

1

MICHAEL

The pregnancy of Michael's wife, Sara, became a threat to her life. They were expecting their first child. Sara's doctors recommended to abort, but the young couple chose not to. Their son, Daniel, was born in the 31st week. It was nearly a year later before Michael and Sara brought their baby home from the hospital.

Eliya: Tell me about Daniel's birth.

Michael: Daniel was born after a very difficult pregnancy. There was not enough amniotic fluid and more than one doctor at the hospital recommended ending the pregnancy. They couldn't see anything definitive, but they thought the chances of Daniel making it were very poor. And they were very concerned about Sara. But we didn't want to abort, so we left the hospital and waited to see how things developed. But as the pregnancy progressed and we saw how Sara was reacting to it, we decided to end the pregnancy. We sought advice from our Rabbi and we were told that given the doctors' concern for Sara's well-being, we could have the abortion.

The hospital's policy was that if you're admitted to the hospital and they see how things are developing and they recommend to abort, they will do so. But once you check out you can't check in again for the express purpose of having an abortion. So once we left the hospital we had no place to go.

I totally freaked out. We had a Rabbinic ruling to permit the abortion, but no hospital to do it in. I called up the head of the department in the hospital where Sara had been admitted and said, "What do I do?" He recommended a well-known gynecologist at another hospital in the city. We called the gynecologist's office and his nurse said, "You can have an appointment in six weeks," and I said, "We have a question of an abortion here. This is critical." So she said, "Come in today at 6:30."

That day, waiting to see the doctor, was the hardest it's ever been. We sat there not knowing if we wanted to kill this embryo, our first child, or if we should keep it alive; whether either outcome would turn out good or not. We hadn't a clue what the doctor would say. That was the worst day emotionally. I've never been through anything that hard since then with Daniel. It was just Sara and me with no family around or friends for support.

Eliya: What happened with the specialist?

Michael: He was amazing. He was a chain-smoker and an unusual fellow, but we felt that we'd come to the right person. We told him the story and I could just hear his brain putting everything together. We felt that he was taking care of us.

We went to ask him whether we should terminate the pregnancy and we ended up continuing it for two more months, because the amniotic fluid had returned. The fetus had stopped growing for a period and then it started growing again. We did ultrasounds, checked this, and checked that. The doctor said, "We'll keep monitoring you and see what's doing." He prescribed medication for Sara to keep her blood pressure down, because it was a bit on the high side. But she wouldn't take it. Sara was very anti-medication and into natural healing.

So after meeting the doctor, we had a reprieve of two months or so, until things got so bad that they had to take Daniel out.

Eliya: What happened?

Michael: What happened was that Sara developed toxemia. Toxemia is a very dangerous condition where the baby is basically poisoning the mother. The only thing they could do was to take out the baby.

Sara's blood pressure went through the ceiling. We went for a checkup and the doctor put Sara right into the delivery room. "Too dangerous," the doctor said. She stayed overnight and in the morning they said, "We think he should come out."

Eliya: How did you react?

Michael: What do you say? Who do you ask, who do you talk to about that? We didn't talk to anyone—we just decided we would take him out. We said, "Okay, we'll roll with the punches. We'll take him out and see what we get."

Eliya: You were all alone in the decision. At the birth did you get any support?

Michael: There was a nurse in the delivery room. She said to us, “You know, these kind of babies, they’re fighters.” I was encouraged when she said that. But it was very hard at the birth. Daniel was born two and a half months early and weighed only 605 grams.

Eliya: 605 grams? That’s less than 1½ pounds.

Michael: Right. Daniel was in the hospital for ten and a half months. For one solid year, my wife expressed milk with a pump. He didn’t drink anything for the first three months. He was our first kid, and he was a challenge on many levels.

Eliya: Did you have support or encouragement from anybody after the birth?

Michael: Yes. My wife is a healer, so many of her healing friends were around us. There was one healer lady around at the time who told us the baby was fine. She told us that his name was Daniel. We had not named him yet. Also, we were very close with a very religious Jewish family with ten children. It was two or three days after Daniel was born that I got around to telling them. After hearing the news, the wife was at the hospital within an hour. One other family we were close with also came to visit.

Eliya: What complications arose with the birth?

Michael: In utero an ultrasound could not show for sure what gender Daniel was. At birth it was seen that he had a hypospadias, a malformation of the male genitals. The doctors didn’t know if he was a boy or a girl, but the healer had told us that he’s a boy, so we knew. Because of the malformation, instead of the traditional way of circumcising the baby on the eighth day after his birth, we had to wait three years to perform the ceremony on Daniel.

Eliya: Three years? Michael, how did you handle all of this? Daniel was your first child.

Michael: I think I’m graced with a positive outlook. Nobody gave us a doomsday scenario or said, “Listen, he’s going to be this, he’s going to be that.” Since they didn’t say that he’s not going to be okay, I said, “Okay, he was early, but he’ll be okay.”

I was essentially positive. My motto was: “We’ll just keep going, doing what we have to do.”

Eliya: After the birth, how did Daniel progress?

Michael: He was in the hospital for a few weeks and he got very, very sick. He almost died at one point. Somebody gave us a book about preemies and I read the chapter about what to do when babies die. But then he got better.

The beginning was hard because Daniel didn't really react to the world. He was eight months old before I saw him look at something. One day the nurse walked across the room and I saw him following her with his eyes, for the first time. I said, "Wow! He's landed!" Until then he was out there someplace.

Eliya: How did you keep connecting with Daniel when you got no response from him?

Michael: It was really difficult. Sara was much more giving than I was. She would hold him, even though there was never any reaction. He was just doing his thing. He was there physically, but not emotionally, as far as I could see.

We didn't have to do much with him when he was in the hospital. Sara expressed milk and we'd come and visit. Every so often she would arrange to hold him next to her skin, with all his tubes and wires. We called it "bonding."

We would see him, but there was no one to react with. So you do what you have to do, but there wasn't a lot to do. We took several videos and we sent them abroad to our families.

I would hold him, too, but there wasn't much to play with. That was a drag. I would think: *He's not here*. I didn't know where he was. We hoped he would be okay.

Eliya: And after ten and a half months in the hospital, you finally took Daniel home.

Michael: Yes, it was very exciting. From an association which loans medical apparatus for free we got oxygen and other equipment. Then shortly after Daniel came home, he didn't need oxygen anymore, which was a great relief.

As we left the hospital, one of the wonderful doctors there told us, thank G-d, that we should expect several hospitalizations every winter.

Eliya: What made you say "thank G-d" after hearing that your son would probably be hospitalized several times per year?

Michael: If he hadn't mentioned that, then we would have had a rough couple of

first years. Since we knew what to expect, we were prepared. The problem is that when a baby is that small, they are actually capable of surviving and functioning fairly well—except for their lungs, which are not sufficiently developed to breathe. So the respiratory system is challenged for the first few years, until the lungs grow and develop. In the first years, any virus that came around, Daniel got it. And any cold he caught landed him in the hospital.

Daniel has always gradually gotten better. In the beginning, he was sick every year, and they said to us, “Listen, he’ll be in the hospital a lot, but this is one of the few diseases that gets better as he gets older, not worse.” As the lungs grow, they get healthier. He still gets sick where he can cough all night, but it’s not like before.

Eliya: What was it like to have your son hospitalized just to fight a cold?

Michael: Sometimes it was horrible to watch him. He would just cough and cough and cough, and they couldn’t do anything for him. They would just give him oxygen and antibiotics and hope for the best. But when he came out of it he was smiling again.

Eliya: This is the first mention you have made, Michael, of any emotional reaction in Daniel. How did you react to Daniel’s first smile?

Michael: Daniel was a little over a year old when he first smiled. I said, “Wow! Now he’s a kid!”

Eliya: That smile must have meant so much to you!?

Michael: It did. I remember it to this day.

Eliya: What other special attention did Daniel require?

Michael: In the beginning, he needed lots of medication. He was tiny and needed tons of physiotherapy. I was very gung-ho in those days. I made arrangements with the health fund clinic, which paid for a private physiotherapist to come to the house a few times a week. We had to teach Daniel how to roll over, how to sit, and how to stand. It took him months and months and months until he could roll over. I would practice all these exercises with him. I was very, very supportive. I became this real doer.

Eliya: It seems you were connecting very closely to Daniel.

Michael: I was. It encouraged me a lot that Daniel was responsive, very cute,

and very sweet. Plus, I learned an enormous amount from being a partner in his physiotherapy. The therapists would say, “You’ve got to take him to the park. You’ve got to put him on the slide.” To this day, Daniel has gravitational insecurity. He’s not secure in the world physically or emotionally. We all have levels of mistrust, but Daniel’s level of mistrust is greater than average. From Daniel’s level of mistrust I learned what basic trust means.

Eliya: Please tell me more of what you learned about “basic trust”?

Michael: “Basic trust” is a minimal, “functional” level of belief that the world is okay and that one can survive and flourish in it. Daniel has less of that trust than most people. He is very insecure. He’s always worried that a calamity is about to happen, or that he will become sick.

Working with Daniel taught me that basic trust is very relative. I basically trust that things are okay, that G-d is watching, and that I can relax. Daniel doesn’t relax that much. His body is tense, and so is his mind. Things that wouldn’t upset me at all are difficult for him. Something as simple as choosing to walk home a different way than usual might cause him anxiety. But watching him, I realized that my own level of trust, or of faith, is nothing more than “normal,” no great achievement. A wholly righteous person may have a level of trust that’s way up high. My level of trust may be lower than that, but it’s in the “normal” range, so I’m lulled into thinking that “I’m OK.” In truth, I need to work on my trust in the universe, my trust in G-d, as much as I think Daniel does. Daniel may worry more than most of us, but we all worry, and our job is to realize that we don’t have to worry. You know that wise saying: “Don’t worry, be happy.”

Eliya: That sounds like a very deep insight that you learned from your son. Did Daniel ever trust himself on the slide?

Michael: I worked with him for many, many years. I would take him to the park and I’d put him on the slide. He didn’t want to go on the slide. “Slowly, slowly,” I would tell him. “It’s fun, it’s fun! Slides are fun!” But they weren’t fun for him. Then he would do it once, and I would say, “Wow! You did it!” And then he wouldn’t do it again for another four months. It was very frustrating. What happened was that as Daniel got older, I got sort of worn out.

Eliya: What wore you out?

Michael: For long periods of time I couldn’t see that my work with Daniel resulted

in much progress. I began to think that my son might not be able to progress any further than where he was. I would talk to Sara about it. But she couldn't deal with hearing that it was hard for me. My wife has this Pollyanna side to her. She's always saying: "It's fine, it's wonderful, it's great." I needed my wife to listen to me when I said, "It's hard for me to see Daniel where he's at." But what I got was: "Yes, but... but...but..." I didn't want the "Yes, but..." I just wanted her to hear that it's hard for me. That was the thing we had to work through. Sara had to learn to listen and accept how I felt.

Eliya: Did it take time for Sara to hear you and accept your feelings?

Michael: I don't remember how long, but yes, it was a sore point for a while. Eventually, we went to a therapist, who told Sara, "You just have to listen to what your husband is saying." It took time, but eventually she learned that she could hear me and accept my feelings without feeling the same way, and without feeling threatened. In the end this challenge turned into a big opportunity for Sara and me to learn how to communicate effectively with one another.

Eliya: I am impressed, Michael, how you have been able to take challenges Daniel has presented to you and turn them into opportunities of significant personal growth. Let me ask you, what was school like for Daniel?

Michael: We had a wonderful preschool for Daniel in our neighborhood. The school integrated typical children and children with disabilities. The director was amazing. She put in hours and hours with Daniel. She took videos of him and showed them to a big expert in America and asked him, "What can we do?"

The director would invite me to school after hours to play with Daniel. We were trying to encourage him to interact with me. At that point, though, he was more interested to play "kindergarten" by putting dolls on chairs which he arranged in the room. But he didn't interact with me. I would watch Daniel for a while at his play and then I'd fall asleep.

For several years, I felt deeply disappointed with Daniel and began to think: This is what I get for all of that tremendous effort that I put in—therapy and exercise and taking him all those places?

Eliya: How long did your disappointment last?

Michael: Until Daniel was eleven, which is when he started to eat like a growing boy should eat. Up to age eleven he hardly ate. We took him to several specialists.

He just wasn't interested in food. Once at an appointment with a doctor, Daniel was nibbling on a rice cake. The doctor said, "That's what you give him—rice cakes!?! He needs food!" and I recall thinking, "*You try to feed him!!*"

At one point, doctors suggested putting in a gastric tube that would feed him directly into his stomach. But we didn't want to do that. For eleven years, food was just not Daniel's thing, but we made ourselves crazy trying to feed him. And then came the big event. He started eating! His hormones kicked in early and since then he's been eating like a teenager. Today he doesn't stop eating. He's into food, but he's skinny as a rail because he burns it up. Even though he's been eating well for a number of years, seeing Daniel eat still makes me very happy.

Eliya: Did the change in Daniel's appetite change your relationship with him?

Michael: I remember the moment when our relationship really changed. It was on a public holiday and we had been to three barbecues that day. I'd never eaten so much meat in my life. At the last barbecue, Daniel was kind of sailing around in the kitchen and he eyed a tray of brownies and said, "Are these made with milk?" He really wanted some brownies. But there was no way he would touch one if it was made with milk because of the restriction in Jewish dietary laws which prohibits eating milk and meat together. He wanted to know so he could do the right thing. In that instant, I merited to see something that was so beautiful—his desire to do it right, that he was willing to pass on the brownies if they were not permissible. I looked at him and said, "Daniel, you're great!" He looked up at me and it just broke my heart. He said, "Really?" He'd been waiting maybe five years to hear me say that. From that moment on, everything between us changed. It was from that moment on, that moment with the brownies, that Daniel and I became great friends.

I was finally privileged to see who Daniel really is. My wife was always saying, "He's wonderful, he's wonderful." And I was saying (halfheartedly), "Yeah, he's wonderful, he's wonderful." She'd say, "Everybody loves him, he's so cute." And I'd say, "Yeah, everybody loves him, he's so cute." She'd say, "Look, he did that." And I'd say, "Yeah, but what's he gonna be, what's he gonna do?"

Eliya: Prior to that turning point, Michael, what kept you from seeing Daniel as your wife and others did?

Michael: It happened, I think, because of my tremendous effort in doing, doing,

doing, doing. And after a while, I began to think, *This is what you get?* That prevented me from seeing. I got worn out. And then my wife was always telling me how wonderful Daniel was, but I couldn't believe it.

That was the block and, thank G-d, this event happened and it changed everything. Since then, Daniel's great. He's a sweetheart, although he's a pain sometimes when he doesn't get what he wants.

I once met the father of a child with Down syndrome who was also blind and had various other disabilities. It was very difficult for the child to speak. The father called his child "my biggest teacher." The man said to me: "Instead of wanting my child to learn *my* language so he can speak to me, why don't I learn *his* language? He has another way of talking. Who says that my way is the right way, and not his?"

I can't move into that mode myself, but I was very impressed that somebody could look at his disabled child as his biggest teacher.

Eliya: You said, Michael, that sometimes Daniel is a "pain." (And what child isn't?) How do you react to Daniel then?

Michael: When I get upset with Daniel, it's because I think that he's not the norm. But so what? Why does he have to be the norm? He is who he is. I have X amount of patience for a "normal" kid, and he needs more patience. That's what he needs. And I have to be real about that and not have my preconceived ideas about what's normal. "Normal" is only what I'm prepared to do. I wasn't always prepared to do what Daniel needed.

Eliya: What does Daniel need?

Michael: He needs support! And patience. In learning, he needs constant support. Sometimes he says, "I can't do this, I'm stupid, I don't understand it..." I say: "You can do it." I have to be supportive, but it's not easy for me to be one hundred percent supportive. For example, when he's doing homework and he's freaked out, I need to remain calm in the face of his losing it and say, "Yes, you can and it's okay."

It's not easy to be encouraging if I sometimes don't feel encouraged. But I know that is what Daniel needs of me. I need to let go of my ideas of "what he should be" in order to be able to simply see what he is and what he needs. "What should be" just gets in the way.

Eliya: You are a gifted musician, Michael. Have you been able to teach music to Daniel?

Michael: He started to play the piano. That was great, but it was also very awkward because he couldn't take any direction from me. Or maybe I couldn't give it to him in the way he could accept it. It was very uncomfortable and awkward. Several teachers tried to work with him, but that didn't work so well either. He was just playing by ear with his left hand because he's a lefty. At a certain point I was able to move him forward by showing him, with great patience, how to play the melody with his right hand and chords with his left hand, and how to find the correct chords. He's very musical. He learned to play by ear.

A few years ago we found a very creative piano teacher. Because of his unique way of working with Daniel, the teacher has gotten him to do things I never dreamed he would do. Daniel always needed to play everything exactly right, just like he heard it in his head, or on the disc. And this teacher actually got him to improvise freely. I'm sure it's because the teacher was totally accepting of Daniel, in a way that I think is much harder for a father to be with a son.

Eliya: Do you spend much time with Daniel now?

Michael: No, he's busy and I'm busy. Also, when we do music stuff his attention span is very short. He'll play a piece, walk around the house and do something else, and then he'll play another piece. Sometimes he will ask me for help in deciphering some chords for a song. I've found more patience and calm to teach him in a way that allows Daniel to learn at his rate, which is slower than mine.

Eliya: Does Daniel carry a label, a specific diagnosis?

Michael: He's unique. He doesn't have a syndrome. He's his own thing. I can describe him in a hundred ways, but it's very hard to pin it down and say what it is exactly.

He's been analyzed by a thousand people. He's had every kind of therapy: One Brain and homeopathy, healing and acupuncture, play therapy and art therapy. You name it, he's been there, but he's never been given a specific label. I say he has "Daniel syndrome."

Eliya: What expectations of Daniel do you have?

Michael: Expectations? I don't know. I'll just see how he develops. My expectations have sort of evolved to trying to be happy with whatever he can do.

After he graduated school, we took him to counseling and they asked me, “What do you want him to do?” I said, “Whatever he can do.” His needs are somewhat simple, which is great. He is limited, but he’s very happy. He’s a happy kid. I call him “kid,” but he’s a young man.

Eliya: What challenges do you now have with your son?

Michael: He can get very obsessive about nothing. He’ll just start talking, and you might ask, “Daniel, what are you talking about?” You can’t move him off the track. That’s very frustrating. He takes horseback riding lessons. The instructor tells us that sometimes Daniel is great but that sometimes when he insists, “I can’t do this; I don’t want to do it,” he’s just out to lunch. That you can’t reach him.

I said to the riding instructor, “Please help Daniel to be more aware by saying to him: ‘You know, last week you were here and you were riding and you were happy and this week you’re not. What’s different about this week from last week?’” Daniel also has a personal gym trainer with whom he has trained for years. The gym trainer also tells us that sometimes Daniel is just not there.

Daniel has to develop more awareness of where he’s holding and what he’s feeling.

In the last few years, he has made great strides in developing self-awareness, to be able to see himself with a bit more perspective. But there is still much work to do so Daniel can develop even more awareness.

Eliya: When Daniel gets stuck and “isn’t there,” how does that affect you?

Michael: When he gets stuck and begins to obsess about something—although he’s doing it less—sometimes I have to tell him, “Daniel, I can’t take it anymore. Go to your room, I can’t deal with it.”

He also has a lot of fear, but he will not recognize that he has fear. That’s frustrating. We sent him off to camp in America two years ago and he was very scared. He kept saying, “I don’t want to go, it’s not fun, I just want to stay in Israel. Camp isn’t fun.”

He was a kid who had never been away from home. We took him to a disabilities camp in the Catskills where the kids were very low functioning. We stayed there with him for a couple of hours and we didn’t think it was very inviting. All of a sudden, Daniel said, “Okay, you can go now.” We left him there for six weeks, and he was fine.

The next summer, we found what we thought was a more suitable camp for him, but Daniel announced: "I don't wanna go there. I want to go where I was last year. This new camp is not good for me" We tried to talk to him, but when he's like that there's nobody to talk to and nobody home. We sent him to the new camp anyway, and he loved it. He had the time of his life.

The same thing happens when he gets sick. If he has any kind of illness, he thinks he's never going to get better. We tell him, "Remember you were sick last year and then you got better?" But he can't see it. He lives in his experience of the moment.

We went to pick up Sara's cousin at a bus stop many years ago and she wasn't there. I remember that Daniel got very upset. If something is not the way it should be, he gets so upset. He feels insecure inside, so he needs the world to be very orderly to compensate for his inner tension. His first therapist suggested that we have him repeat over and over again sentences like: "Tragedies don't happen so fast."

Eliya: What do you think is beneath his fear?

Michael: Daniel is missing the basic sense that things are okay. He can get very shaken up by something that wouldn't shake up the average person, and he's always ready for something terrible to happen. For instance, if somebody's sick, he'll say, "Oh, is she going to die?" I think it's part of this tightness that he holds in himself.

In general, it's hard for him to deal with emotions. He almost never cries. I think he has cried only three or four times in his life. He'll laugh inappropriately at something, like when someone dies. That happened when my grandfather and then my parents died.

He has difficulty recognizing emotions, as in: "Oh, now I'm afraid," or "Now I'm sick and not feeling good." He doesn't have a lot of perspective on where he's holding emotionally and so there are limitations on what he understands about himself and others.

Eliya: Tell me about Daniel's recent progress.

Michael: Actually, he is always developing, which is amazing. Physically, he was always a pushover, because he's very short and had a lot of fear. I could squash him easily. He's been working out for years and does some punching and things like that, but then he started taking boxing lessons with a guy in the neighborhood. A few months ago in play, I attacked him, and he really fought back. He just wasn't going

to take it, and he laced into me. I had to work hard to get him down. That was new.

He doesn't know how to use a computer, but if somebody sat with him and helped him, I bet that he could figure it out. On the horses, sometimes he can do a really decent job. On his good days, he is quite independent. I've seen him making progress on a lot of fronts. He's always been developing and that's been very wonderful. It's not like he got to a certain place and that's as far as he can go.

Eliya: Tell me how your other children relate to Daniel.

Michael: Sara had a lot of miscarriages after having Daniel. When he was six we adopted twin babies, a boy and a girl. They're fabulous with him. Sometimes, though, they kind of take advantage of him. I might ask them: "Could you guys clean up?!" They'll turn around and say, "Daniel, clean up!" and he'll do it. But mostly, they love him and they protect him. It's great how they're so understanding of him.

I have a good friend who has a daughter with Down syndrome. When we were considering whether or not to adopt the twins, considering all the work involved, our friend said, "Michael, the best thing you can do for Daniel is to adopt those twins." And he was right. I'm sure that a lot of the progress Daniel has made is because of the twins. His brother is a super-athlete who takes Daniel on hikes and always tells him: "You can do this and you can do that." The twins really love him.

Daniel's brother told me that he had been talking with friends, and one of them had said something derogatory about Daniel. My son was incensed and said to his friend, "How can you say that? He's such a pure soul!" The twins are very good with Daniel.

Eliya: What are you looking forward to for Daniel?

Michael: He's has been studying for the last few years in a program that trains adults with disabilities to be caretakers for the elderly. We have seen him at work, and it is truly inspiring to see how beautifully he interacts with the residents in the old age home where he does his field work. He is genuinely giving to society and using his talents to provide a real and valuable service to the people in the home. This is way beyond the menial tasks he performed when he worked at a pizza shop before entering the training program. Daniel will soon be eligible for a certificate that will certify him as trained in a recognized profession. Hopefully this will lead to a salaried position for him.

Eliya: What about Daniel living away from home?

Michael: Earlier this year he moved into in an apartment about ten minutes from here. It is run by the institute which is training him as a caregiver. He lives with eight other adults with disabilities. After the initial adjustments, he is quite happy there. The residents have a counselor who comes to be with them in the evenings and who works with them to enhance their growth and independence. Daniel now does his own laundry and is making good strides in learning about money. It's great that the setup is not merely babysitting, which it often is in these apartments. He is doing really well there.

Daniel has also been taking part in the institute's new program for learning about building and maintaining relationships, which has also been great. We may see the day when he could get married. Overall, we and the institute feel that Daniel is making great progress and will continue to do so for a long time.

Eliya: What a journey you've been on with Daniel.

Michael: Yes, we have. After we adopted the twins, someone said to us, "You two don't have kids, you have projects!"

Eliya: But through it all, Michael, you have maintained your optimism and your faith.

Michael: Daniel is always growing, always doing better, and getting more and more independent. He needs guidance and care, but all things considered, he's a healthy kid and he is blossoming into a fine young man. That keeps me going.

Eliya: Michael, thank you for sharing so much of yourself with me.