

A Case Study from Three Perspectives: A life story

Eva Scher

Once upon a time, in December 1957, a baby girl was born in Paris, France. Not quite a beautiful princess, but I was born with a heart and soul, a wish to live and grow, a thirst for nourishment and for light and love. Those who looked at me could not identify what was wrong. My eyes were slanted, my ears tiny. My face seemed unfinished with no chin or bone structure. I was a very strange baby indeed, bringing tears of distress to my bewildered mother, a deep disappointment to my confused father, and shame and anger to family and friends. On the other hand, I brought excitement to the hospital medical staff as they searched for a name for this rare disfigurement. It was described as Franceschetti or Treacher Collins Syndrome.

In the midst of the confusion, a kindly fairy bent over my crib and whispered in a silent language that only babies can understand, "You are a very special baby, a four-leaf clover, a rarity. Your path won't be easy. Like all living creatures on this earth, you will struggle, suffer and at times wish to give up. To face this challenging journey that will be your life, I chose for you the most deserving parents in all the world. They will be your allies and your strength. They will show you a pathway that shall become your very own. You will be gifted with a heart that captures subtleties of human emotion. You will see through your soul. Many who cross your path will love you and want to be with you. You will learn faith and the ability to trust life, even in the hardest of times. You will desire to learn, grow and make the most out of your stay on Earth and beyond."

So life began. In spite of great difficulty eating and swallowing food, an aspect of the syndrome, I grew. I loved music and the lullabies my father sang to me in Yiddish. I didn't want him to stop singing to me and cried if he stopped. I learned to trust and love animals. I had no fear of dogs twice my size.

For the first four years of my life I was raised by a nanny and spent a lot of time alone. I became aware of my difference at a very early age. I remember vaguely the unkindness of other children and mean comments that I didn't understand. Slowly, day after day, I created a shell, a protection against an aggressive world. In silent dreams, I imagined a kinder, gentler world in which I was a just, ruling princess. Silence became a refuge. Taunting, teasing boys were waiting for me when I started going to elementary school. Before entering the gate and facing my tormentors, I looked at the statue of an angel with only one arm, who put a finger to its mouth inviting me to be silent, to endure with a smile. This kind angel reminded me of my good fairy and the whispered words, "Endure, smile and keep your head high." So I did. Neither my parents nor my friends saw what I was going through. Like a beautiful princess, I passed by my tormentors putting all my energy to pretending not to see or hear them. I discovered an inner power to endure the world, although I had no words to express my feelings, my fears, or my hopes. None of the books, stories, and fairy tales matched my experience. Yet I wanted to discover the outcome and the meaning of this very special journey of life.

And life went on: a strange face; a growing child; the outside world, demands, expectations and silence. Sounds seemed to come from far away because my hearing was impaired. I juggled with reality, feeling like a funambulist walking on a tight rope, taking one step at a time and not looking down. My face was strange even to myself. I could understand why a little boy hid behind his mother when he saw me. I frightened him. We were both scared.

What was the meaning of this strange way of going through life? Fortunately, I was curious and had faith in dreams. I visualized a better world. Somewhere there was my twin soul, an older boy who looked just like me and lived far away—a fearless boy who would protect and console me.

School was difficult. Not hearing well, it was a huge effort to be an average student. I feared making mistakes, saying or writing something ridiculous because I didn't hear correctly. I was constantly on guard for some incoming danger and never dared to take risks that might put me in trouble. I remember the day we read a story of a little girl whose mother and father became sick and died.

I couldn't imagine how a little girl could suffer so much and have so much misfortune. I was in tears and when it came my turn to read aloud I was unable to utter a word. The class laughed. Malicious classmates said that I used this strategy to avoid reading aloud. Everyone waited for me to begin to cry but I could not stop the tears. There was also difficulty with abstract learning like math. None of the facts we memorized seemed to help me understand my world. It all appeared a bit useless though I tried very hard in order to please my mother and my teachers. Anxiety occupied much of my attention and made it even more difficult to understand abstract calculations. I was functioning to survive. However, I was a sensitive child and I was learning.

When I was 16 years old my mother discovered Dr. Tessuier, the forefather of reconstructive surgery. I began the first of ten operations. It was scary to entrust my face to someone; it was a difficult moment this letting go. For my parents it was a dream come true.

Changing a face every six months is no picnic: There was the unknown of how I would look, the swelling of the first weeks and, of course, the pain. Bone grafts were taken from my ribs and from my hip to make my nose, my chin, and my cheek bones. I couldn't walk for weeks. Breathing was also very painful. Results did not appear right away. For months after surgery, I had all the mirrors hidden or covered. I didn't dare to look at my face. Dreams of inventing the life I would live carried me through—the love, the traveling, the studying, and making friends with people from all over the world. My objective was to live an interesting life and to learn. The surgeries throughout the high school years were a parenthesis in my life. They were like swallowing a big bowl of sour medicine: You take the bowl and close your eyes, stop breathing and hope it is over quickly until the experience becomes a vague remembrance. I never cried before surgery. I had an idea of heroism, of being courageous. I would clench my teeth and have faith that it was all for the best; I believed that my angels were a protection for me and that everything would be all right. Throughout those years of metamorphosis, I kept dreaming and I drew my face. I drew the image again and again on every paper and in all my notebooks. With each drawing I invented a life, a destiny, adventures and romances—ideal lives. Dreams and imagining better times kept me going. A smile from my good fairy assured me that I was doing OK, that in spite of hardship and a feeling of failure, I was creating my life with every passing year, overcoming a lot, doing great, and walking toward a fine path.

Changing my named from Evelyne to Eva marked the beginning of another reconstruction, of taking my destiny into my hands. I went to Israel and met an American man who asked me to marry him. This too was the beginning of a new life: changing countries, speaking a foreign language, adjusting to a different culture were all ways of soothing wounds and becoming a new person, living beyond bad memories and the feelings of failure. And just as my face seemed a separate part of myself I rejected the reality of living with TCS. It was taboo, ignored; I would not allow anyone to bring up the subject. I hid all the pictures of myself as a child and teenager. I went so far as not telling my husband about my past. He accepted the story of a car accident. Immersed in a new language and culture I lived my young adult life refusing to address my past, forgetting all the surgeries and the past pain.

In the USA I wanted to make up for my difficult school years and take revenge. I enjoyed the American university system and earned a BA in Latin American studies at UCLA, and then continued on for a master's degree in Special Education. I became a teacher and taught elementary school in English and in Spanish while I pursued my Science of Education courses. Then, although I denied my past and never accepted seeing myself as a special person, I became a Special Education teacher working with children with learning disabilities. I never addressed my hearing disability and always used adaptation as camouflage.

When I was living in Los Angeles a dance friend and roommate went to Israel for a few months. She enrolled in an Alexander Technique course there. When she came back I was startled to see how much she had changed. Her posture, her way of talking and addressing people were different, much more engaging and easy going. I never imagined that one had the ability to change so much in so little time. I was intrigued by her carriage, her bearing, but never inquired more.

Back to France at age 33, divorced, with a master's degree and an American passport and way of life. I wanted to live closer to my aging parents. I continued teaching children and adults, but the return to France was difficult. The past was jumping back at me and sticking at me. As part of my quest for understanding I was immersed in the search for my clown. As a theater clown, I sublimated my past. I was the initiator of laughter and no longer its victim. It was in my beginning clown workshop that I discovered the Feldenkrais Method [of somatic education]. Heinke Aschemann, my clown professor, was in the second year of her Feldenkrais training program and was eager to share all she was learning with us. I will never forget the first Awareness Through Movement (ATM) lesson she taught. I was unable to raise my right arm and my left foot or something like that. The most simple movements were incredibly complicated. I was clearly facing a lack of coordination which had always made me clumsy—breaking dishes and whatever was in my way.

The difficulty of doing the simplest movements didn't discourage me. On the contrary, I immediately knew that I had something precious to discover with the Method and I volunteered to be Heinke's first pupil. The first Functional Integration (FI) lesson revelations came as miracles—a golden door opening new possibilities, new relationships to myself and to others. I could perceive how one may indeed change and overcome negative and limited feelings of oneself. When I first felt the connection between my head and feet I burst into laughter. That I could feel sound and vibration through my feet or the mobility of my ribs and shoulders was miraculous—I loved all the rocking movements and loved discovering possibilities. Heinke was going back and forth to Germany and so I found other Feldenkrais teachers. I benefited a great deal from Francois Combeau, Jessie Lebovicy, and Anne Marie Berger's teaching until I felt ready to apply to Myriam Pfeiffer's practitioner's program.

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The Face Behind the Mask

Chava Shelhav-Silberbush

A young woman of average height, a pleasant build, and fair curly hair that covered her forehead and part of her face was at the door. She was smiling. Her face was scarred and asymmetrical. As I look back at the first FIs I gave Eva, I ask myself, "Why did I touch her face right away?"

During our preliminary interview she complained about limited movement in her chest and a tingling sensation in the shoulder. This was her reason for coming to me. I asked her to take a few steps around the room. I noticed stiffness in the chest and hesitancy in walking, as if she was walking on an unstable surface. I asked her to lie on her side, thinking that this position would allow me to easily check the movement of the ribs and give her a more complete picture of them. I could then make the connection between the ribs, the pelvis, and the legs.

It became apparent that she had an implanted conductive hearing aid. I considered the likelihood she had undergone complicated surgery to rehabilitate her hearing. If so, the area would have been traumatized by the cutting of tissue and muscle, which would lead to a lessening of sensation there. So gentle, present touch was required. Although I noticed her facial scars and asymmetry on our first meeting, I thought she might have been burnt and I didn't relate to Eva's face as a "problem." Instead, I addressed her face as part of her whole self, like any other part of the self that needs to be touched in order to develop sensations.

Through touching, I first clarified each part of Eva's face in relation to the whole. I asked myself, "Why do people tend to keep their hand on their painful area?" Indeed, there is an instinctive reaction we also see in dogs and cats who constantly lick at their wounded paw. The real problems

appear when one suppresses this instinctive reaction and wipes out the injured part from the body image and self-awareness. In the Feldenkrais Method [of somatic education], we purposely don't directly address the painful or delicate area. We work around it or far away from it; if the pain is distal, we work proximally and vice versa. But since Eva had no recognition of her face and skull, only a direct touch could allow her to become aware of their presence, and only this direct approach allowed her such an amazing change.

The face is a primary focus of recognition. In infancy it is a source of discovery, enjoyment, games, and security. Babies learn to read the faces of their parents and others. They react and act in response to facial expressions; a smiling face is encouraging, a sad face can cause an infant to cry. An infant's facial expression is actually reflected in the entire self. Just picture how a baby's broad smile is expressed by a full body wriggle.

An infant plays with his hands, bringing them to his mouth, using them to explore his face, touching objects. This is the way he connects with his environment and also differentiates the internal and external world. This experience was a void for Eva and affected many layers of her life. To integrate her face into her self image it was necessary to take her through all the developmental stages she had not experienced.

When working with babies, I will provide proprioceptive information if parts of themselves do not respond properly. For example, when a baby does not support himself with his hand, I will put his hand on the floor so that he can feel the support. By doing so I allow for the "mapping" of his hand into his body image. However, with babies and in Eva's case, I came to look at this strategy from a different perspective. I acquired insight about the importance of addressing the delicate area first instead of avoiding it and thereby reinforcing the inhibition. In order to overcome a dramatic pain situation, there is a necessity to connect the painful spot not only through the interaction between all aspects of the body but also to connect it with a new movement behaviour, posture, stability, a new scheme. The pain or inhibited part then becomes a stepping stone.

Babies play with their hands and mouth, explore their face with their toys. They bring a toy to their face and the face becomes a primary focus of recognition, a source of games, discovery and enjoyment. In Eva's case, her face was cut off from her awareness. As a baby she sensed it was stigmatised. She slept on her belly, the pelvis high up, her face hidden in the pillows. Her face was not a source of happy new contacts and discoveries. As a consequence, she did not bring surrounding objects close to her face, touch them and bring them to her mouth. Her eyes were not accustomed to seeing objects clearly, to scrutinize and investigate them.

Eva told me she felt awkward eating, that it was difficult to bring food to her mouth without dropping it and making a mess on the table. Even today she still feels a bit nervous and self conscious when eating around people in a new environment. She pays close attention to every gesture so as not to spill. Thus proving when an inhibited part becomes clear it is a pathway to overcome inhibition.

Each of our facial orifices has a specific function such as seeing, eating, smelling, but are not primarily designed for making faces. As I worked with Eva, and clarified the global facial picture, the kinaesthetic sense was available and she was ready to apprehend her face in a different way. In child development the senses come first, and only later orientation is connected to the movement. In my work with Eva, I differentiated separate development of her facial kinaesthetic sense, her skull, and then brought her to feel rotation—to feel how the front is oriented in opposition to the back.

At the end of the lesson she reported a new sense of stability. She began to tell me her story. She talked and she cried. I listened. I let her cry. The spontaneous crying that took her by surprise was a great relief. When a person feels more physically stable, she can then take the risk of exposing her feelings, sharing her sadness or anxiety.

Until now her head and face were not part of her self image. In the past, her movement lessons concentrated on her body and her face remained out of bounds, like a mask. The question was how to include her face in the body sensation. I gently touched all the facial bones to communicate the location of body parts to her nervous system, connecting the areas touched to others to map the part

in the self image. I lingered over each area of her skull and face, and I verbally named each bone. I continued using different types of touch paying attention to all the details of her skull. I also touched her neck and shoulder, on one side only. Concentration on one side at a time allows a clearer sense of the differences between the sides. This new relation of the face and skull resembles the way babies learn about their bodies and create their self image. Babies begin their developmental journey through proprioceptive touch and when the proprioceptive picture is clear, they are ready to move. So in a subsequent FI lesson, I added movement to the proprioceptive content of the lessons. She stood, turned to one side, and remained in the twisted position. Then I asked her to tell me to which side her face is facing and to which side is the back of her head. She could not answer these questions. There was no differentiation between her face and skull in her self image. Her orientation was clearer in other parts of her body. Therefore, I turned to clarifying the sensation in these places: abdomen versus back, pubic bone versus sacrum, the sternum versus between shoulder blades, throat versus the back of neck. Through these explorations and clarifications we arrived at her face—nose, jaw, eyes, until the location of the front and the back became clear and coherent. The idea was to present a functional introduction to parts of herself that were absent from her body image. It was a long and emotional process. This brought me to ponder anew the importance of the whole self image Feldenkrais often talked about.

I used verbal questions to help internalize an additional perspective of self-image. The lessons became a dialog between non-verbal and verbal questions, asked by touch and utterance. The way she answered clarified for both of us where she was. Over the last few years, the importance of verbal dialog and sensitive, probing questions has become clearer to me. The questions must be without an agenda, questions that don't lead in a particular direction, questions that leave a wide range of choice, questions that allow a person to search for an answer. There is a great importance to the words that are chosen.

As a child, Eva could sense that her face was taboo. It was a face that was never actually touched. Her childhood memory was of a lowered head. The mouth, eyes, ears, nostrils were used only for survival. Her eyes never became accustomed to examining objects at close range. Our journey started as an FI for a shoulder complaint. An unanticipated process unfolded. When a repression becomes clear the repertoire of everyday life opens to permit discovery of the collaboration of movement, feeling and thought. It was much more important to leave myself available to the as yet undiscovered than to respond to the original complaint. When I meet a person it is hard to guess what is hiding under the skin.

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Eva's Responses

Two Lessons with Chava

Thank you for yesterday's FI. For a moment I could actually feel my face breathe. It was an extraordinarily new and unexpected feeling for me. I went home feeling complete—like a child who has a new toy. For the very first time I started touching my face, feeling curious and playful. Can the skull be as mobile as the other parts of the skeleton? Can indeed the nose, the cheeks, the eyebrows, the jaw be differentiated one from another and move in opposite directions just as Myriam taught us to do with our toes? How does breathing affect the mobility of the face? What is the amplitude of this mobility? Besides the jaw, is there such a thing as distal and proximal movements of the nose, ear, etc.?

I am looking forward to continue this exploration with you next Tuesday. I know that this work will enable me to bring significant guidance to my fellow friends with TCS.

The last FI was amazingly important and structuring for me. It took me a few days to be able to verbalize what happened. I felt for the first time the relationship between my FACE and my ribs, my torso. Throughout my training, I had integrated the relationship between the head the torso, the pelvis. But as I now know the head is not dissociated from the face. Up until your lesson, Chava, I had the perception of the head and face being like a Nô theater mask:

MASK - A face covering. Usually it is something worn on the face, with openings for the eyes, to conceal one's identity, either for partying (as at a masquerade ball), to frighten or amuse (as at Halloween), for ritual, or for performance (as by dancers, or by actors in Greek, Roman, and Japanese theatre.) It may be worn principally to protect the face (as a gas mask, or a hockey mask, or a physician's mask, etc.) It may also be any two- or three-dimensional representation of a face — as in the covering of an Egyptian mummy's face depicting the face of the deceased. A mask can be a mold of a person's face — a death mask if made after death, a life mask if made before it. It may be used as a verb: to cover in order to conceal, protect, or disguise.

Japan, Nô mask of a young woman, 18th-19th century, carved and painted wood. The white paint composed of crushed egg-shells in a binder, British Museum, London. Nô (also called Noh) is the classical drama of Japan, with music and dance performed in a highly stylized manner by masked and elaborately dressed performers on an almost bare stage. A skilfully carved mask will appear to have subtle changes of expression depending on the way in which the wearer turns his head and the angle at which it is held. This is one of several variations of a young-woman mask based on an original design by Zeami, known as Zô-onna.¹



How can I describe the surprise when I could feel my cheeks, my eye sockets, different parts of my forehead and my chin rubbing the towel under my head as you were twisting my ribs? The sensation was so deep that I feel that I was like a potter artfully molding my own face, deciding on the pressure, the heat I wanted from the supporting table. I was becoming the creator of my face. As I write a new association clarifies. Most of my facial bones do indeed come from my floating ribs and hip joint grafts so it's no wonder this movement had such an extraordinary impact. It freed me, it liberated me. My face was born. At home I explored the movement of turning the hips and feeling the face following the movement many times as well as the opposite movement of the face inviting the vertebra and ribs, pelvis and hips to turn. I practiced many times to recapture the amazing sensation when you did it.

I felt sad and destabilized at the end of the first summer training. I had learned to feel the movements of the ribs, the hips. I could feel each of my vertebrae and how each one was related to my breathing and yet, this new awareness made my face even more of a mystery and more isolated from the rest of the body.

Since this FI, my face is present to me at every moment. I can feel my smile, my eyebrows, my cheeks, my breathing, the wind and the sun, the state of my muscles. My face is becoming three dimensional with different volumes, just like my ribs. I have always had difficulty recognizing and remembering people's facial features Since the FI, I pay more attention to people's faces. As I feel the volumes of my own face I can also pay attention to other faces. I can see more than just two eyes, a nose, a mouth, and hair color and length.

1. <http://en.wikipedia.org/wiki/Image:Masque-no-p1000705.jpg>

The last but not the least effect is how clearly I can now distinguish between the front and the back of myself. Before it was an intellectual abstraction but not kinesthetically integrated. As I can now differentiate between the back of my head and my face and pay attention to every bone, muscle and feel the skin of my face, I can finally clearly distinguish between my back and my front. It gives me a new stability and sense of direction in my life.

This lesson is a turning point in my evolution and as a future practitioner. I can see how each lesson has built up to the next. I felt you were genuinely interested in my situation and in enabling me to discover and feel my face. It felt an echo to my questions and it was reassuring. I knew that I could let go of my fears, to let go of the walls and unnecessary barriers, to accept and express all the sadness. All this was necessary to awaken my attention, my readiness to learn, to feel and to discover my face.



In 2006 I was invited to participate in a TCS panel for families and others concerned with this rare genetic disease. A geneticist from Necker Hospital in Paris explained in allegoric terms the genetic origins of TCS. He compared the gene causing TCS to a spelling mistake in a single word from a book of the DNA library. I was the final speaker. I placed my notes on the table and took a big breath in order to speak in a clear voice.

The spelling mistake wishes to speak and to be heard. A spelling mistake cannot be erased and corrected without leaving a smudge or a scar. A child that is born with TCS carries scars that cannot be erased. They leave a smudge that will never entirely disappear. I am asking all participants in this conference to become aware of the words they use to talk about us; because words will determine how we accept and perceive our self, our difference. Words can sooth and help us grow and overcome our difficulties but words can also harm, cause everlasting scars, and destroy our self-esteem. A single copy of a unique book with a "default" is called a rare book and is worth a fortune. In a green meadow a four-leaf clover is considered as a lucky talisman. I therefore invite all of you to perceive us with TCS as invaluable rare books, as unique as four-leaf clovers in a green meadow. You will see this brings new perspectives and possibilities to our lives.

During this panel I have heard about fixing, repairing and operating as early as possible. I have benefited greatly from science, but I believe there are more simple and efficient ways of making meaningful improvement in your child's life. It is called enhancing self esteem and self image. Self image will endure despite all the surgeries in the world. How many gorgeous people feel ugly and unworthy of love, while the not so pretty women will feel confident? I am sure that some famous movie stars have never been loved the way that some women who I met this week with TCS are cherished by their companions.

Here are some thoughts based on my experience and my training as a Special Education teacher to meditate on and to apply without moderation. I promise this will not cost you a dime and will foster growth and joy in the whole family.

Parents, accept your child as he or she is. If it is difficult to do so, work on your self, seek professional help to overcome the feeling of guilt and a sense that you must repair your mistakes.

You may be concerned that your child will suffer. This enhances guilt and uneasiness with your child's difference. Think of it in this way: Who doesn't suffer on this earth? Don't we all learn from our sufferings and hardships? Think of all the children on earth who suffer from poverty, racial discrimination and wars. The idea of happiness is a modern concept. In former centuries children were forced to work under horrible conditions. We should therefore rejoice at the freedom and happiness of our daily lives.

A child with a difference will learn to adapt to his or her handicap, compensating for the difficulty. Observing and talking to children, teens and young adults who have difficulties I see that we

developed better social skills and find ways to compensate for our facial difference. I saw little kids developing survival skills at a very young age. The more you overprotect your child, the less he or she will be able to develop his or her own survival device. That is a much more severe handicap ensuring it will be harder to integrate a group, change schools, meet new people.

Make your child an actor in the surgical process. Explain to him or her what will be done. Don't do anything against his or her will. After all, it is your child's body you are talking about. Your child must feel the owner of his or her body. Even deciding on the day of the surgery is important. I suffered a lot from being deprived of that decision power.

Your child's sense of time is not the same as yours. As parents you are projecting years ahead, how your child will be able to work, study, marry, have normal children: all of these are pertinent questions and valid concerns but your child's preoccupation lies in the present—in facing a group of tough kids who will certainly laugh, or tease, starting a new school year with a new teacher and new classmates; wondering about how painful the dentist session will be, or worrying about not being about to hear the teacher well enough to understand the assignment.

Parents should be attentive to what their child is facing in everyday life. It is not easy to develop a happy balance between overprotecting your child and letting him or her battle without your emotional support. Communication is a key factor in accompanying your child in a helpful way. Listen to what they are saying, his body language, his expression of stress and fear. Bear in mind that your child is doing the best he can, given the circumstances. Do not ask him to compete with kids his age, to obtain the same school results. Your child with TCS will need twice as much effort to obtain the same results of average kids. They will need to face hearing impairment, and a higher level of stress when the relationships with the classmates or the teachers is difficult. The psychologist Maslow demonstrated that in order to learn and reach a higher level of thinking and development one must have the basic needs fulfilled: food, a dwelling and basic security, and group belonging. When suffering from a facial difference one often feels in a state of imminent danger, which slows the learning process.

Another factor that parents tend to forget in their rush to fix things is how much the child is helping you. My parents had no idea how much I kept to myself so as not to worry them, not to burden them further. If you accept the child as an actor in the process, it will become a lot easier to find solutions. If the child is regarded as a thing to be manipulated the child will feel like a victim instead of a participant.