Comunidad Compasiva de Getxo

Fundación Doble Sonrisa

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Who are you and what is your relationship with the Doble Sonrisa foundation?

Itziar: My name is Itziar Grajales. I am the director of the Doble Sonrisa foundation. Doble Sonrisa is a family foundation, from Álava here in the Basque Country, that began in 2017. It started as a response to a concern of ours, which was “how do we give back to our community what it has given to us.”

We are three sisters. One of my sisters and I are economists and our other sister is a palliative care physician. One day we got together and decided that we wanted to start this foundation as a way to deal with the concerns, the worries, the challenges that we were facing at that moment. So we decided that we would create a foundation dedicated to end-of-life issues and to childrens’ issues, since my sister and I had already become mothers by that point.

Naomi: I am Naomi Hasson. I came to the foundation in 2017 because I am a nurse. My speciality has always been palliative care, advanced illness. And, in all of my years working in different settings and in different countries, I have always asked myself, “what are we doing to ensure future sustainability for people who are approaching the ends of their lives and requiring palliative care or additional support?” More and more we were seeing more shortfalls in the community. And, there was also a sense nobody trusted the community any more. I was very lucky to come across the foundation in a moment of deep uncertainty for me. Around the same time, I heard a lot of discussion about the creation of “compassionate communities.” I had been asking myself how this could be done where I lived, and, fortunately, the Doble Sonrisa foundation decided to lead the way in this area and they reached out to me to help make this project a reality. I had been living and working in London at that time, but I decided to return to the Basque Country. The Doble Sonrisa foundation is based in Álava, in the Basque Country. And the Zurekin project, which is the one I am focused on, is in Bizkaia, which is one of the provinces of the Basque Country.

Why was the legal formula of a Foundation chosen?

Itziar: Because looking at the situation in the Basque Country at that moment, both legally and otherwise, it seemed to us that it was the vehicle that made the most sense. We could go further with it. And then, when it came time to seek funding it would be the most effective formula. And so, we decided to become a foundation. Once we decided on this formula, we started to look at how we were going to give it substance. And that’s when we started to reflect on what our main focuses would be for the foundation

and what its regional scope would be. Because it's true that up to that point we had been working at an international level. However, after that reflection we did in 2017 we decided that Doble Sonrisa would be a foundation that would focus just on Euskadi.

Once the Basque Country was chosen as the region in which Doble Sonrisa would work, how did you decide what issues you would focus on as a Foundation?

Itziar: We decided that the two subjects we would focus on were end-of-life care and helping children in vulnerable situations. We decided that the ideal place for one of our end-of-life projects – Getxo Zurekin – would be Getxo. Why Getxo? Because there were already different groups in the Basque Country, not exactly compassionate communities, but rather community projects focused on compassionate care. There was already one in Vitoria, for example. And since our project was about joining forces, we decided on Getxo. It was a community that we knew, that had a population of only 80,000 people, and so it was an appropriate population for our first pilot project. Why? Because it had health centers, it had a city government that was involved in the community, it had other infrastructure that could ultimately help us reach our goal of creating an effective compassionate community. And that's why we decided to start in Getxo.

Why is the Foundation called Doble Sonrisa [Double Smile]?

Itziar: It's named Doble Sonrisa because of the smile of the person who offers help and the smile of the person who receives that help.

Are there any full-time employees working for the Foundation?

Itziar: We have two full-time employees. We have Naomi, who leads the Getxo Zurekin project. And then we have another girl who is in Vitoria and leads one of our other projects, which is Barreras Invisibles (Invisible Barriers). And then, there's my sister, Maider, who helps lead the end-of-life projects alongside Naomi. And, then there's me.

Can you explain what kinds of projects the Foundation works on?

Itziar: The Foundation doesn't have a specific focus. The projects are definitely local, since we're working in Vitoria. What we did, at first, was approach different associations to get a sense of what needs there were within the organizational fabric that existed in Vitoria. And it's true that our projects are distinct from others. There are projects we support that are led by different organizations. For example, we work with Itxaropena, which is an association for people with low vision. In that case, what we do is support them economically so they can do programs with the kids, such as chess workshops and running a Goalball school. We help them cover the cost of visual rehabilitation. The only requirements they have to meet are that the programs are for children under 18 years old and that they are for children from underprivileged backgrounds.

We also work with another organization, Berakah, which we have collaborated with for a number of years. Berekah works with people who have migrated to the city during the first months, or years, after their arrival. What we do is help them economically to cover expenses, such as paying for snacks, breakfasts, and living expenses for migrant children. They have a couple of shelters, so we help cover some of those costs for the children.

And then we have our own projects, which have become cultural projects. The first is Barreras Invisibles, which is a project that came from the Fair Saturday Foundation, which is a foundation in Bilbao that we are very familiar with given that they have now been working on their “Fair Saturday” project for quite some time. The idea for Fair Saturday is that after “Black Friday,” a day dedicated to an avaricious level of material consumption, they said “why not try consuming culture, especially culture with a social aspect?” So on the Saturday after Black Friday, they promote different cultural activities like concerts, dances, and exhibits. And then, each one of these cultural activities is connected to a social project. That way they give visibility to social projects while also satisfying that desire for consumption. We met the organizers of Fair Saturday some years ago, and aside from their main project, which we loved, they had another smaller project that was called Barreras Invisibles.

Barreras Invisibles consists of a series of projects providing cultural grants to children from underprivileged backgrounds. In addition to providing a grant to each child so that they can participate in a cultural activity that interests them – dancing, playing an instrument, etc. – each child gets a handful of mentors. Beyond providing monthly economic help to their mentee, each mentor takes this child to one or two cultural activities within the city throughout the year. Because what often happens is that these children don’t go to free cultural activities because they don’t feel welcome. There are times when they think, “I don’t feel like I’m part of this community,” or “that I don’t fit in, so it’s not my place.” So, what this project is about is not only getting these children involved, but also helping them become familiar with different cultural activities.

It’s true that before this year we only had the grants because we started the project in January of 2020, just before the Covid-19 pandemic began. So, that has made things more complicated, but we do have the grants and, if everything goes according to plan, this September we will begin to include the mentoring aspect.

And then we have another project, Ensayedero, which involves creating rock bands. The goal of these rock bands isn’t so much that they are super artistic; instead, it’s about working together as a group and providing female empowerment. We work hard to make sure that girls take on roles like playing the drums or the guitar, which are usually roles given to boys. We also work to make it intercultural because ultimately everyone has their own religion, their own story, their own family background. So, the goal is that everyone is working together. And, for us, the most important part is always just that they are making it to class. So, this is ultimately a recognition of both of those things. Then, there is a concert at the end of the course – we just had our most recent one – and it’s very sweet because you get to see how these families come to see their children and get to see them in a very positive light. Before, most of the time these parents may have just gotten calls from school about their child’s poor behavior. Now, they’re getting calls about how well their child is doing, how they are super involved. And, that involvement ends up lowering the school dropout rate, which is also one of the goals we pursue.

One of the other goals of the project is to show them different career options that are related to the world of music, like being a sound engineer or a lighting technician. They also get to design their own logo. And we’ll ask them, “Why did you design your logo like that?” So, they have to think about it. There’s one former participant who’s doing design courses and once they finish them they’ll keep doing design. Ultimately, what is important is that they see that all of these possibilities are there for them.

How is the Foundation funded?

Itziar: Some of the funding comes from our family. We make an annual family contribution to cover the Foundation's expenses. And then we cover a smaller amount with public funds, agreements, or donations from people who agree with our projects and want to contribute.

Many people may find it odd that a foundation dedicated to social transformation is partnering with businesses. Can you explain this commitment from both parties?

Itziar: We have a social responsibility to help everyone. So, you say to yourself, "How can I give back? How can I help? How can I support others?" And then, when you become a mother, it also becomes a way of teaching our children that they also have a responsibility to others. If you come from a privileged background, it's "How can you use that background to make a positive impact? How can you share with others?" So, that's where we're coming from.

One of the Foundation's areas of social intervention is being present during the aging process and the end of life. I noticed on your website that this activity is centered around the Getxo Zurekin project, which is the first compassionate community in Euskadi developed under the New Health Foundation's "Todos Contigo" methodology. Can you explain to us what a "compassionate community" is?

Naomi: The term "compassionate communities" makes reference to a series of thinkers who have been warning that we're putting a lot of emphasis on the prevention of health issues and much less on who is providing care for existing health needs. For example, Allan Kellehear, who has been a big proponent of compassionate communities, used to point out that we place a lot of emphasis on health. For example, you should eat an apple because it will help your heart, or you should wear a helmet when you ride your bike so that you can get back up when you fall, or you should wear a seatbelt when you're riding in a car. But, as he would point out, where is that attention with respect to suffering? Why aren't we talking about who helps you when you fall into a moment of great suffering?

As our world continues to advance, there is increasingly this sense that there is less support for people who are suffering. It's true that Karen Armstrong, in the late '90s, was already talking about how compassionate communities have to be spaces that embrace discomfort, that go against the status quo. They should raise questions that we don't normally consider day-to-day, especially out loud and within our communities. Because in moments of suffering we often spend a lot of time thinking, but we don't feel comfortable sharing how we feel. And I think that's very closely connected to what the Foundation does and what Itziar mentioned before about being invested in what happens in our communities. So, in 2015 when they said, "Alright, let's start in Getxo," the idea of the compassionate community was introduced here.

It's true that compassionate communities have already emerged around the world, especially in the United Kingdom, Australia, and India (specifically in Kerala, where the first example of a compassionate community, "No One Dies Alone", began). And then in Milford, in Limerick, Ireland, where there was already a hospice program, the "Compassionate Community Milford" project emerged. In Ireland and the UK, starting with hospice programs, lots of compassionate community initiatives began to appear. And then in Canada, there's also Pallium Canada.

On a state level here, the New Health Foundation (which was formerly led by Emilio Herrera and Silvia Librada) understood that there were many compassionate communities being created around the world. They made a visit to one and thought, “Alright, what’s actually happening here? What is each one of these communities doing?” So, what they tried to do was build a methodology with a certain structure that would show others how to create a compassionate community from scratch. From what I understand, the first compassionate community in Spain was Sevilla Contigo and then afterwards, others emerged on a statewide level, like Vic Ciutat Cuidadora and Vivir con Voz Propia. And these communities have been popping up just like mushrooms: compassionate settings, compassionate neighborhoods, compassionate cities. And then the name itself differs depending on whether people feel comfortable using the word compassion.

Can you explain the relationship between Getxo Zurekin [Getxo All with You] and the New Health Foundation and their methodology?

Naomi: We began to work with the New Health Foundation because Maider, my colleague and Itziar’s sister, was working with them. When we first started out we used the New Health Foundation’s methodology for Getxo Zurekin (which means Getxo Contigo in Spanish and Getxo All with You in English). The New Health Foundation has a lot of literature about this methodology, which they call “Todos Contigo”. So, we started to work with the New Health Foundation’s methodology the first year, which worked out well for us because it gave us a lot of guidance and context about how to start a new project. And, at the same time we started to work with a research center at the Universidad del País Vasco that works with these issues through more of an ethnographic lens. So, what happened next?

The first year with New Health worked out quite well and we carry a lot of New Health’s philosophy and methodology in our organizational DNA. But, of course, when we started to look at the context and the culture in which we find ourselves we realized that we couldn’t continue with the same methodology. It’s a very rigid methodology that was very helpful when we were starting out. And it’s true that they have changed a lot about how they work. But at that time, from 2016 to 2017, that’s when in our second year we were trying to become a platform for listening, for creating together, for establishing a contrast. We had to go in a different direction with a different pace. So, we have a relationship with the New Health Foundation because they are connected to everything we do. They’ve been our teachers. But, then we had to move on to contextualizing the process to Euskadi, to Getxo and its 80,000 inhabitants, and to every neighborhood because each one is its own world. In fact, ethnographic research has helped us a lot in this regard.

Who builds a compassionate community?

Naomi: It’s built by the community itself. That was a lesson that we learned a lot from. I’m a nurse and I’ve spent 30 years working on these issues; I thought I knew what the community needed without asking the community. I thought that I was seeing the same needs in Guatemala, in London, at home in Barakaldo, in Ireland. I wasn’t seeing the differences in the deficiencies we were facing; I was worried more about how we solve those deficiencies. So, when we started out, I would say, “As a nurse, I know such and such…let’s use this methodology” And later on when I talked to people who had a more systematic perspective, they said, “Look, if you start out this way, you’re not going to have accomplished anything in the first six months and they're going to tell you so, too." They would have pointed out how we were talking about compassionate communities, in Spanish, in Euskadi. We were talking about a foundation, the Doble Sonrisa foundation, which has a name in Spanish rather than Euskara. And I was an Irishwoman who didn't speak Euskara, so...

Itziar: Not to mention the two women from Vitoria who were coming here to tell us how to do things, it would be...

Naomi: So they told us, "Forget what you think you know, you have to go out and start talking to the community." And that's how we started. So, who creates a compassionate community? The community does. It's incredible.

What does community mean to you?

Naomi: When we use the word community we're talking about the whole system at all levels, not just the people in the street. That means institutions, outpatient clinics, stores, funeral homes, cemeteries. All of that makes up a compassionate community. And seven years later I would say that we still have a lot to do. We aren't a compassionate community yet, we're still building it. We always say that with the greatest humility.

What role does the Doble Sonrisa foundation play in building this compassionate community?

Naomi: I'd say that thanks to the perspective those at the Foundation have, we are able to enjoy freedom and flexibility in our work. Because without that you can't achieve anything. And, I believe that is essential. And then there's the absolute trust they have. I say "they" because ultimately even though I'm a part of the foundation, I'm still an employee, although the relationship is very horizontal. It is a relationship of trust. Because if you don't have trust you can't work with the community. You can't build community. And, that's fundamental.

Itziar: I believe that what has also helped here is the fact that when we started the compassionate community in Getxo, through Getxo Zurekin, we had a very clear idea from the start (Naomi also had it very clear), that the Foundation was not trying to install a project but rather it was more trying to "coach," you know? Ultimately, what we were looking to do was help the community undergo a transformation. That Getxo Zurekin would make an impression and at a certain point the Foundation would be able to disappear. That the community would have its own group and its own volunteers. That they would become the ones making decisions independently and that the Foundation, at that point, would be able to leave Getxo and help support a compassionate community elsewhere.

What steps are necessary for creating a compassionate community?

Naomi: In our case, we started with listening and sensitivity. Because we have to be able to talk about death. One simple thing is starting to organize casual discussions, every month, about what we are hearing. The first step was to connect with the community, saying "Gee, we already have discussions about sexuality, intimacy, and caretaking." Or, we'd talk about suicide, which no one had been talking about.

So, people felt motivated to start coming to the discussion and they'd say, "Look, this girl took the time to talk with me. She listened to me and she's doing something about it." So, that's sort of how we started. We started gathering people who wanted more information. Because, of course, we were on our own. We didn't have a connection to the community at first.

At the same time, we began to create a systemic map: "What's happening in the community? What already exists? Who is here already and what are they doing? What are we doing and what do we want to do? How can we find a way to work together harmoniously?" We started building relationships with institutions, associations, individuals, and then we tried to figure out what was missing. Based on what we had heard, we went back to the community and asked: "Hey, we're hearing this. Do you agree? Do you disagree? Are we missing anyone? Who are we not talking to?"

I remember that back at the start, in 2018, someone told us, "You're not talking with the migrant caretakers. And, you're not talking to the people who have lost someone to suicide." So, it was like, "plop!", alright, now we have to go there, right?

So we started to connect with the community in that way, then people started coming to the things that we organized. And then when people started approaching us...At first, I was focused on organizing talks and creating a platform for really listening. And then there was a moment when someone said, "we need an organizer, in the same sense as when you have a construction site and you need someone to coordinate between the plumber, the carpenter, etc. Well, we need that kind of figure for caretaking." We took that idea, we brought it to the community, and with the community we co-created this figure that in Euskara we call lokarriak, which in English would be the "community connector." (Right now in Spain there's a lot of talk about this figure, including a project from a government ministry). But, in 2018-2019, when no one else was talking about this figure, we co-created it with this community. At that time, the Foundation decided to test out this idea, and so I became that figure, the lokorriak, the "community connector."

Back then, we didn't want volunteers because it was more important to us to bring power to the associative level (like our mapping and the relationships we had built) with tools that allowed us to accompany and be present at the end of life. So, when a family would approach us we would be able to put them in touch with the existing social fabric: we might say, "Get in touch with the Red Cross, get in touch with Cáritas, get in touch with the Asociación Española contra el Cáncer" because they have training. They're experts on accompaniment, on end-of-life issues, on palliative care, on dependence. Our intention has always been to build networks, join forces, and work together.

What happened after Covid? Well, after Covid, we started to realize that there were certain spaces that nobody was creating. So, in this case what we did was go back to the community, to the entire associative fabric, and we said: "We think we need more spaces because what we have and what you have is not enough. We don't have spaces to, for example...One important thing to point out is that everything has already been invented. We don't have to reinvent the wheel. We saw good things that were being done in other places and we brought them here. We opted to co-create this so that it would make sense for the neighborhood. That's why we started our "Cafés en compañía" activity on Monday mornings. We started a project focused on shared pain. We started a project focused on community suicide prevention. Of course, all of that was impossible to do on our own, so then we said, yes, we do need volunteers.

You mentioned volunteers within the compassionate community. How did this group of volunteers emerge?

Naomi: So, how did we connect with the volunteers? Well, as Itziar mentioned, it's been really sweet and very natural. People have been coming forward and wanting to be a part of this. Sometimes they ask, "How can I help?" And we say, "How do you see yourself helping?" So, it's about showing them the whole range of things and asking them, "where do you see yourself here?"

Each person who connects with us finds their place. And, also, we don't call them volunteers. We call them "community connectors." Right now we don't have many because we don't have the capacity to support all that many. So, we hover around 20 volunteers. And, all of the volunteers have something specific that they focus on.

We also work a lot on a concept that comes from Julian Able and the compassionate community in Frome, in Somerset, UK. There they have a figure called the "Health Connector," which would be like our lokorriak, our community connector. And then they have other community connectors, who are volunteers. So, in our setup of interconnection first, there is the lokorriak, the most structured position; then, we have the community connectors, who are volunteers; and then, we have a third group, who we call "network weavers." This group is made up of anybody from the community who does some very brief training so that they can say, "I have stepped in someone else's shoes, I have a different perspective, and I am available for my neighbor." It's also very sweet because you run into the people who've done the course and they say, "Hey, Naomi, I haven't seen you in a while, but don't worry because I'm doing a lot of weaving!"

Why talk about compassion? And, how does compassion differ from empathy or solidarity?

Naomi: Here in Spain, there are some different names like "caring community" or "caring city." The word "compassion" was very important to us because compassion encompasses everything. Obviously, empathy is wonderful. We talk about empathic relationships, empathy at work, in supportive relationships. But, of course, compassion always goes one step further, doesn't it? As Enric Benito says, "Compassion is empathy in action". I think that in English this relationship is very well understood; in Spanish it's more complex. Because people in Spain connect the word compassion to the Church, with emotions like pity, sorrow, right? For us, even with all the barriers we already had, we decided to work against this one too by not changing our name. We call Getxo Zurekin, "Getxo with you", a compassionate community. And in all the talks, in everything we work on, we always mention that we're a compassionate community and we explain what compassion really means. So, little by little, the community starts to realize, "Ah, ok, so that's what compassion is; I thought it was something else. It's not what I thought it was." And, for us, that part of changing the narrative around how people approach the word "compassion" is super important.

What would you say is the greatest enemy of compassion in developed capitalist societies?

Itziar: I think we're at a time when individualism is becoming more and more dominant. During Covid, everyone said, "We're going to come out stronger as a community, we'll support each other more." And then you realize, four years later, that it almost seems like we've gone in the opposite direction, right? Where, ultimately, it feels like I'm living more and more for myself. For example, when we were thinking about names for the Foundation, one of the names we came up with was "Maria Theresa's Staircase." Because staircases used to be a space that brought people together. The interactions that happened in those spaces were very important. You may have talked to the woman on the third floor, or the woman on the fifth floor may have taken care of your children. Those interactions supported super important relationships and sustained communities, which is what we are trying to get back to, in a sense. We may not be able to go back to that way of life specifically. These days, I may not know my neighbor who lives next door. Sure, you don't have to know your neighbor, but why don't you know your neighbor? Maybe you should try to get to know them. That's what we've been working towards.

Naomi: I think there's one thing that hasn't been talked about much lately but that I have been thinking about a lot. And that is that a lot of people are scared. We can talk about individualism, but I think that really we are living in a world full of fear and that deep down a lot of people are feeling very scared.

Why do you think that death and aging are social taboos?

Itziar: Because we're scared of dying. At the end of the day, that's what it's about. It used to seem very natural when everyone lived in small towns. If someone was dying, everyone went to say goodbye, including the children. We often want to protect, which isn't ill-intentioned. I want to protect my son. I don't want him to suffer. I want to take care of him. And then, with the best of intentions, given that we always assume that everyone wants the best for those around us, and for the next generations, we have created this taboo and this additional fear on our own. Because death is something that is going to happen to all of us. It is the only disease that is going to affect 100% of us. And, instead of living with it and learning and having tools to deal with it, we have decided that it's easier if we pretend it doesn't exist. What does that mean for my son? I don't give him the tools to deal with it. Death no longer happens at home. Instead, it mostly happens in hospitals. Doctors, quite often, don't know how to let their patients die. They have trouble accepting that patients die sometimes. They think that they always have to be saved. Well, not always. Hopefully they are, but, ultimately, maybe it's better to let the patient die well, to say goodbye, to be accompanied. For doctors, the death of a patient is a failure. Well, ultimately, I think that we all, as a society, have wanted to do better. So, maybe we've made a mistake, right? Maybe there are things that we have to go back and fix.

Naomi: I've been reflecting on this topic quite a bit lately, and I think that, with everything that is happening in the world right now, I have the sense that there is a lot of fear about living, you know? So, those of us who are very closely tied to death try to see life through another lens. I'm here today. I don't know if I'll be here tomorrow. If I embrace today then life does not scare me because I don't know if I'm going to be here tomorrow and I do what I can today. But, I think that from a more individualistic perspective, it feels like there are so many people who are really afraid of life because there is so much happening to us. There is so much uncertainty, so much fear. My God! Look at what is happening in Palestine, and Russia, and everywhere else! It feels like our world is getting smaller and smaller. We see everything everywhere as if it's right here when it's still the same distance away as when I was 14 years old. But with globalization and communication, it feels like it's right here. I have enough going on with just my life that I am able to start thinking about how someday I will die. So, I have to give the best version of myself today because that's my reality. But nobody wants to talk about that because they have enough to deal with already. It's funny, though, because when you open spaces for people to come, they do come. They're grateful, they want to be there, they want to talk about things that they normally don't talk about because they put their blinkers on and that's it.

From your perspective, what does a "dignified death" involve?

Naomi: Since we work on building this community by incorporating what the community feels and what they consider a good death to be, I think that we must go very much to the person and their environment. So, for us, a dignified death depends on what a person feels is a dignified death for them. And, what feels like a dignified death in the context that surrounds them. I think that it's very complex. As of late, it seems like death has become a fashionable topic. There's a lot of discussion about dying well, but I've seen a lot of people die and not everyone dies like they do in books. There are many people who die suffering, and there are many people who die peacefully. For us, a dignified death is whatever anyone sees fit for themselves. And, this is very important because when we study death I think that we are given an ideal way to die. And, then we work towards this ideal and it causes a lot of frustration. If I enter someone's life – even as a professional, or a friend, or a neighbor – trying to apply my own concept of a dignified death and it doesn't match theirs, then it destroys the relationship I have with them instead of solidifying it.

Itziar: That's right. I think that we talked about what a good death looks like in our very first presentation session. One person responded, "My mother said a good death is one without pain." And we replied, "But what does pain look like for you?" Is it physical pain? Emotional pain? The pain of those you're leaving behind? The pain of those who are already gone? By understanding what that looks like for each one of us, the important part is realizing where to look to decide what a good death is. But, you cannot make that determination if you have not previously thought about it or reflected upon it or shared your reflection with others, which is also very important. Ultimately, it's about making sure that when I go, those who are still around tomorrow know what I wanted. Where I wanted to be buried, or where I wanted to be cremated, to whom I wanted to pass on my belongings. And that's just figuring out the will. But there are other details, too. What if I want a party instead of a sad funeral? And so on.

To get to that point you had to make that previous reflection, and you had to have a space where you could talk about it. What we often see today is that these types of spaces don't exist. Ultimately, what we promote is giving people that secure space in which they can talk about those concerns. So that it's normal to have a coffee with your parents and talk about those things. In our house, it's reached the point where they say, "You can stop talking about dying already." You have to create those spaces. That also comes from awareness, training, and education.

It is important to add that not all people have the same material conditions and possibilities and thus not everyone dies in the same way. How does this compassionate community deal with that difference?

Naomi: The issue of resources is still quite important. At the Foundation, what we try to do is connect families to the resources that exist, which they often didn't know existed.

For us, the most important aspect is always connecting families to resources. Putting families in contact with the people, getting resources moving, guaranteeing that people have the maximum amount of resources available to them. Then, through volunteering, we also try to maintain accompaniment. For example, a family that is exhausted may need a little respite, so we provide that for them. And, we also try to connect with associations that, for example, help the most disadvantaged people, such as the homeless, when they are dying. Or, we'll help people who don't want to die in a hospital by connecting them with an organization that helps them die elsewhere. We collaborate with these associations because these families are not experts on end-of-life issues, so we try to help them learn about all these resources that exist. Our job is always to try to make these connections. But, we try to do so with dignity in mind. That is, how can we help the person who accompanies the person who is dying so that they connect with that person's biography, with everything that is that person's life narrative? With everything we know about this person, how can we make sure that the end of their life aligns with who this person is? That is critically important.

What is your opinion of the fact that Spain has introduced a law permitting euthanasia, yet there is still no law regarding palliative care?

Naomi: Well, first of all, we're not experts on this issue. But, in Spain we have had a law since 2021 that permits euthanasia. It is a law that allows people who have reached an advanced disease state and are terminally ill to be able to ask to end their lives. It is a very strict law, and you have to meet certain requirements to utilize it.

The problem we have in Spain is that we do not have a palliative care law. If we don't have a palliative care law, then people don't have a choice. As the president of SECPAL (the Spanish Society of Palliative Care), Rafa Mota, said at a conference, "I'm not against the euthanasia law, but I am against people not having a choice." It is very important to us that the Autonomous Communities work towards a palliative care law. Because it makes no sense to have a euthanasia law but no palliative care law. They should have passed a law regarding palliative care prior to the euthanasia law. But, the problem is that people have no choice and then how you die depends on your zip code. And that's how it is across Spain, including the Basque Country. It also depends on the doctor you see and whether they understand the end of life, and when to incorporate palliative care, as being the last three days of your life or as starting from the day you are diagnosed with a terminal illness. Even today, there is still a lot of variation in those understandings. I don't know if I answered the question. But, I will say that there is still no social right to palliative care. And then there are resources to help but those also depend on the case.

From the experience of this compassionate community, what situations of vulnerability do the elderly face?

Itziar: There is a very large percentage of the population that has reached an advanced age. And, many of them live alone without being alone. What I mean to say is that when you have children and you have a family it feels like you aren't allowed to say that you live alone. That's a much more troubling kind of loneliness because you can't verbalize it. You don't have the right to say that you're lonely. People often come to us doing well physically, doing well mentally, with a lot to contribute. But, sometimes it seems like they can't find how, where, or with whom to direct their efforts. In fact, Naomi can tell you about our mutual accompaniment groups, how people at those ages are really able to find friends and meaningful relationships. A lot of the time it feels like we're doomed to only make friends when we're young. But, actually you can make really meaningful friends at 60 or 70 with whom you can do a lot of things, which keeps you from staying cooped up at home.

Naomi: I believe that it's tied in very closely to population change. Young people are very active and suddenly it seems like we're saying that aging has to be a very active process. All the time, here in Spain, we hear about "active aging" and "healthy aging." From the very start, we have heard about this through our platform. People tell us things like, "What if I don't have the capacity to be active? Because I am getting this information now when previously I had no physical activity included in my education, or my healthcare, or my preventive care."

And then, a lot of emphasis has been placed on behavior and activities. The message becomes that you have to be active and that you have to have certain activities to have healthy relationships. But, actually, all the research suggests that if I don't have connections and relationships that's much more dangerous to my health than if I smoke cigarettes or eat hamburgers, which ties into the whole social issue of inequalities in aging.

So, what we have seen, thanks to ethnographic research, is that people said "of course, in this city (or in the Basque Country, in general), there are lots of activities for the elderly." But, then we heard things like, "We leave the yoga workshop and go straight home. We have no connections and we feel very lonely." We discovered all that in those years of building the community because we hadn't identified loneliness, especially "unintentional loneliness," until we started to work a lot with caregivers and people who had spent many years caring for dependent people. What we realized was that there is an unintentional loneliness that is very closely linked to the whole issue of care. So, we said, what are we going to do about it? As Itziar said, we decided that we weren't going to do activities. Instead, we decided to create a group, "café en companía" (Coffee with company), to see what happens.

What type of space is this "café en compañia"?

Naomi: "Café en compañía" takes place on Monday mornings. It's on Monday mornings because weekends are often more difficult for people dealing with the loneliness Itziar mentioned before. "Cafe en compañía" has been like the trunk of the tree, from which lots of twigs have sprouted. It has shown these people of a certain age that it's possible to have meaningful connections with others again. And, additionally, there are people who have their first significant relationships and connections through these spaces and environments.

So, I think that we have to change some of the language we use about aging. Let's get away from "activities and behaviors," and get back to "relationships and environments" because otherwise, no matter how much activity I do, if I go back home and don't have anyone to talk to, I won't be able to fix anything.

For example, we have people who come to us and have very bad relationships with their partners. But, they have reached the age where they won't take the step of separating because they don't want to end up with no connections. We have mostly worked with unintentional loneliness, linked to widowhood and care, in particular. Many of the people who come to us will tell you, "weekends are very hard for me," and we'll ask them, "what do you need?" That's sort of what the Foundation says from the very start: “What do you need?” and “What can we do for you?” They might say, “We need a place,” and we say, “Here are the keys.” It’s about working with that flexibility, from listening to everything, and from the understanding that there are no experts. Because the aging problem is also a business. There are many consultants making a business out of people’s dependency. From our point of view, it’s about saying, “How can we accompany you to self-manage your needs and your relationships?”

Itziar: For me, the most important thing is that these people are able to say, “And, now I have friends. Friends who care about me and call me.” That statement alone, to me, is worth everything that we have worked for and everything that we have put out there. That’s what I’m looking for, for them to not feel alone anymore.

Contemporary ageism usually manifests itself in processes of invisibilization and infantilization of the elderly. It’s also true that when a person retires and their professional activity ceases, they are no longer perceived as being useful, socially speaking. Is this compassionate community pushing back against that situation? Are mechanisms being put in place so that these people can contribute socially?

Well, you know what’s actually very nice about this issue? I am a nurse, but I’m not really an expert on anything. So, it’s true that we – me in particular – learn from these people every day. When we started thinking about having volunteers we had a lot of doubts. Because we weren’t sure it would be ethically correct for another association to come in with their own volunteers. But then, when we saw what we were building, since no one else was doing it, we saw that we did need a certain profile that was a little more specialized. So, we have a community connector, who is a volunteer (I make that distinction just so that people understand that this isn’t a professionalized figure); he has really helped me understand how to approach this topic you’re asking about. He always says, “I work for the Foundation. The government pays me on the first of the month.” I struggled with that because he works with us a lot, and I felt very guilty, and he told me, “You can stop feeling guilty. I’m 67 years old, I want to stay involved, and I don’t feel like I’m a volunteer. I know that I am one because we have an agreement, but I feel like I’m still working. The government pays me every month, and your work helps the government pay me.” We’ve discussed this concept a lot here because if everyone had that perspective, when we retire or stop working, we would stay involved. It doesn’t come from a perspective of volunteerism, of “look how good I am.” Although, I know the Volunteer Law doesn’t want it to be like how he put it, which is why there’s some disagreement, right? When volunteers come to us now, we all speak with that sort of language.

Do you provide support to at-home caregivers?

Naomi: Demographics are changing a ton. So, what’s happening here in this city? Getxo has one of the highest percentages of at-home caregivers in all of Spain. What’s happening with the city’s population? Well, it’s getting older and, as it ages, it is missing a lot of the network and resources it needs. These groups are at a much greater risk of being excluded. So, for us, it is very important that we try to connect with these groups in everything we do. And, like everything that we do, the spaces are free, which means that you don’t need money to be able to be there. That’s a very important part of aging, particularly in this city.

Do you work in tandem with social services, outpatient clinics, and health centers?

Naomi: We've been working since 2017 and it's been hard for us to get health centers, outpatient clinics, and hospitals to understand what we want to do and that it can be valuable. But, we have to admit that since 2021-2022 we have been very lucky. In compassionate communities, we are always talking about connections and relationships. This is the same thing. It's about not getting frustrated along the way, staying hopeful, and continuing to move ahead.

There are three clinics in Getxo. Two clinics have completely connected with our project and trust us. If they refer people to us, they do so for two reasons. First, there is a bureaucratic barrier because social services are very saturated at the state level. Social services are becoming a place to organize resources, so wait times are getting longer and longer. So, we've tried to become a quicker alternative, and a cornerstone in the community. We offer easy access, a quick response, and the confidence that we're going to be able to connect with social services and associations when we can't take it on ourselves. With all of the complex problems that exist, we can't even start to think about solving these problems if we don't have a systemic perspective. While we have had luck in connecting with two of the outpatient clinics, we've had more difficulty collaborating with the third one. I think that they don't quite understand our mission. And it seems that they don't quite realize that by relying on the compassionate community they could reduce their day-to-day burden and experience less stress during patient visits.

There is also home hospitalization, which is a service that goes to people's homes from the hospital to treat more complex health issues. They also rely on us. At the same time, we don't have the resources to do this alone. The doctors themselves say that it would be very interesting to be able to perform an analysis of how the number of people having to come back to the doctor has decreased or how much antidepressant use has decreased since they have connected with the compassionate community. So, yes, the more local medical institutions do connect with our resources. I would also add that Osakidetza, the Autonomous Health Service, is increasingly taking us into account as well.

Itziar: I think the key to answering this question is also related to time. The fact that we have been able to rest assured that we did not have to meet any deadlines, or that we had to have a certain number of patients referred to us, has allowed everything to progress much more naturally. When we started we were called "do-gooders," but that was because people didn't understand that this was a free service, that we wanted to accompany, that we wanted to improve, that we really weren't looking for anything more than that. So, sometimes it takes time to make that clear. And sometimes there is also the sense that "This person is my patient. And, if I give him to you he won't be my patient anymore." Our compassionate community says, "no, that's not 'your' patient." And, we're not trying to take a patient away from anybody. What I want to do is help you and help the patient, above all. So, we learn by doing. It's true that, ultimately, it feels reassuring looking back and seeing all the time that has passed and all that we have done because these health centers see that we are serious, that we know what we are talking about and what we do, and that we work together, right? That's why time to me seems to be the key here.

Do you do any educational work with schools and universities regarding social awareness of aging and dying with dignity?

Itziar: Less than we would like. It's true that since the beginning this has been one of the areas we wanted to work on. But, it's something that has been more difficult for us to get into. Perhaps it is also because at the end of the day we have to dedicate a lot of resources to other things.

Naomi: When we tried to contact schools, more than anything, the answer we got was "we don't have time." The curriculum here, both at the national level and in Euskadi, the Basque Country, is a very theoretical curriculum. There's little room for creativity. I'm from Ireland and theater and art are part of the curriculum there. The system here in Spain is very mathematical and very focused on the classroom. That would have to change first of all.

I always say the same thing. There are very few spaces for this. We did have one really nice experience with a school here. We agreed that we didn't have to really go in and talk to the kids because we believe kids have their own references and don't need us to show up and have all the answers.

We feel that we have to work more with the teachers. The teachers say, "Ok, what protocol can be created with this?" Because there are very few protocols in schools on how to work with children or families who are dealing with advanced illness, palliative care, or bereavement. Or how to process the death of a teacher, for example. If you ask questions about these protocols when you go to schools, very often there aren't any. And then we realized that many teachers had no idea that their colleagues were having a terrible time or that they were grieving. And, if something happened to a child in their classroom, one of these teachers would not be able to work with the family because they still had to resolve their own grief. But, no one knew.

So how are we going to rally around these teachers if we're not even having those conversations with other teachers? We believe that first we have to encourage conversations in faculty meetings. Then in the AMPAS (parents' associations) because we also want to work with parents. Later, if at some point it makes sense to work on something with the kids, then sure we will; but, we are not their guides and we shouldn't be. It's more about how to create compassionate environments within this system because the school itself is a system. And, then it's the same thing with universities. And SECPAL will tell you the same thing. Very little is said about death, or compassionate communities, or compassion. When kids leave university they leave without knowing about these topics. So, there is a lot of work to do.

Do you do activities geared towards future professionals in the fields of medicine or palliative care?

Itziar: Simple things. A few years ago, in what was one of our first educational activities, we helped with an FP, a vocational training, for nursing home technicians. They told us, "of course, many of these kids will start their internships and will be sent to palliative care nursing homes." Many of them have never suffered a loss, so when someone dies they don't have any kind of tool to deal with it. They will know how to put in an IV, clean a patient, change the patient, move the patient. But, they won't know what to do with this person and their family. We've been working with this group for several years as well as another association in Vitoria that, once a year, organizes a chat over coffee for these FP students. Because otherwise they have no way to talk about death. It's something they are going to have to face because of the professional training they are involved in. They're 19-year-old kids who suddenly find themselves in their internships not knowing what they're getting into. The truth is that the first chat was very nice because there were people of different ages. When they started talking about who had made a will, there was a 19-year-old girl who had made a will and a lady in her forties said, "I haven't even thought about making a will and you've already done it!" It's about creating those spaces to give them some tools to be able to keep moving forward in their work.

Can you tell us what encourages you personally to continue working in social transformation and in maintaining this compassionate community?

Itziar: My children. That is, really trying to leave them something better. I know it sounds cliché, but it's true. Ultimately, what I see, what we talk about, is that there is fear and that we are at risk of falling prey to individualism. I don't want my children to live that way. I want them to live differently and to have other opportunities. But, that won't happen if I sit on the couch waiting for something to change. If I don't take that step to try to change it, it won't happen. Nobody is going to do it for me. So, it's about helping them see that things can be changed and leaving them something better for tomorrow.

Naomi: I think, for me, death is such a sacred thing and I feel like not all people die well. Some do but not all. There's a lot of work to do. And, I think that, when it's my turn, I want to be able to feel like my family, my husband, they're going to be ok. And, I feel like it's something so important that we give so little attention to. That's why. Then, there's the community part. Working in the community is very difficult, but I trust in the community. I believe that if we don't move the community, if we aren't activists in our communities, we are going to suffer a lot and we are going to see a lot of suffering around us. So, I believe very, very, very much in the community, and I am convinced that a lot of things can be done.

At the Constellation of the Commons (CC) we are working on the production of a useful and propositive imaginary that encourages citizen participation in transforming a hegemonic system.
Can you share some good news on this front with us?

Itziar: That we have a space given by and for the community. That more than 100 people pass through this space every month and feel accompanied, and every day it becomes a little easier for them instead of more difficult.

Naomi: I agree with what Itziar mentioned. It's about seeing that in these spaces, people are connected, they are having discussions, and they are taking care of one another. To see everything that has been done (and we still have a lot to do) means something. There's also a sense that – although we keep generating more things, more relationships, more feelings, more connections, more wellbeing, etc. on the issue of suffering – there's this feeling that "ah, maybe they don't need us anymore" because they've incorporated these ideas themselves.

One thing that is very important for the Foundation is to be able to describe where we see ourselves being in three or four years in relation to Getxo. And then, it's also about becoming an increasingly autonomous project. I think it's also good news that there are other compassionate communities that decide to forgo the use of the word "compassion" in their work because they don't like it.

We have continued to be a compassionate community. For us, it has been a fundamental part of the language we use. And what has that led to? Well, a year or so ago, the volunteers and the community connectors created their own association, which is called Asociación Getxo Biosvera, Comunidad Compasiva. So, that is good news.