#1

P: Patient

C: Caregiver (his cousin)

**Interview to the patient**

Interviewer: How is it going?

P: Everything is fine Doctor, from XXX (hospital) they sent me here because they indicated it as their "noble parking lot", in fact they made me more exams here than at XXX (hospital). They made me a textbook dressing, I feel like I'm in a hotel, I usually make my own dressing I wear gloves, now they have hospitalized me because the wound got infected, a bacterium that is easy to catch, but these three years have gone well, I have worked a lot, I am a university professor.

I: Would you like to tell me your story?

P: I had a heart attack when I left the Senate, I'm not very lenient with politics, I got angry every day. Then also the life I led, cigars, I happened with ministers and senators smoking cigars so I was breathing passively and then I liked them too. There is no familiarity in my case.

I: What about stressful life?

P: Yes it was stressful, I worked with (removed for privacy), I organized conferences, I am an expert in (removed for privacy), I ate irregularly, late in the evening ... Now it seems the time has come because Dr. Fxxx declared me in emergency 1, fear I do not have it, because I know the surgeon, the operation is a ritual, there are risks associated with the operation, there is a risk in the same anesthesia. I rather wonder what I will do later because, in general, transplants are fine except for a few cases. One of my predecessor from Brianza just bought a motorcycle and just put under a Moroccan, so I told him "Finish the newspaper", in fact they wrote: "Transplanted at XXX (hospital) invests a Moroccan with the motorcycle! (laughs). The mood is not bad here. Also because I'm busy, I don't have the time...now i've written a letter to (Politician), since I'm a student of XXXXX, at least he's putting it on the minister's table in such a way that the law, on the structure of the labor inspectorates that don't work...I'm sick at heart, they can't put me in jail, so i'll make some accusations and slander... I'll make some accusations...

I: It seems to me to be very upbeat...

P: There's another atmosphere here, at the XXX (hospital) it's a mess, here I'm adapting myself, the other day I went down to have a cup of coffee, a nurse arrives, telling me that I had to warn him, but at the XXX (hospital) it was a sea port, they come in, they come out at all hours, the other time I was unlucky because I ended up with a deaf person in my room... It's not so much the machine is that being sick of heart. Climbing stairs involved heart fatigue, tying shoes... Trivial gestures of everyday life are not normal in heart failure, brushing your teeth is heart fatigue. I can't for example do a lesson, because doing a classic lesson involves a heart fatigue, like tying your shoes eh .... The gestures of normal life, are not normal in heart disease, do the rinses with the mouth is a heart fatigue, then one feels the breath ... I'm 64 years old, I'm not yet retired.

I: I would like to understand a little bit your story, would you like to tell it to me?

P: Luckily my illness was born late, because at XXX (hospital) I saw boys from 26 to 30 years old with heart problems, I finally had it at 58 years old, at 58 years old I put LVAD. The offer of organs in Italy, I do not know if I will make a battle afterwards, it is not that we shine for offer of organs, so the waiting time, are very long compared to Germany and England for example. Paradoxically there is an English LVAD patient who married a woman of the brands, so he took the Italian citizenship and is forced to follow the Italian waiting times which are more than double the English ones. The country of Bengodi is America because cardiovascular disease is more widespread. It is therefore a story that begins in 2012 was a year of much stress of various kinds, emotional, work, political, smoking. I had a premonitory signal to the sea a few months before totally not understood by my family doctor, so I'm a little 'angry with the doctors, in my opinion the signal was clear, now that I'm like almost a graduate... I was at the beach, not on vacation, but with the Turkish delegation, I was in a suit and tie in that very hot summer, an anomalous summer, 2012-2013, I got all sweaty and cold, and went down to get a coffee, I had a premonitory signal and I told the doctor to give me a stress test to see that the coronaries were suffering, but he gave me an electrocardiogram on the phone. I didn't choose legal avenues Dr., you can't fight all your life, then Bruno is a friend. Instead the heart attack came two months later while I was going to Rome, at night I wake up with cold sweat and chest pain, I still don't understand...if I had gone to the Holy Spirit my heart would not have been damaged. It was already damaged, the main descendant was already plugging up, but I still didn't understand... I went for a walk near Piazza Navona, to get a glass of water, the pain went away and then I went back to bed. In the morning it came back, while I was driving to SXXX (city) by the sea, so I walked to the Holy Spirit. After it happened ambarabam, cardiologist, pills, doctors say that that kind of heart attack there is 80% fatal, in fact the next day I had a cardiac arrest, which I did not notice, I saw the doctors around the cradle.

I: How did it make you feel knowing that the heart attack you had was so serious?

P: The doctor on call said so to my brother and sister-in-law, and indeed it was true. Ah then the dilated cardiomyopathy began, I did the surgery in AXXX (city), replacing the valve, but with hindsight the following year I put the LVAD, maybe that surgery could have been avoided. And after AXXXX (city) decided to send me to Milan, and decided that maybe the time had come also because they saw that I was full of liquids. I have to tell the truth, I do not love this machine, but I think it has improved my life . Now finally I am suitable for transplantation, the wait for the transplant in my opinion is a bit long in Italy, also because I believe that the age factor in my case, every year is a small advantage. I believe that the sooner you do it, the sooner you resist better . I look at who is worse, if they can do it, we can do it very well too. Now the cardiologist told me that I am quite tonic, tonic in a general sense, the parameters are good, the mood is good.

I: How does it feel to be attached to this machine?

P: Eh, so, the LVAD at the beginning, in fact the doctor before leaving made me give instructions to a Ligurian who put the LVAD (laughs), in fact I told her "Are you sure I am the right person?", because I have a relationship of love and hate with this machine. I know it saved my life, and it allowed me to take the stairs at home. However, it's a technology a bit obsolete, a bit intrusive, apart from the really unnatural medium, unfortunately LVAD has that weak point, sooner or later it gets infected, you can be the cleanest person, clean 10 pairs of sterile gloves, sooner or later bacteria colonize the area of the medium. The drugs associated with LVAD are a bit 'heavy, I know that afterwards it is not that you do not take drugs anymore, but life is lighter. The alchemy that has allowed me to wear it is that it has allowed me to do many things. I had other thesis done, I took another degree, I have run an engineering firm, the only thing is that I stopped doing active politics. So who has the LVAD, I would blunt some doctor's attitude about fatalism and other things...

I: In what sense?

P: LVAD is still a sacrifice , so sometimes I have heard inappropriate phrases that have hurt me, like the heart is not an organ in the drawer , how to say the chance, the case that will decide whether. On the other hand we LVAD think that the transplant is, in fact it is called bridge, but I repeat the wait in Italy is too long, we should commit ourselves because ... It's like a couple adopting children: the couple that has no children, for heaven's sake the gesture is noble, but you understand that there is a strength. A couple that already has children and adopts a child, I see it in a different way, I see it as a gesture a little more exemplary, to be pointed out. Now I am interested in the transplant, however, the culture of donation is important, but not because it is a noble gesture, but because it is a civil gesture. It's not that if you donate you die first, but for charity! It is a certain bureaucratic gesture because you need the will of the person who is going to die or the availability of the legitimate heirs . The machine is a burden, I think that some patients are very devastated by carrying the machine, and that they do not process .

I: What do you see at the end of this bridge?

P: That's a good question... No one has ever asked me that question...in fact do you know what the question I ask myself most often is? "After what you do?", I would like to go back to traveling, then in my opinion the most suitable thing is to go back to university teaching, because in the end it's the thing I liked the most. I am deciding what to do next, what a good question, it's not easy... (detour). Now I think about it calmly...I am scared to travel by plane with the LVAD, I don't know why, on the plane I am really scared, if something happens it is not that you can get off .

I: What do you fear?

P: Yes, I am afraid there is no electricity, it is a constant worry.

I: It can also happen at home, but no?

P: Yes, but at home you have some antidotes, but it's not good for you to go by car, you can get stuck to the battery. Then at the XXX (hospital) they gave me a letter that we sent to Enel that assured us that the area will be as little as possible marked by power outages. It is a theoretical danger, because the batteries last 16 hours. At XXX (hospital) they told me "But you do not attack at night?!", but I know I wake up. My LVAD has never surprised me, things that other lvads have given alarms, sometimes it has not been tolerated and has led to transplantation before, because for some patients LVAD is problematic. I remember that my bed neighbor to whom the heart went in my place had two cardiologists standing next to the bed all dressed in operating room clothes and that is the moment you realize it has arrived. It is a bit of a ceremony even the wife with the mask...

I: So you faced everything on your own because you have not wife?

P: Yes, I only have my cousins who are always here every day, even too much. Now I don't need much, except linen and various things, even after the surgery I won't need much...The LVAD one of the conditions was not to be alone... I like to be independent. Everyone knows that I am more jealous of books than of wives and cars, I have stocked up on books even here in the hospital...

I: In fact, excuse an active person like yourself, how do you find yourself here in the hospital?

P: Do you think that Dr. Fxxxx al XXX (hospital) asked me, she could ask a thousand painful questions, she asked me "Are you bored?" and I answered "no... "Well, i've been dismayed for a few hours, for example the other night I didn't sleep because I thought about all the things that went wrong in my life (she laughs), a psychologist's thing, that I shouldn't leave the Normal, but to stay in Pisa, that my German wife didn't want children, instead I wanted them, then she got pregnant and had an abortion... (detour), the heart let's forget it that came later. So I took a Halcion (benzodiazepine for treatment of severe insomnia), I do not use it, but if I sleep late I take half a Halcion, I hope that some doctor will give me a prescription, I do not abuse it because I do not need it, I have always slept poorly and badly, and the heart disease is not that helps ... (detour).

I: How does your heart expect it?

P: Thirty years old and handsome (laughs), I'm joking, I don't think one should have psychological problems compared to those who donate the heart, i've heard stories of transplanted men who had problems because they thought they had the same problems as the donor , ok it's not an organ in the drawer, that one opens, the machines, however perfect, will not be able to match nature . Then my heart was healthy, it was me who ruined it (1\*).

**Interview to his caregiver**

Interviewer: Would you like to tell me how the initial phase of LVAD implantation went?

Caregiver: Well, after a hard period of continuous hospitalization for heart failure they put this machine that works like a real heart .

I: And you are close to him? He has been designated as caregiver, so he will manage the machine with him...

C: yes well I have been close to him like a brother, he is the only cousin I have, we grew up together, I could not leave him alone . So even with the LVAD nothing has changed, it will always be ups and downs , because the doctors said it will not be easy, but there are two of us5, so we will make it this time too, indeed there are three of us! I consider the machine as a friend more than as something to manage. It is an ally in this story, not an enemy to fight, on the contrary, it will be a traveling companion that will accompany us to the transplant, because I am sure that the heart will arrive for XXX (name) .

I: You seems optimistic to me...

C: I am optimistic in general, but I am aware that it will not be easy for him to accept this machine . I talk easily, but I don't carry it around all day like he has to. So I don't know if he will accept this life easily . I will try in every way not to burden him with both the machine (laughs) and the situation. I will try my best.

I: Is there anything in particular that scares you?

C: Everything (laughing) more than managing a machine I don't know what it will be like . It will certainly be strange to run a machine and not a person like I have done so far . There was a moment when I was in panic I didn't feel up to it. He saw him calm and therefore I also felt calm. I have also made some changes in my life, because I have reduced my hours at work, to dedicate myself to him now and also afterwards of course, it won't be easy because my life will be upset too, but there are two of us: I support him and he will support me and he will support me since in this matter I have to do the bad and strict one that must make him respect all the rules and it won't be easy since my cousin is a free spirit .

I: ok so he feels able to manage the situation, but he recognizes aspects of fatigue...

C: well yes it will not be easy I know . But the spirit counts for a lot. And then I humbly say to myself, at the end I have to do a bit of the gendarme and yes help him with the dressings, but much of the work has already been done by God (laughs) . I am just the tool to effectively lead him to the transplant that I am sure will come soon . But if it hadn't been for God he wasn't here, because he saw some really good ones . And then what he has lived has changed him, to think when he worked all day and was never tired... Now if there is no one to help him, he physically collapses, because he is mentally there. He is fine (1-4).

#2

P: Patient

C: Caregiver (his mother)

Interviewer: Would you like to tell me your story?

Patient: Then it happened to me, in 2011 I had a heart attack, while I was doing sports, I was skateboarding, i've always been passionate about skateboarding. I had finished an amateur race, something like that between friends. I had this heart attack, not really there, I did it in the morning, at six the next day, and nothing I put a defibrillator, but I also accepted that thing there, I never had any problems, I accepted it, because anyway I had my dad who passed away at home, he also put a LVAD, not of these types, but of the old ones, because it was in 2000, when my dad died, he had the surgery and then he had a problem during the surgery, he had what's called the one that takes the head, damn I can't remember what it's called...

I: A stroke?

P: no...

I: An ischemia?

P: Yes, an ischemia, and after that surgery there lasted six months, it was really serious, it had reached the last one. Anyway, I accepted it and I never had any problems, I did 8 years without even having problems and I continued my life, not like before, because I stopped working, I dedicated myself to my health...

I: Help me with math in 2011 how old were you?

P: I was 21, I am from 1980. The situation has already changed because I had to leave sport, I got a little turned around at first, but then I said, first my health and then come the other things. After that I change... I have often changed my job too, I have always been a fairly quiet person, I have had my experiences, I have worked abroad, it hasn't affected me emotionally, I have always had a good relationship with my family, they come to visit me, now that everything is over they are calmer too. I am from Valtellina, not from Milan. Even with my friends we feel like we are on whatsapp, because they don't come down often, it's a bit uncomfortable... But we feel like we have been friends for more than 20 years, because since I was 14 years old we are always the same company, we always find each other, we have a good relationship. I have a good relationship with people, I am used to talking to everybody, I have no problems. I am such a simple guy. And I accepted. On the other hand, even with this I had to accept because I was so bad that I said "Or so, or so!", when you arrive at a fork that you say turn right or left? If you turn left, I feel very bad and I die, I go to the right, I don't know what it will be like, but I follow myself, after all I can't do anything else.

I: What is your relationship with this machine?

P: I still have to get used to it a little bit, because you ask yourself "What will it be like?", but I think that in the end I get used to it as it was for the defibrillator at the beginning that you think I have something inside me. I have to get used to it, because I still have to take a shower, the shower will be later, but if I also think about the first days that I was careful to wash my face, I used only one hand, now I use both hands, slowly you get used to everything.

I: when they told you that you had to put the LVAD the first thought what was it?

P: a little frightened, but I asked a little bit of those of the XXX (hospital) that I was seeing...who did it...

I: What concerns did you have in particular?

P: and how it worked... What was it like, what problems it was giving , because then I saw so many who had problems, but afterwards what happens is that in my country there was a boy conscripted by my sister, who put her there. He had a strong heart problem, both he and his brother, and his father, all three of them...his father passed away when he was in kindergarten. He had the LVAD, he kept it for two years and did the transplant, and when he had it he was fine, he went around quietly, he didn't go around much, he didn't live like before... In my country there is an association called Il granello which is in charge of making dressings, and then my doctor, is one of them, I have to thank her, I live in a small lost country, we all know each other....

P: (digression)

I: So there is another guy in your town with LVAD?

P: And now you have done the transplant. He's fine, he even smoked at the conscripts' party, which he shouldn't even do, but he smoked it.

I: Did you smoke?

P: Yes, I smoked...afterwards I quit, before the heart attack, then after the heart attack I started again shortly afterwards, and afterwards I just quit, I didn't smoke anymore. Smoking kills you, eh! Smoking is a shit, it's a disgusting vice.

I: So you did the LVAD implantation at XXX (hospital), how was that period?

P: Well well, I did that period in resuscitation, even the doctors were happy because they told me you do everything, you are a collaborator, eh in the end you are in their hands, I am in your hands what should I do?!

I: Listen, how does it make you feel a bit dependent on this machine? Or the others?

P: From the others... You know that I don't care about that thing anymore. At first it was weighing me, then it doesn't weigh me anymore.

I: at first when?

P: and at the beginning, even when I put the defibrillator on, I felt the fatigue in doing certain things. I also sold the machine because I didn't use it, I didn't work. And my friends always drove me left and right. They too have always told me, don't worry, we're here for you, we're here for you, don't worry. There a little bit that thing bothered me, but afterwards you get used to it, i've made up my mind a little bit, I said enough, yes ok, there's my family, who put up with me, there's my brother, my sister, my mother. My mom is over 60 years old, but I also collaborate at home, my mom is happy like this, she tells me not to worry that you do that little bit and it's okay in the end. Because she also says to me: "I'd rather do it this way than see you feel bad. I have been, look at the beginning it's ugly but then i've come to my senses.

I: When did you get over it?

P: It took me a while to tell you the truth, but I did it...

I: Are you missing something in particular?

P: Sport... That I miss...

I: Do you feel lonely instead?

P: Alone? Nooo!!! Because at home where I am, one is never alone...there are my cousin, my aunt, my cousin's children...there is always movement, there is always comings and goings. Not by myself, no, indeed I feel almost more relaxed here than at home...at home there is always noise. Here, in fact, I relax a little bit, you're a bit in your thoughts...

I: What do you happen to think about?

P: They're not negative, maybe I think that my mom is worried about, but I don't think that much, because she's been through so much... I'm also an epileptic, you understand? She's been through so much seeing me that (laughs) I don't even know what to tell you. I did this surgery and I had a blockage and then I passed this and I said to myself that my mother is a rock...

I: Well, so are you...from what you tell me...

P: (laughs) yes even my doctor's secretary told my mom to say hello to me and told her that she believes I have seven lives like cats because I had an accident with an epileptic seizure. I was on the ring road there in SXXXX (city), I hit the accelerator full throttle, I bumped into the car in front of it and it realized that I was sick and tried to slow down a bit but it didn't make it. My car turned around, I bumped into it, a head-on collision with the car. My backrest broke, I only got a cut here. The one that came up was much more injured. There was nothing left of the car. I did this thing here that I had a heart attack, and even then I got out of it, this one. Now I don't know what to do anymore, i've given enough (laughs). What more do you want from life? I must also be happy because if you think, look there are so many who look, I have also seen at XXX (hospital) the children, the children who have to do the implants like this. I saw that a team came down from Padua to make a baby, a newborn baby!!! You see them as the ugly thing in life, but when you see the parents who are young and have to do something like that to a child, it makes your heart cry. I tell myself in my life I have run, I have done sport, I will miss sport a little bit, do you understand? I've had fun... I've had my drunks, i've had my experiences as a teenager, what will that child do? He'll get used to it later, but it's bad, it's not right. In my opinion, to get out of these things here you have to be a bit aggressive, towards the situation, if you are not aggressive you go to a hole.

I: Have you experienced moments of sadness?

P: No sadness no trust me, maybe days of melancholy that maybe you miss yours can happen, that's normal. I have a friend who has studied psychology, we have always confronted each other, he gave me books to read. I do not believe so much in psychology, because it is right to talk, talk to people, talk to your people, talk to anyone who understands? If you have a problem it's good to talk about it, don't keep everything inside, because if not you are insecure. Even with the first person that happens, you are at the bar talking about it!! Instead many people are not like that, they are afraid to confront each other, they are afraid to socialize. Maybe only on Facebook, on the monitor, but in front they can't make it, I'm one of those who never use Facebook. I like to communicate more.

I: Listen, I'm going to ask you a delicate question, you don't have to answer, what made you feel that your father also faced this LVAD experience and then he couldn't make it...?

P: Surely it's not something that since it was his turn, it will be my turn too. It may be that it is a hereditary thing, heart disease, diabetes, my mom also has diabetes due to my grandmother. It could be. Also my lifestyle, I have always smoked maybe this thing has engraved, maybe I never smoked. It touched me. It touched me. What should I say?! I cannot blame myself. Nor can I blame my parents, fate is enough! When it's destiny that goes like this, you don't have to make trouble, one can go outside, take the stairs, slip, hit his head and die.

I: What about the fact that you were implanted with a machine that was the cause of your father's death?

P: Luckily there is. I saw the difference with my dad's. My dad's machine could be heard, you could hear the noise, beating, and then it was big, it had to be in bed. When I saw this one they showed it to me, this one is very small in comparison. I don't feel anything, I can move, I can walk, I can do everything. It's a so-and-so thing. Totally . The first few days I felt the weight of the device, now I don’t even feel it anymore .

I: Do you remember your father with this car?

P: Yes yes yes yes I was 21 years old. I remember everything about my dad.

I: He died, excuse me, in what year?

P: At 21 years old, in 2000. I remember everything.

I: They were also the first LVAD...

P: That's right, they were the first, everything has changed, even in the medication... My father did it at (hospital) in (city). It was like a machine, you know the comparison between the machines of now and those of before? Then to say that the batteries are old too, I was talking to Stefano earlier, the batteries of cell phones are lighter, but the batteries of cell phones do not last. This one lasts a bit longer. I see with my computer without battery my computer dies.

I: How is the management of the machine going instead?

P: Yes, yes, I learned right away, it's very simple! My mother was taught a little bit, the engineer was there, then i'll show my mother everything well, I manage everything.

I: Do you do it by yourself?

P: Yes yes, you must be with a person who manages the thing, afterwards if I find that I don't feel good, a person must be close to me, in fact with my mother I will do it at home, which is quieter. You have seen only once, you learn little. All of a bang, even she says I did not understand how I have to manage how to change, if I have to use one, two, even she does not understand much, it is a bit 'chaos in his head. After a while. My mom is quite matriarchal as a person, the house has always carried her on, she is passionate about the garden. She is quite tough. After that she can explode, you know, the stress. I do not want to stress them and tell them come down, I do not want to be a burden. That my mother is stressed that yes, in fact I told her to stay home and rest. Then I told her to be quiet, now I see the finish line there, I'm there, I'm at the end , don't worry, now I'm almost at the end, now i've done everything.

I: What do you mean by end?

P: The end of that path that I have done so far , I arrived so badly that if you saw me you would say: "this guy is scary". I came down by helicopter and said to hurry up because I couldn't take it anymore. I arrived at the XXX (hospital) so badly, my arms were all purple, I could hardly breathe, I couldn't take a step from here to the closet, I couldn't stand upright. I said do what you want to me, I was struggling to talk and do everything, I couldn't stand up anymore.

I: How long did this last?

P: It took me a while, I struggled, I was in coronary therapy, for a while. I said after I did this, I do everything, it was like a climb up, now I see the end and I tell myself how I was. I came down twice with the helicopter from SXXX (city) the time with the heart attack, that time there was a walk, they had stabilized me. This time I lay down here and I could not even move, I was in such a condition that I could not move anymore. It was really hard. So for me this is the end, this is the finish line, because when you get to rehab having already done one, it will be hard, you have to get used to the briefcase, the handbag, and call it what you want, it will be hard at home to get used to it, you have to shower and move with the bag. But then do whatever you want, it's only the head that commands. In the end we are all habitual, we are machines. We are machines, man is a machine. Between this (touching the LVAD) and us there is nothing different .

I: Are you saying that you feel like a machine because your heart works like a machine?

C: Well, I don't know if this machine will affect my emotions and the way I feel and see things…

I: Ok. Finally, the LVAD is called the bridge....

P: Yes, they told me about the transplant...

I: How do you imagine this bridge? If I had to imagine it in your head...

P: I can't tell you yet because it's still early. I imagine it as a real bridge that I do from one side to the other, and there I am there waiting so that I can say goodbye while running. Ready to go. There is a video on the internet always of this brand here, of a black guy who instead of a bag has a backpack, if you want i'll show it to you, he basically puts the backpack on the treadmill, he runs, and at the end he takes a crazy running shot, and yet he has the LVAD.

I: So you have this expectation?

P: A guy who has a LVAD does all those things there.

I: And at the end of this bridge what do you see?

P: I see myself ready to shoot, then there will be another path even more difficult because the transplant is even more difficult, because I met a girl who also explained to me that it is a long path, but she told me that I am already advantaged, because as age I am there, weight and height, everything counts. It's always a long way, we'll see!!!

**Interview to his caregiver**

I: How do you expect CXXXX's LVAD to be managed?

C: I always hope that it will go well and that the heart will come . Therapies can go well or go badly, but they are there. One always hopes. I always tell Cxxxx, you have to go ahead, then as it is. If you stop, it's over. If you stop everything stops. He has been a fighter until now, let's tell the truth, yes yes, he has never complained.

I: it's an important change of life, this machine allows him to do things he couldn't do before...

C: he also accepted this intervention well. At first he was a bit hesitant, and then it was said either this or die. I am sorry to see him like that, attached to a device, but at least he is here!

I: And how did you take it when they told you that his situation was so serious that he needed this machine to live?

C: By now it was known, because you could see that he had gotten worse. In our country there is a guy who has done the LVAD, so we said to each other, well, he has succeeded, we hope that he will succeed too. He had pulmonary pressure that was not good. Now he is clinically stabilized. The doctor said that more or less his tests are going well. Then when he comes out he is a bit in our hands. However, the family doctor is also present and asked him to make the video to see how the dressing is done. She wants to see. Yes I am not alone. Then everything is there in the country eh. Also the pharmacist told me if you need me there.

I: Instead I wanted to ask you, how did you feel knowing that Claudio had the same operation that was fatal for his father?

C: That's different, I immediately thought, 17 years ago it wasn't at this level of cardiac surgery, then with the excuse that there was that guy in the country and he had already done it... I said "well, there he is too...". His mother also called me and told me about it and I calmed down. Because then his dad had an ischemia during the surgery.

I: He told me that he feels a burden for his family...

C: He feels a burden, but it is 7 years that is like this... I do not know what to say to convince him that he is not a weight. I told him that if we were needed, he would do the same thing. If there is need we are always there.

I: You had also had this experience in the past with your father...

C: He had been in the hospital for 6 months, he never came out of the hospital in Pavia, he hasn't been there anymore. His head was gone. He did not recognize us anymore. In fact, one night they told us that the heart had arrived and I said to myself: "To transplant a heart to a person who is no longer there with the head? I was not happy at all... Because even to see it like that. Claudio saw little of his father in those conditions, because he was working in Switzerland. He was young. He worked seasonally. You didn't see the whole situation, do you understand? Even the LVAD was different, there was a very big cable, he was forced to stay in bed there were no batteries, you had to stay connected to the current. It was not like now. He could not get up. It was another situation....

I: are you worried about something in relation to lvad management since you are the designated caregiver for your child?

C: Well, unlike the time with my husband where I had little to do with it, it was a hospital problem to manage, now my son really needs someone to help him with this LVAD. It scares me a little bit. We have to learn how to manage everything, the batteries, the alarms, then he will need 24-hour assistance, because if he feels bad and the battery stops, I will have to call for help. But in addition to the organizational plan, will I be able to handle the situation emotionally? I am a strong woman, I am positive, but I can not know, sometimes I wonder. Also because I am no longer young and already last week that I saw CXXX a little 'down I did everything to avoid visiting him at the hospital. I recognize it in short.... Bo have him at home all day, I do not know. But just not alone and I will exploit the people around me (laughs). Anyway I thank God for this solution.

I: Finally, the LVAD is called the bridge because it is the device that is waiting for the transplant. I wanted to ask you how you imagine this bridge, if you had to depict it...

C: I hope you will get to the top of the goal, with many problems that can be solved and get to the end.

I: What do you mean by end?

C: Well, that this heart comes.

#3

P: Patient

C: Caregiver (his brother)

I: Would you like to tell me your story?

P: Yes, of course. I was sick after some symptoms that I didn't give any weight to. Even though my doctor told me to check my heart. After the separation I neglected myself, I know I got sick because of me (1\*), but I don't look back, now I have a companion nearby who allows me to live .

I: How did you experience this important change in life? What was the most difficult moment?

P: I didn't have much choice. Either live or die, and luckily there are solutions . Nothing explained to me that my heart was too tanned and I couldn't live as a person my age normally does, so the only solution was it . I took it well at first, now let's say we are getting to know each other (2-3). Let's say that sometimes it's a bit of a break to have this thing that prevents you from moving , I'm afraid to disconnect the wires, then I'm not a delicate guy... I have to take some measures . Just like a person you don't know (2-4).

I: Are you afraid of something in particular?

P: no no that no, I know I am in good hands, both for the hospital and for my brother who is following the whole process of dressing, knowing the alarms and everything. We will be a team!

I: Do you and your brother have a good relationship?

P: Well yes, very much. We have supported each other in many moments of life. Especially after the separation from my ex-wife our relationship has been strengthened, after a period when we didn't think much of each other, because of my ex who took everything from me: money, friends, work and my brother. Not having my parents anymore, he is the only one I have... Let's say that with the separation I took away a burden, but my heart has suffered and you can see the results.... Now I could be a young man, meet a new partner, why not, I find myself making a life as an old man (laughs) . And then if I have to be honest I feel better than before, because the last few months I was really sick, but I didn't understand why I thought an influence that had left me with consequences... And instead your heart thinks. How strange life is ...

I: How do you imagine life with LVAD?

P: If so it is downhill (laughs). I joke I know there will be delicate moments. I am ready. But no sincerely I live it well. Maybe I'm denying it... Is that what you psychologists say? (laughs) I try to be optimistic, but I know that I will have my moments of emotional down, I have always had them now. But I have accepted her and I accept everything that comes with it. In the end the alternative was to die so I'd say it went pretty well . I am a bit of a burden for my brother...

I: in what sense?

P: It weighs me to be dependent on others. He must come here to follow the lessons (laughs) and I know that even in these years that will come his presence will be fundamental. I owe a lot to him as well, not everyone has a brother willing to be your caretaker, right?... He too is young he could not give a damn and yet he was the first one who worried. I have only him, so perhaps he has accepted because he knows that I have no one else...but I know that he does it with his heart. I know that he too will give up...I will try to repay him by calling him as little as possible...except just when I need him.

I: But it is important to have a person who supports you both practically in the management of the machine, and emotionally. Do you feel able to open up to him if you need him?

P: In general I am not very expansive, I have a bad temper (laughs) no joke. I feel different from before, maybe this experience has really changed me and maybe from rigid and cold I become a crybaby (laughs), with a machine instead of a heart I should be even colder though (laughs). No anyway my brother is much more careful than I am and I will surely rely on him. The relationship is close, in the last months we have practically lived together. He helped me at work, at home, so I'm sure I won't be disappointed and he can count on me too.

I: how does it feel to depend on this machine?

P: but I repeat I am fine. I have to thank God for giving me this second chance and I will not waste it. Surely I don't smoke and I don't drink anymore here. I have to take care of myself now. And my metal heart (laughs). I feel a bit Jeeg robot.

**Interview to his caregiver (brother)**

I: How do you expect LVAD management?

C: An ordeal awaits him. One day he will be fine one day he will be sick, even at home he will be like that. The life that awaits him will be like this, hospitalizations. I don't think he will always be at home. For the next 6 or 7 months he won't even be on the transplant list anymore. It will be an ordeal, it will be something to live for now. You have to live in the present, don't buckle your head. Let's go on like this, when the problem arises we'll see what to do. What I hope for him is to always be well. I also said to him on Sunday that it will always be long, it will always be hard, it will always be hard. (1-2)As long as he will do the transplant , I believe that after all this tortuous moment he will still be able to have a more or less normal, almost normal life. I always have these doubts, I am not sure of anything.

I: In what sense?

C: In the sense that, as they have already told us and as we know, this is gone, we do not know, because there are also contraindications from the machine, because it can take a depression, an infection, there are many contraindications, unfortunately we must be ready for that too. And then secondly, if the heart arrives, because the heart may not even arrive. We do not know if it arrives or does not arrive, and if it arrives and goes well or arrives and also goes badly . I do not know if I can explain myself. There is always a question mark, but there is a great hope . This is the solution. You have to take the pros and cons. But at least there is something!!! We live in a world where disease is around us and in some cases there is no cure. Here there is a great disease, but there is also a great hope of cure and recovery. If he caught another disease that they told you he had four months to live, nothing more can be done. Instead here in his case, he has a bad disease, but there are solutions. I always tell him, you have to go on. Seven years ago when he had his heart attack, put the defibrillator on, he came home and did his life what he could, which was not a great life . He went out with his friends when he felt like it. There were days that he was energetic, and days that his body, he lacked energy. He didn't do a lot of things he did anymore, but he adapted himself to doing other things, he was also fine, he never collapsed! He has a particular character, he's a bit critical, underneath it all he listens to you. He's never been demoralized. I was expecting this failure when he came out of resuscitation, and I said to myself, now when he wakes up and sees a cable, he sees a battery.

I: it is an important change of life, this machine allows him to do things that he could not do before...

C: he still has to know his limit, and his body, in my opinion, he will not know it completely here, fully, he will know it slowly when he gets home. I always tell him that it takes a lot of patience and a lot of work. It's not that with this machine you don't see the world anymore, also because if he couldn't do the surgery, he had to stay in the hospital attached to the machines until your body resisted.

I: And how did you take it when they told you that his situation was so serious that he needed this machine to live?

C: the situation had become unmanageable... When I was naive, I thought I would get a transplant right away, but a transplant isn't just a transplant that you get to a hospital and they find your heart. There are people who are definitely worse off than (NAME), even my friends ask me and I tell them that it's not like going to the supermarket, it takes a lot of luck and then patience. Because there is not only you, at the beginning he was not even suitable. His vital parameters were right on the limit and he couldn't even stand it. 7 years ago the doctor had already anticipated everything that would happen. With a heart like that you can't live, I still remember those words... He said the right thing.... I'm also satisfied, I saw it super badly, they told us that it's a very long thing, then I also looked into it. You realize that it takes time, it will be tiring. When I saw it down there, I got scared, because on Thursday I saw it really bad, then I went down on Friday and I saw it better... But it's almost worse to see it down there than to see it attached to machinery. I'd rather see him attached to a machine than see him down there. He kept crying. Now he is still a bit on the limit, on Sunday I went down with a friend of mine and it was he who told me that he had a moment of collapse and I told him that it was normal, he had a bit of tear, then I changed the subject. When I saw him sad, I got scared, because on Thursday I saw him really badly, then I went down on Friday and I saw him better... But it's almost worse to see him sad than to see him attached to machines. I'd rather see him attached to a machine than see him down there. He kept crying. Now he is still a bit on the limit, on Sunday I went down with a friend of mine and it was he who told me that he had a moment of collapse and I told him that it was normal, he had a bit of tear, then I changed the subject. Is also normal, his heart is mechanical, but his emotions are human ... He has worries, emotions, fears like everyone else. (7-9)

I: Finally, the LVAD is called the bridge because it is the device that you put on hold for the transplant. I wanted to ask you how you imagine this bridge, if you were to depict it...

C: Well, me more than a bridge, an ascending staircase, like the Japanese ones (silence), with many small but long and high steps. More than a bridge, here is a bridge with many steps. To be crossed on foot, not with a Ferrari. If it was a bridge to cross with a Ferrari at full speed it was the best, but I see it as a bridge to walk on foot with steps. Small steps, but always... You always have to go one step at a time, a small one and then another, another, another, another. It's hard to do the steps, they are many, and then you get to the top. I know that without this he was no longer there. This is the solution. You have to take the pros and cons. Whether it's good or bad. But at least there is something. Because we live in a world where the disease is all around us and in some cases there is no cure. There is a great disease here, but there is also a great hope of cure and healing. Then you see people like CXXXX that you see more or less those who have done the transplant have gone through what he is going through, and you see them around. Also at XXX (hospital) there was a girl, she has been waiting in the hospital since November. She also saw transplanted boys, it was an important thing that one there. That he was also able to compare. He is also us, because you see people who are even worse. Even staying there in the hospital for months. I don't know if it is better to do the (name)'s surgery, rather than wait. If you're at home it's always a wait, but it's a bit better than waiting at the hospital. Then he still has to learn how to manage himself well with batteries and everything...

I: Yes is a machine to know, you will study it slowly. You seem optimistic to me...

C: yes...I always think that my brother is not well, I'm sorry to see him like that... If I could give him my heart, I would give it to him, but then I will die. If it was a kidney, I had already given it to you. It will be hard, but we are two. There will be positive things also from this experience. After the intervention I said to him "You are like the bionic man" (laughing) , if he really wasn't there, but he started laughing. He didn't fit the joke, but I know him and I said to him you can say it. You also have to find something positive so that you don't have to worry about everyone, because you can’t always think if the LVAD’s battery is charged or discharged, otherwise you will discharge yourself afterwards, and it is over!

#4

P: Patient

C: Caregiver (his partner)

I: Would you like to tell me how you feel? What happened?

P: i've been suffering from heart disease for several years until 2007 when I was really sick, when I was transported by helicopter to CXXXX. I was in intensive care, I don't remember, maybe for two weeks and there I didn't think I would recover. Instead they tried to revive me and saved me. Then these years I was sick, I felt weak, continuous hospitalizations, I fainted several times. I went to NXXX (hospital) and there they put me on the transplant list. I was on the waiting list for two years. Then I recovered, but I had checks every 6 months. In December 2017 I was put back on the list here at NXXX (hospital) and since then I was checked every 3 months, going back and forth from south to north Italy. Then in March they told me that they had to operate on me and they told me about LVAD .

I: And how are you taking it?

P: I did not want surgery .

I: you did not want surgery? Why not? Were you afraid of something specifically?

P: I was given 9 months to live if I hadn't put this machine on. But I didn't want this machine .

I: But did you have the opportunity to confront the doctors? With your wife? Why didn't she want to wear the LVAD?

P: Yes, they told me that I had to wear it. That I am young and that I could wait longer for the transplant if I wore this thing.

I: But you were not convinced?

P: no

I: But was it a decision made together with your wife and the doctors?

P: yes yes

I: What worried you the most? The intervention? Or the management of the machine?

P: I was always worried about taking this thing with me (tugging it), the driveline, the tools, the batteries and everything .

I: Of course, it is a remarkable change in life what you have undergone. But your wife and the doctors are right when they say that you are young and that you can handle this situation...

P: yes I know

I: it does not reassure her knowing that her heart is working anyway, before her heart alone could not make it, it was very damaged...

P: it's always a machine, it can be good or bad (4\*).

I: so you do not feel reassured by the presence of this machine?

P: I feel confused...

I: in what sense do you feel confused?

P: that I have not yet fully understood how it works...(4\*)

I: so you feel worried because you don't feel you still have control over the management of the machine?

P: yes exactly, I feel confused...

I: But you are here to learn how to manage it. You will have meetings with the engineer who will explain all the alarms to you, and your wife I know she comes to the meetings, she will learn too. How does it make you feel that your wife will accompany you on this path?

P: yes I am calm, also because some things alone I just can't do them.

I: for example? What are you referring to?

P: also wash or make the dressing

I: ok and do you think your wife is capable of handling this situation? Do you feel in good hands?

P: yes yes we have a good relationship

I: And how do you think she is?

P: she is stressed, on the other hand, it was not an easy period. And then she has had her problems for years so...

I: Do you also have health problems?

P: let's say she's stressed about these years of hell we went through for my heart, she's down, I know she doesn't have a life anymore because of me

I: I think your wife is happy to be able to help him, as demonstrated by the fact that she has been with you over the years despite the dark times you have experienced.

P: yes yes I know

I: what is your relationship with LVAD? How does it feel to be attached to this machine?

P: and I do not feel that I am in control (4-5)

I: Don't you feel you have control over the machine?

P: yes, I must know it, like with a friend ... I don't know what it's like yet. And then here in the hospital it's easy to be in bed all day long, you don't have to do great things, and then there are the nurses and the doctors...at home I don't know what it will be like... I feel confused

I: Do you feel safe here in the hospital?

P: yes here yes, at home a little less, but because in the South hospitals are what they are. There is not the assistance that there is here and so if I am sick I have to go to a hospital that is far from my home, because it is the reference center for the south of Italy for heart patients like me who bring LVAD. But it is not like here at MXXX (hospital).

I: so there are also logistical problems for moving and so on, you mean?

P: for example I know that the doctor called the hospital that will follow me because she has to explain all the procedures in case of emergency, but they are not trained...

I: And how does that make you feel?

P: I feel I am not in control of the situation

I: we have said many things to each other, I would like to conclude with a metaphorical question that I often ask. The LVAD is called the bridge, how do you imagine it?

P: which leads me to the transplant. I hope as soon as possible, but I doubt it.

I: so your goal is to get to the transplant?

P: yes, it was better if I did it right away...

I: So you would rather do the transplant now than put the LVAD in?

P: yes it was better, now I had my new heart and that was it...

I: but you know that it is not so easy even with the transplant anyway you have to be under control, take some drugs, then there is the risk of rejection. Why do you think transplantation is better than LVAD?

P: yes I know that in Italy the lists are very long for transplants, especially heart transplants. But at least I didn't have this thing, and then this LVAD causes problems too. They told me that there are risks of infection, then the heart has shocks...

I: and this worries you

P: yes the infections and everything else as I was saying.

**Interview to caregiver**

I: How are you?

C: I see my husband a little depressed because he never accepted this machine. He only put it on because the doctor told him that he had 9 months to live, so he put it on in front of this proposal. He would have preferred the transplant right away, because he complains that it bothers him, that he can't move and surely at home it will be worse. We haven't slept for 10 years already, we are anxious, even I am a little destroyed sincerely. We did not believe that it would come to this point, because he still does not accept it. I have been taking sedatives every day, for ten years, and even more after implantation. I have been suffering from depression, I am nervous and after the implantation even more (3 I probably do not accept it any more than he does.

I: What worries you the most?

C: we have to be careful, we are worried about infections. But mine is more afraid, that something will happen, maybe he gets an infection, then he is not well, then I am alone and we are far away from the hospital. It was a life-saving machine for him I try to convince him. Also manage the machine, all the alarms, say I'm ready no. But I have to do it, I do, of course.

I: How are you?

C: I feel old, I don't feel like going out, I don't see a future, now we are going to be at stake with the LVAD then with the transplant. This operation is as if I had done it myself, I was afraid to see him intubated, and the others will tell me where you found the strength? Then he must not see me cry...then he must not see me cry... I weep from sorrow, frustration, stress. He didn't want to wear it I told him: fight at least for your daughter. I believe that the only thing that machine cheer him up right now is the harmony and union of the relatives. It takes a very strong support from the family. At the same time I know that staying at home with him like this will be an ordeal, before he was nervous because of the heart insufflation, now it will be even worse, because he is not completely autonomous and then you have to carry this machine always behind. I already know I am going crazy. I don't think about a beautiful future, I think it will get worse and worse. I also need a machine to recharge myself.

I passed 10 years from hell, and now with this machine it will be worse. It will amplify his and my nervousness. Every time he takes it in his hand he looks at it badly, he pulls it.

The worry he has is that the transplant will not come and that after 7 years this technology will be obsolete and he will die.

My fear is that something won't go well at home, for the infections, etc., and that they will make me go back to the hospital. I am afraid of management at home, just to try the dressing here, put on gloves, disinfect scissors, I tremble, and here I am supported by doctors, at home I am alone. And then also the knowledge of the alarms worries me. Now I am trying to rearrange the house, I also have two dogs at home, I am sorry to bring them to the kennel... It is not so easy for me...but we have to do it, we have to do it, roll up our sleeves ... I also have a nephew, I have to see if I can teach him, in case if by chance, while playing, he detaches the driveline or punches him right there! I have to see even if he can stay at home a few hours alone, to be able to go back to work. But I am also afraid to leave him alone. He did not want to do this intervention, because he was terrified, he told me he preferred to die. I took matters into my own hands and convinced him.

I: He was against LVAD?

C: When I die I die, I do not want to do this counter-nature thing he told me. I am tired, I am depressed, I can't take it anymore , and with this LVAD it will be worse and worse . Now you need to be in the middle of the family, because they cheer you up. If he is upbeat, it's okay, otherwise I can not do it. He needs support, someone to talk to, because it is not that the operation went well then everything is okay, now you need to reassure him. On the psychological level he needs support and so do I . If he is in high spirits, he is serene, that’s fine, otherwise I can’t do it

He said that he will lock himself in the house, that he won't come out anymore, because he doesn't want people to see him with his purse. It is also a fact of shame in my opinion . Four eyes are better than two for the complexity of the LVAD management, even now I tell him: “Check the batteries, check the driveline...”. I feel confused. I am worried about everything.

I: how do you imagine these years with LVAD? How do you imagine this symbolic bridge to transplantation?

C: Just thinking about it makes me panic. It will be the most difficult thing I have ever done.

I am tired, I am depressed, I cannot take it anymore, and with this LVAD it will be worse and worse”

#5

P: Patient

C: Caregiver (his partner)

**Interview to the patient**

I: Would you like to tell me your story?

P: gladly. I have been on the transplant list for several years, due to my heart failure after I had a heart attack at work when I was 45. Since then my life has changed. Then in the last few checkups my heart function was much worse, so the doctors I trust a lot decided to put this machine on me. I'm fine now, I don't even seem to have it, I thought it would give me problems instead I have to say that for now we are in tune. Maybe I'm so good because it allows me to do things I haven't been able to do lately.

I: for example?

P: breathing and everything that comes with it. The breath had become really wheezy, I wasn't sleeping, I was swollen...

I: You told me that the doctors decided to implant LVAD, and you had time to decide?

P: eh (laughs) not much. They scheduled the surgery and I did not have time to think about whether or not to do it . Let's say that I am still young so in my opinion they followed the protocols, a man of my age can still be offered LVAD while waiting for this blessed heart . But this choice is fine with me too. I don't want to die yet, I still have to do many things...

I: What would you like to do with this LVAD that you didn't do before?

P: well a nice walk first and then do everyday things. Oh God I'm sure I don't know what it will be like, because here in the hospital I feel good with LVAD, but I'm in bed all day long. At home, shopping, holding my grandson in my arms... I don't know what it will be like . We'll see from now on I'm optimistic.

I: are you a bit worried about the daily management?

P: well yes, I think it's normal. That's also why they call my wife to show them what to do. Because as long as they do them (doctors/nurses), medication, checks, alarms everything is ok. But at home the situation is in my hands.

I: How does that make you feel?

P: no it makes me think about how it will be. Then I know the hospital is near here and they reassured me that they will always be there , in life outside the hospital I think the situation is a little less simple especially in the first period, then as for those who have a crutch, it ends up that the machine becomes an extension of you and that you will do things as if nothing happened.

I: so you think your worries are related to the early stages?

P: yes yes I am convinced of it...

I: Who/what could help you in these phases?

P: well I think wait and get used to it. Every day will get better.

I: instead, how is your wife? What do you think about this period?

P: you should ask her (laughs). She tells me that she's fine, maybe she does it so that I don't worry. But there were no particularly difficult moments after the LVAD implantation. More than anything else, they were moments...how should I put it...a little bit...do one thing, do the other, there wasn't much to think about...

I:Feel instead going back to the lavd how it makes you feel a little dependent on this machine.

P: but, for me it is not a burden. Here. I repeat. Outside I do not know. Maybe outside I have the moment of depression because I realize that I can not do anything will excite me. . But I thank God that this device is there, otherwise I would die. It is a burden, a sacrifice, but thank goodness there is it. . It is a bit strange to say this for me that I have never been such a believer. I thank God and thank science. I feel a bit strange on this point, because I was waiting for a real heart and instead I have an artificial heart that keeps me alive. As if I was a bit half half.

I: in what sense?

P: as if I felt "artificial" kept alive by a force that does not belong to this life.

I: instead, since the LVAD is called the bridge, how do you imagine this bridge and what do you see at the end of the bridge?

P: yes I agree it is a bridge that leads from one life to another and on the other side the heart that I have been waiting for for several years and that will allow me to live many more years.

**Interview to his caregiver (wife)**

I: Would you like to tell me what happened?

C: we had been waiting for a new heart for several years, but lately my husband had gotten worse, so knowing that the heart in Italy is an unobtainable organ, there is an endless list and you don't even know if he will have a new heart , they put him this LVAD that works like a real heart, only you have to manage it.

I: so your husband has been sick?

C: let's say he didn't have a heart attack like the first time, when he was hospitalized and they told him that he would be in treatment for years, that he couldn't live like before, in short he would have frequent hospitalizations and so on. I have to say that my husband was also lucky because his heart was giving him problems and he was always emotionally strong during the hospitalizations. He never gave up. Then I saw some tears, because it seemed that the solution never came. And then we were told that for now the situation is this machine, because in Italy the donation is not fashionable... And there are too many sick people.

I: how does it make you feel that this machine will allow your husband to live?

C: eternally grateful. We have gone through many, but now God has looked down .

I: are you believers?

C: I am. He a little less. But yes, in the end, I believe that someone has chosen for him. Some people call it destiny, I believe in God and therefore I believe that it was his work. It’s all you have left, when your life is hanging by a thread .

I: feel and instead how does it make you feel to have an important role in the management of LVAD?

C: eh they told me that with this LVAD I have to help him with medication, washing and all these things. For me there are no problems. Alone are things a bit difficult to do so there is no problem for me. At the beginning of course there are, then I think he will become familiar with it too and some things he can handle on his own. Then I know that he is an independent, one who always has the line ready so I know he will handle it well. But certainly at the beginning we will be together.

I: what has been the most difficult moment you have lived through so far?

C: well certainly before putting the LVAD that in the last days before the hospitalization was down could not do anything. I had never seen it like that before. Then they hospitalized him and he started to get better, of course he was stuffed with drugs and things they gave him, and then they gave us this news, I thought it was a very big machine that would have remained attached to the bed, but you can not even see it! I really imagined it as a bulky machine, but really if you don't know it, you look like a normal person.

I: are you worried about the management at home?

C: mah... They showed me what I have to do and I have to say I am familiar with it because I took care of it with my mother until the last day. And then they told me that I can ask them (the doctors) for anything. So for now no, come on.

I: to conclude, I ask you the same question I asked your husband. The LVAD is called the bridge, how do you expect it? What do you see at the end?

C: ah yes the bridge said the doctor, yes I imagine myself and I hope it will lead to the transplant, so he can have a really normal life. We will see! I hope that the waiting won't get longer. Now he has this machine for a while, and then when a compatible heart will arrive, they will give it to him...let's hope. We have waited for years, waiting a little longer doesn't change anything for us. But it is really frustrating to wait for others to have the conscience to give and to make an altruistic gesture for others. I will certainly give from this experience. (1-6)

#6

P: Patient

C: Caregiver (wife)

**Interview to the patient**

Interviewer: Would you like to tell me your story?

Patient: After a period in which I didn't feel good for pneumonia, I was really out of breath, on March 3, 2018 I went to the emergency room in CXXX but there was no room there, so the next day they moved me here in Milan to XXX (hospital) in Cardiology and then I don't know what happened there because I was in a pharmacological coma for two months, I don't remember anything.

I: Two months in coma?

P: Yes two months, when I woke up, and they told me two months, I told them "Two months?” (laughs)

I: And who took care of you during this period?

P: My wife and my son

I: What period was it for them, in your opinion?

P: They don't show it, but it was tough for them too. I was not conscious in the end so I stayed there when I heard that two months had passed, but it was hard for them who saw me there almost like a dead man. It does not prove it, but it was tough for my wife too. She went back and forth from the hospital for two months when I was in a coma, my wife had to stay home from work. In fact, I try not to make her weigh this moment, and when I am at home, I will try to be independent.

I: You didn't feel anything? You know, the coma is a situation that few people study, it would be fascinating to understand what the patient feels...

P: I heard voices in the distance but did not recognize them, then my wife told me that the doctors invited her to talk to me.

I: And now how do you feel after the operation?

P: I am fine, I feel good

(Silence)

I: how is the relationship with the machine?

P: I'm getting used to it. They explained me how it works, then on Friday the engineer comes to explain to my wife how to use it too

I: Will your wife help you with the management?

P: Yes, even the doctors told me that being two is better (referring to the wife).

I: is it complicated?

P: no no, at night I have to take the batteries out and put them in here and then I connect to the network, then in the morning I change the batteries, because they last 20 hours, they have an autonomy of 20 hours.

I: How does this make you feel?

P: well I have to get used to it , of course I had to put it on, then it's a good thing I'm here to tell you about it, because it could have gone wrong... and then I hope it works, waiting for the transplant... there was a patient at XXX (hospital) with LVAD who was so used to LVAD that he didn't want to do the transplant anymore.

I: Are you thinking of refusing the transplant if there is a heart available?

P: I don't know, i'll see, i'll have time to think about it because who knows when a compatible heart will arrive, the doctor told me, if we were in America the hearts are there because they are all obese and so the heart is suitable for me too, but here in Italy... I'm on the list, let's see... for now it's a good thing that there are these things here. I thank God! It could have been worse, it could have been less bad that I am here to tell the story!

I: do you have any concerns regarding the management of LVAD?

P: but no, in the end I don't have to do anything, I always have to carry my briefcase with me. The only thing is the work that I will miss, they told me that's enough, also because I'm a pizza maker, you can't stay there with high temperatures anymore, my son goes on with my work.

I: do you think your wife can help you?

P: and yes also to help me wash myself and everything, especially at the beginning, because now I am here in the hospital the nurses take care of it.

I: Have you noticed a change in your physical health?

P: well yes I walk now, I breathe well, i've never breathed like that, also because in 2013 they put me on the defibrillator because I always had problems, I suffered more?

I: In what sense?

P: because in any case when you are at risk of cardiac arrest, you never have the certainty that the defibrillator works, instead here gives me more confidence to be able to manage it, I will be careful, but I have already learned, it is not difficult

I: Are you afraid of something once you get out of the hospital?

P: no (silence) I haven't thought about it yet....

I: I understand...

P: maybe, here's the thing, I am afraid to go among people, to be jerked and the driveline will come off and my heart will stop. I am afraid that my briefcase is stolen, maybe someone can think it’s something of value. It’s an irrational fear...

I: no sure, they are understandable fears

P: but for example there is also the possibility to put it in the backpack, but of course if you are in the subway and they come on you and without doing it on purpose they pull the wire, the machine turns off...

I: And how does that make you feel?

P: A bit worried, but I don't want to think about it, i'll be careful!

I: How has the relationship with the doctors gone so far?

P: Everything is fine, nothing to report also because for two months I was in a coma. Here is perhaps someone has lacked a closer communication, less technical.

I: Can you give me an example?

P: To the doctor who told me that I had an enlarged heart due to heart failure and I had to put in the LVAD, I replied: I do not have an enlarged heart doctor, I have a big heart.

I: did you want to tell him that you are generous? Did you want to communicate that?

P: well yes I am a good-hearted person as they say (laughing) and maybe also the fact that we are not only talking about gears, sometimes having a machine instead of a heart, talking to engineers makes sense right? Maybe technicians and doctors should remember that we are always human.

**Interview to his caregiver**

Interviewer: Would you like to tell me how you feel in this new role?

Caregiver: I know, (she sighs) it's not easy, even for the dressing, today I also have the dressing at 4 o'clock to see again, because I saw it on Thursday and today I see it again, because it takes an hour or so to make a dressing, an hour, an hour and a quarter. I am already worried about this.

I: Yes, why do you attend these moments to learn?

C: both me and my husband, with these batteries that he has to watch well, then when he takes a shower he has to be careful to change all the things, but it takes a little bit that one is a bit behind him. I have not yet asked if he would need assistance 24 hours a day, but in my opinion it would take, because having already been 5 months, then you know. ... Look well if the therapy, all the things, but I saw a session, he explained me, it's not that, two and a half hours he explained me, it's not that I understood everything, then on Monday I have another session.

I: Ok, because as you know you will have an active role in the management of LVAD. How do you feel in this new role?

C: Eh... (sighs) look... For God's sake there are these things , he is waiting for a transplant, but last week he already said that if he is well with LVAD he won't do the transplant...

I: he told me the same thing...

C: Eh... He has already told me that if he is comfortable with the LVAD, he does not want to have the transplant, so in the end he has nothing, he is fine, before he was attached to the machines, now he is walking. It wouldn't be like that, it's not like that in my opinion...

I: Yes, the LVAD is what they call the bridge...

C: Well done, exactly, the bridge in the direction of the transplant ...but now there has also been a period of time in which he hasn't been well for some years, between one thing and another...sometimes you see him stop when you're chatting, he's a little absent, all of these things.

I: And how does he behave when you see him like that?

C: I try to cheer him up sincerely, I have quite a temperament...I say to him, "Come on, hurry up, hurry up, hurry up, there are those worse than you!", you have to react a little bit like that with a person who is like that... He needs someone to pull him up. He's also been in a coma... He's been in a coma. One thing and the other, all of these things, back and forth to the hospital, he came here, they reopened it a second time, they operated on him after two days, they wanted to reopen it, liquid had formed in the right ventricle and they wanted to reopen it, but...come on now... Sometimes I say to them, "There are those who are worse, let's tell the truth," and now it's less bad that there is this science, with these things...but it's quite good...

I: Yes, the technology in the cardiac field is evolving day after day, we were also talking with the doctors that the LVAD previously weighed 7 Kg....

C: They showed it to me, a cardiologist at XXX (hospital), near the operating room, there are some glass things, that there are huge things inside that many years ago ... Now compared to see how small it is now, it's a pump, it's an artificial heart, but you have to get used to it, you have to be close to it, you have to be careful of many things now. It's not for the surgery... The problem is all afterwards... He needs support, someone to talk to, because it’s not that the operation went well then everything is ok, now we need to reassure him. I was talking to my son in the car, and I was saying to him, "Mamma mia Exxx, I don't know if I can face this dressing, an hour and a quarter to understand all of these things, the gloves..." he knows...this afternoon at 4:00 p.m., hopefully before coming home i'll do another one...

I: Do you feel ready to face everything afterwards, because in a week your husband will be home?

C: Yes, then I have the help of my children, it's not that we are alone, he and I, there are the children, the brother, the family is there, the family is there, we are on top of him, but he must also react, he seems so so-so, but then...

I: How do you think your husband is doing?

C: Mhmmm.... To see him I can see him well... But, before operating on him, he told me next to me and my son "i'll be a burden for you afterwards..." even when one says so... It's already not good... For him, who says so, but we told him and also the doctors , Dr. Sxxx, at XXX (hospital), told us "We must proceed... " and we told him "Yes yes...", because he said that there is a lot that they don't want to do it for the aftercare and for the aftercare, but we said that there were no problems, there are my children, that's why there is help...now he should be cheered up a little bit...I come a little bit...also because I come from Como...it's not easy... I have to keep the nephew because he has his mother who takes shifts, so once the brother comes, once we come, once the brother comes, once the brother comes, going to XXX (hospital) was more comfortable here...it takes an hour and a half to come here...that's enough...I can see him well, but what are you going to say to him every time, every time, every time... Did you speak to him? What did you say to him?

I: He was relieved, he said he felt good, because he was able to move in better conditions than before, in this story I have to say the pharmacological coma, which lasted two months and he says he doesn't remember anything, it was a moment that he tells...

C: He two months in hospital in resuscitation, 58 days, he does not remember anything, he begins to remember the About, when he was in resuscitation, who then operated on him, he was in cardiology ... Did he tell you that he doesn't remember anything at all?

I: he told me that he remembers voices in the distance, that it was you who spoke to him...

C: That's right, I was trying to talk to him to see if he woke up...

I: And how did you experience that period?

C: Mamma mia ugly ugly, they told us that we had to stick to that thread, they told us that there was little hope, we are doing everything we can, they told us...but we don't know what to do anymore...also because he went into renal failure...liver... All the organs were going upside down and they didn't have much hope anymore, instead when he started to detach from some machine they found a day just to bring him here to XXX (hospital), he arrived with a lung full of water, blood and lung infection, he was normal with two months in resuscitation, with all those machines, then he did the tracheotomy, then once here he started to be fine. ... They from Erba said, the only one is at XXX (hospital) because we don't know what to do anymore... It's not that they gave us so much hope. He knows it because I told him from the first to the last day, I told him everything, he wanted to know and I told him everything, we were there morning afternoon and evening, every day every day, we never left him a day alone.

I: So being your husband in a coma, they told you that your husband needed this machine...

C: At Erba they told me... If he was 90 years old it's a different story, being one of 58 years old, something we had to do, because he already had a defibrillator and a pacemaker put it in 2013, then he did a year and a half that continued to make imbalances, imbalances... He was struggling to breathe, then with the weight... He weighed 120 kg... Now he's lost more than 40 kilos...he weighed so much...it was a continuous...and the cardiologist said that the only thing he did was the transplant...but it's not easy to do that, so they put this guy on an artificial heart from time to time, I'm LVAD...I hope...you have to see it from the person as well, because you have to be careful when you're doing the dressing, you have to be there to use sterilized things, you have to have the room especially for the dressing...

I: And how does that make you feel?

C: Eh.... It's not easy. It is necessary to see if he is able to stay home alone for a few hours and I am able to go back to work...because it is necessary to work otherwise...how can we do it...then we will see...if the doctor says that he cannot stay alone, we will organize ourselves differently, then also not to leave him alone...I am also afraid to leave him alone...but eh....I don't know...a few hours in the afternoon...to see if he can...they said that he must be looked after for therapy...if he takes it...he doesn't take it...he doesn't take it... He knows...sometimes one doesn't know what's going on in his head...already being in the hospital for five months!!! Who knows what he was thinking...I was bored at the XXX (hospital) as well...he didn't even have television, I would talk to him, but he would always say "No nothing, I don't have anything, it's all right...I'm fine..." But he wouldn't tell you anything at all...it's normal...it's normal... What did he say to you?

I: your husband is very reserved...he also told me that everything is all right...

C: even with me...he always says everything well...even with me it's like that...what am I to do? I don't know...let's see...the dressing frightens me a little bit now...an hour and a quarter, and in my mind I keep saying... "Will I be able?? Will I be able to do these things?" There were six doctors around the bed, who opened the envelope, who put the gloves on...just a moment...I looked...but then I got lost...I said to myself, "Will I be able to do these things??

I: you has this fear…

C: yes, exactly...it's a fear...I was agitated, because I'm a little afraid...I'm telling the truth...for the first time...also because this is it...he's going out next week...he has an appointment on Monday with the engineer. And then we don't see each other anymore?

I: we'll see each other again when he does his rehabilitation for the transplant...and then we'll talk anyway...

C: they told me that it can be one year, two three, even five years

I: How do you live this expectation?

C: it's not easy...but if he's doing well with the LVAD for now, for a few years now, he's already there...with what he's had...with what he's had... The first week they gave us no hope...

I: Look, how did it make you feel to know that your husband was so ill that you needed a machine to make his heart beat?

C: How did it make me feel.... It was a relief for me... Knowing that there was a machine, because at least congratulations to those who do such things... At 58 years old...

I: Of course... But the fact of depending on a machine, how did you experience it?

C: No, it was quite quiet, even talking to the doctor who told me that it's a machine, it's like a heart goes ahead instead of the heart, knowing that there are these things, even my children all happy.

I: Instead in the communication with the doctors, have you been impressed, confused or frightened in a particular way by some words used by doctors?

C: Yes, I am telling the truth, when the doctor I talked to told me, and then I could not talk to them and tell someone, that the LVAD lasts from 2 to 7 years...maximum that lasted from 2 to 7 years, but I did not understand what it means after the seventh year. Maybe those people who put it on lasted 7 years at the most...but I thought if he is suddenly not well, they will take him out and put him back on again, I don't know about these things, I thought about it. They told me that he had lasted 7 years at the most...you say 7 years...what did he want to tell me? After that I didn't have the courage to talk to him anymore and in my mind I said to myself "What did he want to tell me that it lasted from 2 to 7 years? It means that after 7 years a person is no longer there... Only this one, then the doctor was very clear, she made it clear how it works afterwards, because afterwards it must be assisted, it must be looked at the therapy if it takes it well... It must be looked at what it eats, it must not increase so much weight... That's the only thing that has remained with me...from 2 to 7 years of age...but the heart will arrive sooner is normal...one, two, three years at the most...5 years at the most...

I: Yes, whatever doubts you may ask of the doctors, even about a few words that are not very clear to you...

C: Well done, I haven't been well either, i've had a malignant cancer of the cervix, and even when the doctors spoke to me I didn't listen to them, for example, even when he wasn't well at night, he wasn't breathing well, and I said to my mother, I wasn't asleep, I didn't sleep, I looked at the ceiling, and thought many things, if something suddenly happens while he was sleeping. ..I thought a lot of things, because every week I was at the PS, he kept on making imbalances, imbalances and I was afraid... He got down on his knees, he wasn't breathing, mummy look how much i've been through, in the space of two years we've been through it. Also last year he had an accident due to a car accident, he went against a wall, he was in intensive care, he broke all his ribs, that was another decompensation, thank goodness he didn't hurt anybody, the year he pulled out the firemen and they told him it was a miracle, and even now the Lord has looked down... We have been through it...

I: If you were to tell me about the most difficult time you've been through?

C: With him, having him at home, all the moments were difficult.

I: So when he was at home, before being hospitalized?

C: Yes always... Always... At night he used the cpap, he stopped not breathing, they were always difficult moments for me, always... Because it was a continuous in hospital with him with all those imbalances, these were really difficult moments, to see how he was, because he was big, he was struggling to walk and breathe. It is been 10 years from hell. We did not sleep at night. They were very hard moments. He was constantly hospitalized for heart failure. He was having difficulty breathing, he weighed 130 kg. His heart worked 20%. Those were difficult moments for me, yes...

I: and now?

C: not seeing him like this now, for me he's really okay now, I'm telling the truth, he doesn't have any machinery, he's breathing well, he doesn't have the machine to breathe at night anymore, for now he's fine, I can see him well, then what should we do...then coming home in the heat I don't know...

I: Listen and according to you what your husband thinks about the fact that you are so present, because anyway you will have an important role...

C: I don't know what he thinks. Because he told me that he will be a burden for me , but I tell him that when he comes home he will start to go out, go to the bar, go play cards, I try to cheer him up, but we have to find a way to cheer him up eh... It's not that we have to say "Mamma mia how are you doing Pxxx, are you okay? " then I'm a pretty cheerful guy, always, but I try to cheer him up, every day I make him the video and make him talk to his two-year-old grandson, and make him say "Grandpa you've eaten, take the pills don't make the doctors angry!", he needs to be cheered up now. Now in fact I try to be close to him now that he goes out and at home I'm present, and something he does , it's not that he has to stay in a firm chair, he doesn't eh I don't think about it, even the doctor said that he has to live a normal life, he's not a dying person, disabled...he has to do everything he used to do before...when he recovers well, we have to go back to what we used to do before, the life of before, for him too try to get him up and moving. He has always been a joking and laughing person and he is a companion, we are all around him, it's normal, the family is all around us...

I: And how are you?

C: I'm fine, I don't complain, my day is quite eventful, I don't have problems, my children are always there. We are not isolated and alone, we also have a nice neighborhood that loves us and we love them.

I: I would like to conclude with this somewhat metaphorical question, the LVAD is called the bridge, what do you see at the end of this bridge?

C: eh... What should I see at the end of the bridge? You will have to do this transplant, of course, in order to go ahead at the end of the bridge...

I: How does that make you feel?

C: As you put the LVAD, you will also do the heart transplant, after this artificial heart...it will go very smoothly...very calmly. I had confidence in what they did, that they showed me a machine from many years ago, now it's just a small pump...you also have to have confidence, they were good.