

CHAPTER 1

Waking up from Glasgow 3 in Guttmann

The following are a series of flash memories I had while waking up from the coma in the hospital. Here they are written all together but these first memories took place over more than two months.

Darkness... all black... total darkness... without a glimmer of light...

I hear sounds and then I realize they are voices, but I can't understand anything. The voices seem very far away. Suddenly I hear them more clearly, although I still don't know who is talking or what they are talking about... or where we are or even who I am.

Why doesn't somebody turn on a light?

Wait a minute! I hear people talking very calmly and they're in total darkness. Am I the only one in the dark? And who am I anyway? Well I'm sure this will all clear up if somebody would just turn on a light. But there is something else that bothers me; this darkness is too intense, there are no little transformer lights or reflections or anything else... only darkness. I've never seen such absence of light.

Later, I recognize they are speaking Spanish and I can understand them. They are talking about medications, I think. They must be doctors or nurses. Talking in the dark? It makes no sense. Maybe they covered my head with a sheet or a blanket for some reason. I

feel around with my hand but can't feel anything covering my head. Suddenly I'm frightened as I touch something metallic at my side, something like a bar. I still can't see anything and now I'm getting frustrated.

At least I can hear and feel things. Do I have eyes? I think so but, then again, I don't even know who I am, so I better check if I really do. I touch my face and I notice some bandages but in fact I do have two eyelids. When I press on them, I feel my eyeballs in there. Could it be that I think I'm in the dark, but really I have my eyes closed?

It's hard for me but I manage to open my eyes and all of a sudden...

Blinding whiteness... it hurts my eyes... too much light!... somebody, help me!

I try to shout but I can't make a sound. I lie still and quiet with my eyes closed. I'll have to get used to the light because if the doctors or nurses (or whatever they are) can do it, I should be able to also.

I start opening and closing my eyes and end up blinking for what seems an eternity.

White... black... white... black...

And finally, I begin to distinguish something. There is a white ceiling with a florescent light to the side. As I begin to look around, I see medical monitors and other medical gadgets. I'm lying in a bed, but where am I? And who am I?

I think about it for a long time, but I have no clue. Suddenly in a flash, I remember I'm a road racer. If I'm a racer and I woke up in what seems to be a hospital, this can't be good! I don't remember anything and that can't be a good sign either. I have both hands and

a head, but I don't know what kind of shape they're in... and my feet? Maybe I don't have any! I quickly look down for them under the sheet and yes... they are there, but do I have feeling and, can I move them? I concentrate and am able to move my feet and my legs and I can feel the sheets and the bed with them.

I'm happy about that for a second but then I think, why do they have me trapped here? I have to escape! But when I try to run away I can't even sit up in bed. I have no idea what has happened to me or where I am. I am in a bed in what seems to be a hospital and I can move my head, eyes, arms, hands, legs and feet, but not very much.

Then suddenly I go to sleep but it is strange because I can't remember well the passage of time between memory and memory; it could be minutes, hours, or days.

I wake up and there is a girl sitting beside me who, in my opinion, is very hot. She is speaking to me as if she knows me. She explains that I've had an accident with a race bike on a track and that this is a recuperation center. OK, this makes sense, I think. But who is she and how does she know so much? Making a big effort, I manage to ask her. She closes her eyes briefly and murmurs, "... not again!" But I can't remember ever having spoken to her.

"I'm Iana and you're Kenny. I'm your wife and we've lived together for many years," she says loud and clear. "You're a professional motorcycle road racer. You raced for two years in the Moto2 World Championship and last year you won the CEV European Superbike Championship. Don't you remember any of that, Kenny?"

I sit quietly staring off into space, trying to remember something but nothing comes to me. The next time I'm awake, I better remember that she's my wife. If it's true that I'm a married motorcycle racer, I must be older than I think I am. It would be impossible if I were only 16 years old. And I was in the World Championship? I know what that is. That's where guys like Rainey and Rossi race, but did

I race there too? That doesn't seem possible. I fall back to sleep... well, not really to sleep... it is more like a disconnect from what is happening around me.

When I reconnect, my wife has vanished and in her place is a man who looks a lot like me. He's singing and dancing in a real funny way. I laugh a lot, but I have no idea who this individual is. "Wait! Who are you?" I ask him.

"... not again!" he murmurs, just like the girl who claimed to be my wife. "I'm your brother Dennis and you are Kenny the road racer..." He tells me that I had crashed, etc. just like the girl did. I interrupt and say, "I remember that I have a little brother."

"Yes exactly. That's me!" he says.

"But that can't be because my little brother is only fourteen, two years less than me."

"... and you, Kenny. How old do you think you are?"

"Sixteen," I quickly answer.

But wait. That doesn't add up. If I was, I mean I am, married and I raced in the World Championship, I can't be 16 years old.

"OK, how about 26?" I ask.

He smiles and says, "Yeah, that's how old you were about ten years ago. We all get older, no matter what happens."

Whoa! I don't know if I can believe that. 36 is almost 40... impossible... that can't be. But, suddenly in a flash I remember driving in Malaysia, going to a market where they sold imitations of high-end brands in the streets...and I went with Iana. Yes, now I remember she was... is... my wife and we were in Malaysia to race in the World Championships. And I remember I participated in a go-kart race they had there and that I went pretty well and qualified for the final along with Valentino Rossi.

Everything seems to make sense except my age... I still feel I am 16... I close my eyes and disconnect again.

When I reconnect, I am still in the same bed, but my arms are held tight to my body on both sides like a mummy and I have big, absurd, plastic mittens on my hands. I can't move or reach out to touch anything. Why am I like this? Who did this to me? I begin shouting and trying to get loose.

"Stop, Kenny... please stop..." a woman says to me and I recognise her immediately. She is my mother, Heidi Noyes. I stop to think... so I must be named Kenny Noyes, but why am I here in this situation?

My mother looks at me and seems to read my thoughts.

"They had to tie your arms and put these mittens on you because you wouldn't stop pulling the tubes out of your throat," she says.

Then I remember that I have tubes in my throat that bother me a lot, tubes that go down towards my stomach. I remember wanting to pull them out, but when I try to grab the tubes, they won't let me.

It seems like they are all conspiring against me: doctors, nurses and even my own family. Still, a couple of times I managed sneakily to remove the tubes. It was a very unpleasant sensation, especially when they realized what I had done, and the nurses had to shove the tubes back in.

I disconnect again and this time I wake up (well, I think I am awake) in the middle of a naval battle in which one of the ships is actually a floating princess complete with sails and everything. The front of the ship is her head and she speaks to me: "Come with me to the place where there is no pain, here we are floating, floating...

"But the ships are having a battle!" I exclaim.

Suddenly I hear a very loud WWWUUUUSSSHHHH and, incredibly, all the other boats disappear. Just the huge ship that is a woman remains.

I don't have a body or a boat. It is as if I were eyes suspended there, like what happens in many of the early virtual reality games. I can look in every direction and move, but without a body, as if I don't physically exist. While I am trying to make sense of all this, the woman/ship speaks to me again, "Come with me because here there is no pain and we will be floating eternally or doing whatever you imagine."

Help! I think. I don't want to go with you, I barely know you and you seem very strange... I close my eyes and think that I want the sea and all the boats to disappear. I want to have a real body again and to be back in reality. When I do really open my eyes, I am in the recuperation center again in the bed like before. It is reality... a messed-up reality with lots of pain... but very real.

Now, both my wife and my brother are with me for some reason. They tell me again and again in different ways to move my leg. I manage to lift it a little and they are super happy as if it were a great achievement. But I hardly moved it! How strange that something so simple and small makes them so happy. While thinking about that I disconnect again.

One of the times I reconnect, I see and I recognize my dad, Dennis, who is reading me things from a book, a scene that seems very normal to me. But I find it odd to see him sitting in this center that looks like a hospital. He is giving me the recovery rates of coma patients according to different scales, but I am still very confused and ask him directly, "They tell me I am a motorcycle racer and that I had an accident... but what happened to me?"

My dad takes a deep breath before answering and repeats what they have told me before, but in more detail, "... they did their best to stabilize you at the track before taking you by helicopter to the hospital."

"To this hospital... what track?" I ask.

"Not this hospital. You really don't remember? Ok... the track was Motorland, Alcañiz, Spain. We were there for the third round of the FIM CEV Superbike championship you won the previous year. You were fourth in qualifying, but in the Sunday warm-up before

the race you had a fall that left you unconscious. The track medical team quickly realized the seriousness of the situation. They worked to stabilize you enough to take you by helicopter to the hospital in Zaragoza. Your situation was very serious... you arrived at the hospital in a Glasgow 3 state..."

I laugh a little nervously and say, as best I can, "Well Dad, a podium is never bad. It is not a win, but third is P3... and I have usually been happy to be on the podium."

My dad seems very worried and the last thing I said does not improve the situation at all.

"... I thought the same thing, but the Glasgow coma scale is reversed," my dad says gravely. "I studied it and found it is the coma scale used mostly by ambulance crews in route to hospitals to facilitate communication, but it starts at the bottom... death... and the lowest value, with possibility of recovery, is 3 and the highest is 15, normal... it's complicated."

I think about that for a while and ask my dad, with some difficulty, "... so if P3 is a victory then what about P1 and P2?"

My dad breathed deeply and said, "That would be death... in fact Glasgow 3 is like death except you are still breathing and have a heart rate, but nothing else, no responses. You were admitted as Glasgow 3 and they were very worried about whether you would live. But, luckily, you are here with us at the Guttmann Institute."

"... and is this far from Alcañiz?" I ask. Because I have no idea where I am.

"Yes, it is. Don't you remember anything?" he asks me and pauses before continuing to explain, "We are on the outskirts of Barcelona. Since your fall, two months have passed and you are now entering the recovery stage. For this there is another much less dramatic scale. It is the Rancho los Amigos scale devised in the US."

"And, on this scale, am I winning?" I ask.

"Well, this is a less dramatic scale because instead of describing degrees of coma for doctors it is used for your mental awareness. The 'win' that you talk about would be to keep improving until you are off all the scales. After everything I've seen and knowing you as I do, I know you won't stop trying until you achieve this."

Part 2

The second set of memories I have from Guttmann are from when I was beginning to enter the minimum consciousness state. This is why they are clearer in my mind, but I am not sure of their order or how much time passed between them.

They took the tubes out of my neck, but I don't remember much about it. What I do remember is that they started to bring me real food, although I couldn't drink real water yet or any liquid without a white pill to make it thicker. In addition to thickening liquid, when it dissolved it left everything with a disgusting, whitish color and had a terrible taste.

The doctor explained that I was unable to swallow well and that there was a lot of danger that the liquid, instead of going to my stomach, could enter my lungs. The respiratory system in my throat was not separating air and water correctly and that meant they had to add that white pill to almost everything.

There was always a small bottle of water on the food tray they brought and one of my family members had to be ready for it and add the white pill. Every day I watched the tray waiting for my opportunity where they would forget about the little bottle. One day I got my chance because they were distracted talking and didn't realize the tray had been brought in by one of the nurses. I saw it and reached out stealthily and quickly to grab the water bottle, but my brother saw me. "KENNY, WHAT ARE YOU DOING?" he yelled but I already had the bottle and tried to hide it without saying anything.

Then he got up and started walking towards me saying, "Give me the bottle, Kenny!"

I kept quiet but I knew he had seen it. My brother grabbed the bottle and was trying to take it away from me, but I held on with all my might. While we struggled he kept talking, "... remember that they don't want you to drink plain water so you won't choke... later they'll test you and if you pass the test they'll let you drink liquids without thickener... "

In the end, he took my bottle and we were both breathing hard and very unhappy... but for different reasons. Me, because I had lost the battle for the bottle and couldn't drink pure water from it. My brother, for a thousand reasons: for the seriousness of my situation, for not knowing if I would recover or how I would end up... and on top of everything, I just kept struggling with everyone and complaining.

->>> KKK-

Another memory I have engraved in my mind also has to do with food at the Guttmann. They always brought a dessert that I couldn't eat and it was often a flan. One day my friend and manager Fermín was there. He realized that there was a flan that nobody wanted. He took it out of the plastic container leaving it upside-down on a plate. We all wondered what he would do next with the flan. He put both hands behind his back and bent down to bring his face close to the plate. He opened his mouth wide, put his lips around the flan, sucked hard and the flan disappeared. Then he swallowed it whole!

I was very impressed and Fermín, bombarded with questions from my family, told us that was nothing, that his personal record was sucking up thirteen flans one after the other. Then he messed with us saying that on that occasion it was after he had dinner; but, if he hadn't eaten, his record would have been 50 or 60! It scared me quite a bit to watch him eat the flan that way and I asked, "Doesn't that feel bad?" Laughing, he said, "no, pero conmigo el flan no es un buen plan!" (i.e. no but for me flan is not a good plan) That struck me as such a funny thing to say that I couldn't stop laughing. Seeing that that phrase was a big hit, my brother took his felt tip pen and wrote it on the window of my room.

I laughed so much that I consider it one of my best memories of Guttmann and something I will always remember.

->>> XKK-

I also remember my brother doing physical training and playing a bunch of games with me in the room. When I couldn't get out of bed, we played basketball by shooting a mini ball (like a tennis ball) at a small basket that Denny made and mounted at the base of my bed. It was very difficult for me but my whole family clapped and cheered so much when I did make a basket that I was motivated to continue trying.

Sometimes we played with small, radio-controlled helicopters. You had to land them on pillows or books at different heights and be careful that the helicopter didn't hit anything. This was super good for coordination and small, but precise, movements of my fingers. This all helped me, but it was so much fun that I didn't give it any thought. They were games for me instead of recuperation exercises. My whole family helped and now I realize how important it was but at the time I had no idea of anything.

->>> Kfff-

When I could sit up, I was able, with help, to get into a wheelchair and my wife pushed me along the hallways of Guttmann.

I always wanted to get up and walk but I didn't have enough strength or balance to do it well. At first it was always with the help of a family member and beside the wall too. Sometimes just standing was hard enough and it made me so tired I had to sit back down. I was very obsessed with being able to walk and my family was always very attentive in case, in one of my attempts, I lost my balance.

Later I began to move away from the wall. I moved very slowly and was determined not to fall either. I remember walking only a few, very careful steps away from the wall and it felt like I was practicing an extreme sport. Now I think about it and it seems absurd that I was so afraid of falling... but back then it was my reality and I confronted that fear every day.

->>> LEEK-

When my wife pushed me in the wheelchair towards the entrance, I was amazed at the number of new patients that were waiting there. Every morning, there was a row of ambulances bringing in patients and I thought they all were motorcycle racers.

I was sure that each one that was admitted there had suffered a fall like mine. Although I didn't know any of them, I wanted to know what motorcycle they had and if they remembered their accident. I wasn't at all embarrassed either.

I began to ask them before I could move or speak well. I started by making one of my family members do the questioning and, since I was very insistent, I was able to get some answers. But it didn't make a lot of sense because my family told me that not one of them was a motorcycle racer or any kind of racer. The majority had had a bad fall on the stairs or from their own chair while trying to change a lightbulb. According to what they told me, almost all had fallen backwards with the bad luck of breaking their neck or back or hit-

ting their head very hard. A few said they had traffic accidents but on the road, not on a track, and in a car, not on a motorcycle... this didn't make any sense to me.

I believed they were all motorcycle racers and when I could move better, I began to ask them one by one myself. It was very hard for me to speak and there were many distractions. I always had someone by my side, and they did too. When I improved physically, I went to different therapy rooms in which my family left me with a doctor/therapist and where there was a group of other patients.

I thought that these therapy sessions offered the perfect opportunity for me to ask other patients about their accidents. I tried before the therapy began, but few understood me. Those who did, had trouble talking and to the majority it seemed to be a very inappropriate question, especially when it came from a complete stranger. But there were those who did understand and did not mind answering me.

However, their answers perplexed me even more. Not one was a racer, very few had a motorcycle and the majority were pretty confused by the purpose of my questions. Finally one told me he had a motorcycle, "I have a Ducati and I think it is still in my garage, but why are you asking me this?"

"Because of your accident... do you remember how it happened?" I insisted.

"Yes, I remember the accident that left me quadriplegic... but it didn't have anything to do with my Ducati... wait a minute, do you think my accident was on a motorcycle?" he asked me, trying to understand my question. I told him that yes, I was a racer and I believe everyone admitted here had an accident like mine, at a track.

"A racer, really? You are a motorcycle racer who fell during a race? And you think our accidents were like yours?" he asked me quickly.

"Of course!" I answered him. "But my fall wasn't in a race; it was during a warm-up before a race. And yours? How did it happen?"

There was a moment of tense silence in which, at the end, the man who I was talking to smiled slightly and said, "You are so lucky!"

This left me completely confused: We were in a hospital, I was in a wheelchair, I could hardly move, I was unable to speak clearly, and I was in very bad shape.

"Lucky?" I answered him completely incredulous.

"Yes, exactly!" he insisted. "I think when I tell you the story of my accident you will understand me better."

He paused again and in a quiet voice began to tell me his story, which I still remember word for word:

"One morning I got up after various rings of the alarm clock, like always. I made a cup of coffee, got dressed and went out thinking about the breakfast I would have at the cafeteria beside my office building. I was living near where I work because I found the apartment after I was hired. I walked along the sidewalk thinking about what I had to do that day.

"I believe I was softly whistling something; I usually whistled in the mornings. Suddenly I felt a strong impact on my back, and I was flying up and forward. Then I landed on the sidewalk and did several somersaults and tumbles. During the flips, my body hit the cement very hard. When I was almost stopped, I heard tires screeching and a woman screaming, but I couldn't see anything because I was facedown. I tried to get up and that was the first time I felt it...

"At that moment nothing else mattered to me because when I tried to move my legs and hands there was nothing, no reaction, and I had lost feeling in them also. All around me there were frightened people looking for the injured, but no matter how much I tried, I couldn't manage to get up or even move. In one of my at-

tempts, I made a noise like a groan that one of the people there was able to hear. He approached and asked if I could hear him, but he realized the state I was in. Soon the paramedics arrived, spoke to me, and put me on a stretcher.

"Here is when my memories begin to get cloudy. There were a lot of operations at the hospital but after each one I remember that I still couldn't move anything. Finally, they told me that my life wasn't in danger but that when I broke my neck, my spinal cord had been cut... with no possibility fixing it. So, I was going to survive but I would be a quadriplegic for the rest of my life."

There was a profound pause and then he continued, "That's why I said you are lucky, because you knew the risk you were taking each time you put on your leathers and went out on the track. I, on the other hand, was just walking to work like every day and a bus driver fell asleep, ran up on the sidewalk and hit me. It was good that at the time there were not many people out yet, because if they had been walking beside me, he would have hit them too.

"I have always been afraid of taking risks. With my Ducati I went very slowly on the street and never rode on a racetrack. Also, one time when I went skiing for a weekend with my friends, I fell on Friday and scared myself so much that I didn't ski anymore. I stayed up there with my friends because I had already paid for the whole weekend. I didn't go back to the slopes though and I spent Saturday and Sunday in the bar like a true alcoholic. Beginning with coffees shot with whiskey in the mornings and ending at night with a lot of hard drinks. But as you can see, destiny has been cruel. A bus hit me while I was just walking to work like every day and now, I must learn to deal with paralysis."

He stopped talking and sat looking at me. It took me some time to understand what he had said, but when I did an expression of surprise and horror came over me. "Damn, how terrible!" I murmured, trying to imagine myself in his situation.

We sat in silence until one of his family members or a friend came for him and took him to his room. He didn't say anything when he left. I was stunned by his story and sat completely alone going over everything in my head. After a while my wife came looking for me and when she saw my face she asked if I was alright. I told her yes, but that I was thinking a lot...

After that day, I stopped asking the other patients about their injuries. I was feeling very unfortunate about my condition, but I realized that there were those who had it much worse than I did.

"I was unfortunate, but I wasn't so unlucky... Damn, how terrible!" I thought over and over again.

->>> KKK-

When I could move better the therapists talked to me about going for physical recuperation sessions at the gymnasium. It was pretty big with distinct areas for different types of exercises.

From the first moment, I felt like there were too many patients and not enough physical therapists. I didn't say anything though and participated in the activities. I don't know exactly how it worked but there was a schedule and each patient had a specific routine. The problem was that there were a lot of us, and each had a different injury; it was a huge mess.

Even so, I went daily just like the others. My plan was to do everything and get better as soon as possible to be able to leave that place. One day I had a pretty serious conflict with a poor fifteen-year-old who had many mental problems. So many that even I quickly realized that he was in bad shape. He continually bothered me and then laughed no matter how much I told him to stop it.

One day we were both in the same area where there were parallel bars which you were supposed to walk between and hold on to. It was really complicated for me, but I tried again and again. Suddenly, I noticed that someone pinched me on the side of my stomach near the waist. Pretty scared, I shouted and turned around to see who it was, and I saw that kid.

"What are you doing?" I asked him, rather irritated. He didn't answer and just kept laughing. I turned around to continue with the exercise but soon felt another pinch and this time without stopping or turning around I told him to quit it. This happened a couple more times with no change. I was concentrating more on the possible pinches than the exercises until I got really mad. Now that I think about it, I don't know why I didn't say something to one of the physical therapists, but in that moment I turned and threatened him. "If you pinch me again, I will smash your face!"

He laughed and when I turned to continue, he pinched me again. This time I turned around so quickly I almost fell. I grabbed onto the bar with one hand and with the other began to slap at him (rather pathetically). He at first defended himself and then he began to aim slaps (also pathetic) at me. Soon we were both yelling, and the therapists came running and shouting for us to stop. But they had to physically come between us before we stopped slapping.

Once we were separated, they asked me, "What happened? What is the problem? Are you going to fight again?" I told them that there was no way we could ever be together. "He irritates me and doesn't stop no matter how much I tell him to. I'm sure that if we are together again, something will happen, and we will have another fight."

They had to split us up in the gym and we were never in the same area together. But from that moment, I never again felt calm or focused exercising at this gym. Out of pure luck, one day, I heard that right there at Guttmann there was another completely separate area

for working out. I had no more details, but I knew that I had to find a way to go to this other gym. Now looking back, it's a good thing I wanted to change so bad because, as it turns out, this other new gym was better in many ways.

You see, in Guttmann there are different parts, but it is not well-explained, and it is difficult to understand. Basically they need to have better communication because the patients have enough big problems of their own to worry about. As I discovered, one of the keys to proper recuperation is having all of the information on hand in an easy and fast format.

The "Institut Guttmann Neurorehabilitation" is made up of many areas. There are classical hospital-like zones where patients are first admitted. These have rooms like you would find in any hospital where there are beds, bathrooms, medical equipment and all the other elements you would expect to find. Then there are more gym-like areas where you work to improve physically in every way: movement, coordination, balance, speaking, etc. I thought the gyms where I worked were the only ones, that there was nothing better in Guttman, but I was very mistaken. There exists another area that people call "private" but the difference isn't well explained. This area is not open to everyone because some patients are not well enough to use it and, also, not all insurances cover it. As soon as we learned about this gym, my wife got me in there right away to try it out.

This is where my real recovery started, and really I must thank the fifteen-year-old kid who I fought with. Without the problems I had with him maybe I would have never discovered that this "private" zone existed. Without this change I have no idea what shape I would be in now.

->>> LEKK-

This is how I woke up after the accident. I realize it all seems very confusing but that's how I really felt when I was regaining consciousness. I wanted to write it down like this so you would all get an accurate idea of what happens after a TBI... this is the way my road to recovery started.