation because you're condemned to die at a certain time. Because your life is ending as a result of your disease. That is something worth accepting and fighting for. And that is what dying with dignity means. It's about not running away. Is the impulse of climbing up to the second floor and throwing yourself off a dignified death? I don't think so. It's hard to explain. I don't condemn it outright either, but I find it chilling. It's not very humane. We are social beings. We're meant to be with others, to live together and die together. That's a dignified death – to die well, based on how you want to die. If you want to die sooner, you should be able to do it. If you want to die because you are fed up and bored, you should not have to do it alone. You should not have to do it with the threat of the police, or a judge, or the legal system, getting involved. And

you should be able to get to the end of your life the best way possible, right?

**It's possible that defending "dying with dignity" could be interpreted as an invitation to normalize suicide. What is your opinion of that association?**

No, it's not an invitation to anything. First, because you cannot invite anyone to commit suicide. That's a very serious decision. You can see someone who at a given moment loses control in a lapse of judgment and does something crazy. If you throw yourself in front of a train, you have to decide to go to an area where the train passes, and you have to walk along the tracks. But well, maybe on the subway it's easier. There are always unexplainable events and, so, it's not easy to explain.

But I think it's true that rejecting one's own life is something inherent to human nature. From a very, very young age, from the time we begin to reason, we know that we can die and that we can provoke our own death. Because our brain teaches us so. Because we've seen it, we've heard stories, we see it with our own eyes. If I do this, I die. So, instead of being a threat, I think it's an opportunity, it's an invitation to take advantage of your life.

That is, it's a sensitive topic because we end up talking about things that are relevant to ourselves. We cannot compare the suicide of a 16-year-old boy or girl who has had their heart broken and is distraught, or who suffers from bullying at school or whose parents are absent, or who is very contemplative and doesn't understand the world or is anxious about climate change, for example. We cannot compare that with the voluntary death of an 80-year-old woman who has already lived and is looking back at her life. She looks back, reflects on her life and says, well, I don't want to live any more. I'm going to plan it out, and I'm going to die. I think the outcome is the same, but you still cannot make a comparison. So, there can be a beginning and an end.

I don't have an answer for everyone. Because, for example, I know that the son of the friends of some friends – I don't know them – their son, hanged himself in his room at the age of 22. His parents were away for the weekend. Apparently, everything was normal. He was studying philosophy. I can't speak to that, and I don't have any answers to these questions. There's something about it that is mysterious, intriguing, and chilling. There's something a bit scary about that type of voluntary death. But fortunately, I don't work in that field. It's easier for those of us who deal with the other side of voluntary death.

**Legally speaking, is dying with dignity a social right?**

Yes, yes, yes. The law defines it as a benefit, a right, in the sense that you have the right to be given an IV line and a barbiturate that causes your death. It's a pleasant death. Anyone who has had a colonoscopy or an imaging test and has had to sleep knows that you go from wakefulness to sleep with a wonderful high. And what happens is that during that sleep you stop breathing and you die. It's a very good death. The question lies in making the decision beforehand. The whole process is the important thing.

**What does it mean to die by euthanasia? What does it consist of?**

Well, euthanasia is an assisted death. As such, it requires the participation of health professionals: doctors, nurses, sometimes psychologists and social workers as well. That's what the law defines as euthanasia. In every

euthanasia or assisted suicide law, you only want to consider that option in the cases where the situation calls for a framework in which there is that drastic context. Outside that context, you don't have that right.

That basic context varies from one country to another. In the case of Spain, there are two groups. One group is the seriously ill, incurable, with a limited amount of time left to live, terminally ill with cancer and severe chronic disabling illness. Another group is those who don't have a terminal prognosis, like Ramón Sampedro who was a quadriplegic. It includes people who have dementia or that still face years of a neurodegenerative disorder such as neurotrophic keratopathy, Parkinson's, etc. Or, an elderly person with several diseases that makes her dependent and physically limited, so that she cannot support herself. So, that's what the law says.

So, if you meet those conditions, you can apply for euthanasia. You go through some procedures, and wait for approval. And, then you decide the day you want to die, either with intravenous medication, which is euthanasia, or you take it orally, which would be considered assisted suicide. And in other countries – for example, the Netherlands, Belgium, and Luxembourg – unlike Spain, proving dependency is not required. Instead, you just have to prove constant and intolerable suffering. But, it's more difficult to prove that for people suffering from psychological distress caused by a mental disorder. It's not that it's not possible, it's just that it's not as clear. If it's not clear then that's a problem because you need a medical professional to be responsible, you need another consulting medical professional, and then you have to pass a previous verification by a commission. So, requests up to today, with one exception, are being denied in the case of mental disorder.

### **Who can request euthanasia?**

Fernando: You need to be Spanish, either by nationality or by residency, with a residence permit to be registered in the census for a minimum of 12 months. You have to have been here for 12 months, or be a resident, or have a DNI. And you apply through whichever doctor you want. Family doctors and primary care doctors are the ones who are resolving about three-fourths of the applications.

### **What does the process of requesting euthanasia consist of?**

Yes, the process, as it has been conceived of in Spain, something that the legislative group that proposed it wanted to ensure, is that: you make a request on day 1 to your doctor, the doctor makes a decision within 48 hours, and then you can make another request after a minimum of 15 days. In the meantime, the doctor informs you of the palliative treatment options available, if there is a residential option, a type of social assistance. In case you need further evaluation according to the request, the doctor goes through a second decision-making process, you sign an informed consent and you go to a third consultation with another physician separate from the responsible physician. The consulting physician makes his report. And, if the responsible physician and the consultant physician give you a favorable report, you go to the commission. All the papers are sent to the commission and the commission verifies it and documents it. Sometimes the person is interviewed, either just the applicant or with the professionals, but most of the time the requirements are met and they give you what you want.

### **Who is or are the members of the commission for the evaluation of requests for euthanasia or assisted suicide?**

The commission is mostly lawyers and doctors, as well as some nurses, social workers, psychologists, community representatives, and people from social movements. The people are appointed by each health department or each counseling department. There's a lot of variability in how many people get appointed – the law only says that there must be a minimum of seven. Three doctors, three jurists, and a nurse. And from there, each community chooses what it wants to do.

### **Are there selection criteria for choosing the people who evaluate cases?**

No, and that's one of the problems that we have had, that we are having. I don't know to what extent it's avoidable or not. You also have to grant some room for error, some room for improvement. When you are starting a new service, you start from zero. So, it's true that the communities reacted late, some did it better than others, and then some have a cultural tradition of working better than others. That is, Catalonia works better than Andalusia. But that's how it's been in the case of euthanasia. So, well, we will see whether there will be new people appointed, or who have their positions renewed, in a few years. Let's hope that better choices will be made during this second generation of commissions.

### **How many requests for euthanasia have been received since euthanasia was legalized in Spain?**

Well, in the first year there were 75. In the second year, there were 270. And during this year, there will probably be more than 600. I started in June, but there were none until January in Andalusia because they had not done their homework. So, the first year doesn't count. The second year they were just starting. So, in 2023, we will see where things go.

### **What is assisted suicide and how does it differ from euthanasia?**

The difference between assisted suicide and euthanasia is who performs the last act prior to death. If you do it yourself, it is assisted suicide. If you are assisted by health professionals, if they give you the medication, it's euthanasia. If you have an electronic device in your nose because you can only move your nose and you activate the order on a computer to start an IV injection, then it's hard to say. Because someone has had to put you on the IV. You are the one who commits the last act, strictly speaking. So, the bottom line is that there isn't much of a difference. It's all voluntary death, and what it comes down to is the choice. A person chooses to do it, and that's that. That's what the process is fundamentally about.

### **Is it illegal to assist a person who voluntarily wants to end his or her life?**

Yes. In Spain, there are two crimes related to suicide. One is encouraging someone to commit suicide, which is a theoretical crime because it would be convince you, convincing you that you have the desire to die. Which if you're a person of sound mind is practically impossible. But well, at a theoretical level, it could happen as such. And the second crime is necessary cooperation to commit suicide, in such a way that it would be some form of assistance without which you could not have made the decision to die. Information is not considered necessary cooperation. The accompaniment of a person aware of what he or she is going to do and aware of its consequences. Nor is it a necessary act. A necessary act would only be if you bring a glass containing poison close to a quadriplegic person. But if you don't, then there's



no crime. That is, practically speaking, the suicide as such goes unpunished and the accompanied suicide goes unpunished. Only the necessary cooperation can be punished. The problem is that then you have to explain that to the judge, of course.

### **Can a person request euthanasia or assisted suicide in the case of minors with cognitive disabilities?**

We cannot help people to die who have not displayed their clear and unequivocal will. So that includes the very painful case of children who are born with severe cerebral palsy who never get to speak, never get to eat alone, never get to go to the bathroom alone, and sometimes make it until they are ten, twelve years old. It's very tragic, but these children cannot be helped to die with assisted suicide because they have not made any request.

### **What happens in the context of Alzheimer's and dementia?**

You can only do it when a person is really of sound mind, or when it is written in a living will. So, in the case of dementia, they can be helped, but only if they have clearly expressed it in their document.

### **When should a living will be made?**

I believe that a living will should be drawn up as soon as possible. When one remembers to do it, it's quite easy to get through the formalities. Pretty soon you'll be able to do it electronically, with a digital certificate and so on. Otherwise, depending on the autonomous community, you can go to one of the granting offices and do it, or at least make the document with three witnesses. In some communities, it has to be done in front of a notary. Then, you have the will and you can send it to the registry. And then, with time, when you reflect on it again, you can make changes. Because, specifically, I don't really like the text of the law declaring the right to die with dignity. It needs to be improved. We need a second version. We have to start working on it, but it was the best we could do. They tried to adapt it to the terminology of the law. To be clear, because it's a very difficult question to answer, which is: if I don't know that my name is Fernando, that I'm in Madrid, working with *Derecho a morir dignamente*, and I don't remember that I have dementia, then what do we do? If I don't remember that I wanted to die when I was like this, because living like this for me is a life that is devoid of dignity. Since I have no concept of time, I have no life trajectory, my biography has ended, I suffer. And how do we deal with this suffering that the person with dementia cannot relate to because the dementia itself has killed his ability to express himself with language?

So, this puts us in a complex situation that we have to solve. The law supports it. The law is very brave in that sense because, in that sense, it is more forward-thinking than that of Belgium and even a little bit better than that of the Netherlands. And it says, no, if you haven't expressed that desire in a living will. You have to respect the living will. Because then you were Fernando, now you're what's left of Fernando, you're the body of Fernando, but you're not Fernando, you're no longer that person. Since you're no longer present, you're not that person. Maybe you remember something very remote, but you have no values, you're not able to make a sentence longer than four words. Therefore, you're not able to express your thoughts, to achieve any sort of complex thought. And you've also said that for you living like this is a life lacking dignity and that it is a constant,

intolerable suffering. So, please let others help you. And that is the challenge we have now, that not everybody understands. It's that they don't see that need.

**There will be those who consider that the living will is being made without proper information; would you agree with this statement?**

I don't agree with when it is usually applied. Because if you think about the context in which it is usually applied, when life is coming to an end, you can't express yourself if you have brain damage. If you don't know what your name is and where you are. You don't know the people around you. That's very severe brain damage. It's not mild dementia, it's already advanced quite a bit. The person is already delirious. Sometimes delirious and sometimes doing things they would never have done before, things that are embarrassing, that don't fit their personality, because that person is changing. Either they become aggressive or they start wandering around senselessly, the put themselves in danger. So, by that point, the train has already left the station, so to speak. I tell people, if you've been diagnosed with this disease, do it now, don't wait. Because if you wait, the train leaves and it doesn't come back. So you say, what's the choice? The choice is – I want to go on like this, or I don't want to go on like this. But the situation is so serious that, for me, I think it is intuitive. You know either you want to keep going or you don't.

There are people who say, "Hey, I don't know how I'm going to be." There are even groups of people who tell me "No, if I don't know, I don't care." Well, that's fine, everyone can decide what they want and that's where to go. That's where you have to dig deeper. I don't know the answer, but if you start watching videos, it's like you've met someone. You realize what it's like to be there with dementia. "Come on, come on, let's go to the toilet." What if you aren't able to pee and then later I have to take you home with your jeans soaked. "No, Dad, come on, let's go there." You have to run after them. Well, that's what shows up in these videos. For me, that's serious enough that I would want to die.

**27) Do you think that if there were more information and better education about the transition to death, the number of living wills would increase?**

Of course, because making a living will is related to the taboo of death. We ignore that death exists. We ignore that there is a paper that can say what happens when I die. If I'm in a state that I cannot express my will, I don't want to prolong my life any longer. I don't want to make other people have to care for me. I have the right not to be cared for. I also have the right to be cared for, of course. But, I don't want anybody, any person – any woman because it would surely be a woman – struggling to get me up and put me to bed because that's absurd. I don't see the point. I have a different perspective, that it should have a purpose. But that's just my opinion.

**How should we interpret "lucid suicide" or "self-liberation"? What differentiates it from euthanasia and assisted suicide?**

Euthanasia, assisted suicide is a medicalized death. Therefore, you enter into a framework of diagnostic thinking. That is, from the complaint to the symptom, the symptom to the syndrome, from the syndrome to the disease, and on to the diagnosis, treatment, prognosis. So, within that frame of thought, the way medicine operates – which, for example, has many problems in defining what a mental disorder is – nobody knows what to do. You place yourself within that framework and you may

come across euthanasia as an option. If you want to die and either you don't want to count on health professionals or you don't meet the requirements for euthanasia, it has to be by means of a lucid suicide or self-liberation. Self-liberation includes assisted suicide, but for assisted suicide you need to meet those requirements. You decide that on your own. Maybe you meet them and maybe you don't want to resort to them.

A few days ago some doctors came, including a neurologist, more specifically a neurophysiologist, with whom I had worked quite a bit as part of a team. And one of them said, "Of course, I'm going to see if I can get pentobarbital because I don't want to contact anyone. I don't want to tell anybody" And they were doctors! "Because you know that then they start saying such and such and I just want to do it on my own." That is, there are people who, from within the system – although they have all retired already – but they distance themselves from assisted suicide because of their own way of being and others who would never ask anyone for anything, but they want an assisted death. That other person, then, makes up the plurality, right?

### **Is voluntary fasting (VRF) a form of lucid suicide?**

Inducing death by stopping all eating and drinking is a very interesting case. It's something that has always existed. A Galician doctor wrote a book about how when ladies in the villages sensed that death was near, they would tell their sons to take out a box. They would get into bed and five days later they would die. Of course, that's a process that involves stopping all eating and drinking. When you're older, you have kidney failure, heart failure, so, of course, it's very easy. Death comes much sooner. I'm familiar with some cases and they have gone very well, but you have to pay close attention. You have to count on medical and nursing assistance in case you start needing care because, ultimately, it's similar to the palliative process of dying, from cancer or any other disease. It may seem like a really crazy thing to do, as if you were going on a hunger strike, but it's not like that. It's something else.

### **Keeping in mind the scenarios of euthanasia and assisted suicide, what assistance do both the person and the family receive from the healthcare system in those cases?**

Well, in general, euthanasia is working well. Once you start the process – that is, once the doctor in charge says yes, that he is going to help you – usually a nurse in charge is also present and the doctor and nurse accompany you throughout the process. On the day you choose to die, they go to your house, they put the IV in a while before, sometimes the day before, they talk to you for a while, you say goodbye to your loved ones and you die. And it usually goes well. That's the accompaniment process. In other cases, the system says no, and then you have to do it on your own, of course.

### **Do people who ask for euthanasia tend to be of a certain social class?**

That's a good question. I think so. Euthanasia is a bit elitist by its very nature. It doesn't mean – I remember that we were misunderstood once when we said the poor don't ask for euthanasia because they have other things to think about. That makes it sound like the poor don't die. No, that's not what I mean. Instead, what I mean is that reality shows you that people who are concerned about their dying process, in general, have their basic needs covered. They're not people who live on the street, who are going to be evicted, who are in poverty. Because in those circumstances you're just surviving. You don't plan. You don't know if tomorrow you're going to have a roof over your head because you're in a homeless shelter,

or you're staying at someone else's house for a while if you are in someone else's house. If in that process you get a serious illness, you die or you go to the hospital, that's it. It doesn't mean that you can't ask for it. Of course you can ask for it. Not all people who ask for euthanasia are well-off. No, some are not. But, in general they tend to be wealthier. Euthanasia is not typically something chosen by the poor, we could say. Not because they're excluded, but because of the nature of the decision.

I don't really know. It's a little bit more speculative and we would have to be more cautious, but it's something we should give some thought to. It's an issue we need to look into. That's true. What we've seen in the data from Belgium and the Netherlands – which have already had more than 100,000 cases – is that vulnerable groups don't show up. Immigrants don't tend to die by euthanasia. The data from California are very interesting because they show that African-Americans don't request assisted suicide. Roma people generally don't request euthanasia. Not all of them, of course. It's a generalization. But, then there are factors related to culture, religion, and group cohesion, which mean that people who would like to ask for euthanasia cannot choose to do it because of how their families feel about it. That's still happening today. But everyone has the ties they have and the obligations they create. And to die freely you have to be free.

So, sometimes there's this fantasy of having a "free death." In other words, I want to die voluntarily when I decide to die. And it turns out that you don't decide anything in your life. I'm sorry, but it's not just about you. You have to work on it at a personal level, at a family level, at the interpersonal level, at a more intimate level. And, of course, if you're always worried about not disappointing others, you let others make decisions for you. That is, sometimes it's scary to make these decisions yourself. Because now that you're talking about death for people over 75 who've lived full lives. Well, the elderly people who let their families make decisions for them, who let their families put them in nursing homes, are never going to say anything because it is their way of going about things. Most people don't choose a voluntary death. In the Netherlands, about 96% of people die naturally, and in Belgium it's 98% or 97.5%. In other words, the vast majority doesn't decide to die voluntarily, even though they have that right. It's there for people belonging to minorities, it's there for everyone. And among those minorities, there's a personal process to be worked on.

### **What does it mean to die badly?**

Oh, man, dying badly is, for example, to die in an emergency room when you see that things are going badly because there's no bed or there's no room. Or dying in a hospital because you're not getting enough medication. You're in agony – agonizing for an hour, two hours, 12 hours, 24 hours, 48 hours. Just agonizing with a semiconscious expression starting into infinity. Let the doctor come to you and say no, I can't give you any more. Which is not true. To die badly can also be because of a messed-up situation, for dying alone, abandoned like during the Covid crisis. It's not that some of those people wouldn't have died, but they shouldn't have died like that. Alone, or next to someone who died a day or two ago. That really happened. It's deplorable. There are cases where you die suddenly because you have a heart attack. Well, that depends on chance. That's just the death that you ended up with. There's no decision to make, you cannot avoid it. But the other deaths, that you know are coming, are bad when a person suffers unnecessarily.

### **Can you explain to us what agony consists of?**

Well, it's a process in which there's a clear physical deterioration. Death is approaching, and you can see it as the level of consciousness decreases. Sometimes there's delirium, a little agitation, their eyes and nose start to sink. The person is sweaty, pale, sometimes with blue lips. Their breathing pattern slows or changes. Their temperature changes. All of this tells you that this person is going to die in a few hours, maybe 24 or 48 hours at most. But they're approaching the end. Then, if the patient is also in the hospital, you can see that they are not urinating. You can see that their blood pressure is very low and that it drops little by little and they get colder and colder. Then they get a fever. The agonizing process of those last hours begins with rhythmic, unstable breathing and then the breathing stops.

### **There are those who argue that agony is part of the natural process of dying. What is your opinion of that argument?**

Death is not like in the movies in the sense of "Oh, Paco! Lola, I love you so much." And then you die. That doesn't usually happen. Usually, the deterioration makes you suffer. It manifests itself with those symptoms of agony. It's very unpleasant. It's like drowning. And if your eyes are open then you melt into semiconsciousness. If you really want to go that way, then that has to be respected. But if you have an interest in dying in your sleep, it should also be respected and be part of the cultural standard set by medical authorities, right?

### **What is the best context for dying with dignity?**

The best context. Man, having a long life and then dying after a short illness that gives you enough time to say goodbye to your loved ones, that doesn't force you to endure a slow deterioration like with neurodegenerative diseases, that allows you to maintain your cognitive level, that doesn't make you disoriented. You make it to your 80's and then you die. I think that's the best way to go.

### **How should family and friends support the process of dying with dignity?**

Fernando: It's always better to die at home because it's the space where you're most comfortable and there are enough resources and enough support to guarantee you a good death, it's at least as good as a hospital.

Palmar: It's like accompanying the family, how family and friends should be accompanied.

Fernando: Or, one, accepting that death is coming. Two, respecting and exploring what that person wants. It's also about respecting when the person doesn't want to say anything, knowing that there's something they don't want to say. Well, you have to wait. But you also have to create that context of being open, of being able to have unpleasant conversations, being sad, crying together, being in silence together, naturally. It's about joining them on that path that is coming to an end and asking, "What do you want? How can I help you? I'm here to help you." That's what it's about, right?

### **Since death is inevitable, why is euthanasia negatively stigmatized?**

The problem is that there are people who firmly believe that God gives life and that God takes it away. They see it as you're sinning and they're on a mission to prevent sin around the world, right?. It doesn't matter if they're Christian or Muslim or Jewish or Buddhist. They want to prevent other people from sinning. Buddhists less so because they have another way of thinking. But all monotheistic religions oppose allowing women to interrupt their pregnancy, for example. Similarly, they don't understand or accept a person's desire to avoid a painful death. Until recently if you committed suicide you couldn't be buried in a Catholic or religious cemetery. They would burn your property. Anyway, it was like that because a long time ago when you were a slave you were the property of your owner and now you're the property of God. They are beliefs that they try to impose on us for "our own good." But well, fortunately, we live in a pluralistic society.

### **Legally speaking, what changed so that it is now possible to request euthanasia?**

Well, legally it was decriminalized. A new article was added to the Penal Code, which states that it's not if it's done in accordance with the law. So, it's no longer considered a homicide, it's not a crime.

### **How has the medical profession responded to this new legal framework?**

Well, the medical corps, the medical class, health professionals – they need to improve. The response is positive in many, many – I don't if I'd say territories – but there are regions that are better than others. But, we've been living through a moment of crisis in which the public health system in Spain has been really stretched thin. The pandemic was sort of the final blow, but within that context there are professionals who roll up their sleeves and help and then there are people who look the other way. There's a universal principle in all professions, which is "Don't complicate my life, don't mess with me, don't bother me with this extra stuff." Now, they'll also say, "I support freedom, I think it's fine, but don't come to me about it because it's a mess." Because it's true that sometimes you see how the law includes a decision tree or a flowchart. My goodness.

No, we're just getting through the first step. It's just the first application of the law. Then the next one will come. So, that's our job too, isn't it? To be able to explain it. Step by step, so that the professionals are committed to it. But there are also many professionals who are burned out. We're not supposed to be retiring at 50 or 55. It's something we also have to understand as teachers, as bus drivers, as whatever. I mean, it may not be the most thrilling job in the world. You will get fed up at some point. The response has been alright, but you have to go little by little. So, the response can be improved.

### **Do you believe the process of achieving a dignified death could eventually be commercialized into a market niche?**

Well, it's difficult because there's still some casuistry. It could end up, for example, the way it has in places like Madrid. In fact, there was a proposal there to try to solve the problem by privatizing it. I hope it doesn't end up that way. I don't know, but I don't have one either. I personally believe that the public health system is a guarantee of social justice and social cohesion and that you should be able to have your brain operated on by the same neurosurgeon as Severiano

Ballesteros. It's a guarantee that you can be proud of the society in which you live and that you won't not be abandoned even if you're poor. But that's now in question. It's being questioned by the extreme right and in a very possibilist way. And the advertisements are mind-boggling: "the doctor who knows you," and it's a private company. That's deplorably false. That is, they're already resorting to trying to draw people in. Well, for the moment I believe that the public system is going to respond and let's hope that it doesn't end up dismantled. Many parts of Spain aren't going to be good business because there aren't enough clients.

**The association's activity is being developed in three areas of social intervention: awareness, political action, and counseling. In order to influence social awareness, you have collected first-person testimonies. Can you tell us why you decided to make this information publicly available on the web?**

Of course. For us, these testimonies have been very important because you have to put faces to the cause. It's not the same to talk about what it's like to spend 25 years in bed as it is to talk about Ramón Sampedro – which later on Amenábar made that fantastic film about him called *Mar Adentro*. You can talk about someone who writes poems with a stick called "Carta del Infierno." But that's what you see in the movies. It's different. So, we have used people's testimonies and promoted them so that we know what we're talking about.

Because talking about death is taboo. How can we talk about it if you don't let us, if you don't allow us to talk about what it means to die well and to die badly? Let's talk about people who are suffering and who sometimes have to commit suicide in solitude. That's why these testimonies exist. And, I believe that it's been useful in Spanish society. Ramón was the one who started it on his own. And he sort of took us all along for the ride, sending those videos to the television stations.

And then from there, there's the idea that it can happen to you. That's why we're here. I hope it never happens to you. I hope you make it to 80 years old. That you're in the park watching your grandkids and you die right there and that's it. That's great. Well, maybe not with your grandkids. It would be better to die when you get home, so it won't be as messy. But you should be able to have that lovely death, it would be great. But life isn't like that. Life sometimes deals you some cards that are very difficult to manage. So, what do you do? Well, you're allowed to finish and not have to worry anyone.

**Do you think that dying with dignity is taught in schools?**

The taboo of death exists, and it also exists in schools. Little by little, in some schools, there are activities being developed that deal with the subjects of a living will, what's a good death, how death can be measured, what can be done to have a good death. The issue of euthanasia is that it has been around, but that due to the social taboo it's not very common.

**Is this studied in medical school and are health personnel trained to deal with this type of situation?**

No, medicine has always been very resolute and when it writes about itself it's very complacent. And that temptation towards omnipotence, that we save lives and we're going to be able to live 120 years without getting sick – all that is untrue, completely

untrue. No, no, medicine isn't about saving lives – sometimes it does – but above all, what it does is to improve the quality of life of people, delaying death as much as possible. And because of that perspective, palliative medicine has had a hard time. And, well, when we know that someone is going to die, what do we do with them until they die? They have needs that have to be met. Not just pain. They also have anxiety, anguish, fears, and last conversations. Everything that goes along with saying goodbye. And, if they want to move their death forward, what do we do? Well, we also have euthanasia. All of that is being incorporated. But, it's sort of the last priority.

### **Does the idea of dying with dignity align with a certain political leaning?**

Civil rights are always won by the left for the whole population, for all of society. That's the history of humanity. It's sad, but that's how it is. Women's suffrage, well, the left had a big impact. But to bring about feminism and abolish slavery, the left, leftist thought did the heavy lifting. So, ever since the emergence of left-wing political thought, the left has promoted civil rights. Sometimes, there have been steps backwards because it's not always been a rose garden. And, leftist thinking has always emphasized making sure everyone has these rights.

I don't want euthanasia to only be for leftists, but rather for everyone. That's why 90% of the population supports it because right-wingers also know that they are going to die. But it's that kind of morality, that if you look at it and say: Why don't they pass laws? What's there? Well, there's something else there. Something symbolic that has to do with the taboo, with our religious background, that prevents us from opening that curtain all at once. When we open it, well, that's it, it will all be clear.

And, then, we will make comparisons and we will see different cases, as well as mistakes, that may exist. But, it's true that there's something there. Well, it's not a very good moment for the left in Europe right now, but even then Europe is very supportive of social rights. So, why don't countries like Sweden, Norway, Finland, and Denmark pass laws? I think it's because they solve this issue in a different way, with the double standard of the right of "we're going to do it, but we don't need to justify it" which is very, very typical of the right, isn't it. And here we are, for example, we write something down and then we justify it later, right?

### **Euthanasia has been legalized in Spain. What's the next thing you would like to request from *Derecho a Morir Dignamente*?**

Well, we would like the law to be consolidated, to the euthanasia's application to people with psychological suffering who want to die and who express it repeatedly over time and so on. Also, that the law is modified to include minors – in Belgium, there have been five cases of minors requesting euthanasia since it was approved. In other words, they're rare cases, but they still happen and those people need a solution. And then voluntary death should be recognized socially. That it should be seen as acceptable when you decide that your life is over, that your life is fulfilled. For people over 75. Otherwise, it's a little early, but, well, that date is set to be concrete. Then, how would it be regulated? What problems could there be? Who might be shocked by this and why? Because it will continue to be "ah, that's just how old people die. No, no, old people die alone." No, these are problems that need to be addressed. Those of us who defend this right defend all human rights. Of course, the right to not have to live with loneliness, inequality, insecurity, and so on.





#18

Constellation  
of the commons \ Derecho a Morir Dignamente (DMD)

### **What does the advisory work done by *Derecho a Morir Dignamente* consist of?**

Well, you come, you tell us what you want, what you're thinking. We tell you if it's realistic or not. Is it that you're thinking of installing an emergency door so that you can get out in case someday your house burns down? Or, are you really seeing that your house is going to burn down? And, those are different personal situations, right? And then we see what options you have. How can you go? There are several options, and you talk about those options to make your decisions. How to make a plan that harms others as little as possible, how to cushion the impact or how to share what you've got, help avoiding legal problems, etc.

In the case where a request for euthanasia is made, sometimes we've even gone to the person's home during the euthanasia and if it is an autonomous suicide we stay as long as the person wants us to. Normally, people usually have their own environment, don't they? There are no support groups, at least not yet. But in the future there might be, I don't know. Because maybe things will go that way, depending on the outcome of the euthanasia law. The euthanasia law might end up introducing lots of obstacles and turning out to be an insurmountable obstacle course. But, then, on the other hand, there are people who want to make their own decision, right?

### **Is counseling only for members of the association?**

Yes. It's for members who've been part of the association for at least three months. This rule was put in place to avoid bad situations. It would be very tragic if a 15-year-old kid were to impersonate a member, taking his father's ID card. If he became a member and asked for a voluntary death and decided to die after being bullied, that could happen. And, by following our instructions, right? We've tried to avoid that. You have to wait three months. If it's a recent member you get a telephone call. I believe that information empowers. It doesn't make anybody do anything or facilitate anything. I don't agree that this makes it easier for people to make that decision, and besides, we're talking about the extreme of extremes. But, well, to avoid that kind of situation we try to be prudent because it's sensitive information.

### **Socially speaking, how do you think the work of this association is perceived?**

Well, I will tell you that based on what the people who work here, and the people who come from abroad, say, *Derecho a Morir Dignamente* is the entity of reference in Spain on euthanasia, assisted suicide, living wills, end-of-life decisions. They tell us that it's quite prestigious in the sense that it's the place they can come to find the details of all these cases. For example, we've made an evaluative report because the Ministry is dragging its feet a little bit. The Minister of Health should be doing it himself, but, well, we're waiting to see if he reacts. We've made a report that has been very well received by the media, and, in this sense, I believe that society sees us as a necessary entity.

And then, I've got a story. We were sued by a fundamentalist association called *Abogados cristianos*, which actually sued the Ministry of the Interior for considering us a public utility. We asked to be considered a public utility, not for the fiscal benefits, which it certainly has since you can deduct a part of your quota, but rather because it serves as a sort of audit. And the members wanted it to be done. Well, their attempt backfired because they went all the way to the Supreme Court. And the Supreme Court clearly said that if an entity like this didn't exist, another one would have to be created because citizens need some place to share the doubts they have about end-