

THE CORNER: CLIENTS THAT INSPIRE US

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Following a comment of Peggy Sax that some clients “bring out the best in us,” I proposed in 2011 that, furthermore, some clients do more than that, they in fact inspire us. I am sure I am not the only one to think so and decided to write up with Sam, then aged 20, and his mother, Jess, from the letters that summarized our meetings and several other meetings to confirm and review the conclusions we all reached at that time. This follows “Un suffering,” co-authored by Julie King and David Epston, which appeared in Vol. 30, no. 1, 2011, pp. 84–96. Surely I am not the only one who has had this experience. I would certainly welcome stories with or about those who have inspired you.

“I TREAT HIM LIKE A CAT OR A DOG”: JESS, SAM,¹ AND DAVID EPSTON

Meetings 1 and 2, 2002

Jess speaking on their behalf told of their concern that Sam’s continuous “looking over his shoulder” was so frequent and at times violent that they had been advised by a physiotherapist that he might be doing permanent damage to himself. This problem was a consequence of his severe seizure disorder. This was never mentioned again after the first interview.

Sam’s first seizure was at 18 months old, and they occurred on a regular basis until epilepsy was diagnosed when he was 4 years old, subsequent to an earlier diagnosis of cerebral palsy at 11 months. These seizures would “last for 24 hours” and occur at “intervals of a few months.” He was started on standard neurological medication, which from Jess’s point of view “reduced him to a zombie from an alert and happy boy.” Jess searched her soul: she believed that “I had done something awful and stopped him from being him.” Contrary to medical advice she received in New Zealand’s public health system that “if I took him off Te-

¹Although Jess and Sam are justifiably proud of their “insider knowledge,” they have chosen because of some confidential matters mentioned here to use pseudonyms instead of their legal names.

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gretol, I would kill him,” she consulted a private pediatrician who assisted her to carefully withdraw him off his medication and offered them 24/7 urgent care. His withdrawal was eventful but Jess rejoiced that Sam “came back to himself” within a year’s time. She soon lost touch with her pediatric consultant until I contacted him 16 years later.

Jess realized that “when Sam was 4, 5, somehow he was able to control his seizures.” At this age, Sam, according to Jess, “was able to hold a convulsion off.” We named this practice “delaying convulsions.” What convinced Jess of this were her observations that his convulsions occurred only in her presence, never in her absence, and, in addition, they were timed to “the minute I picked him up or the moment I arrived home.” She theorized that, by some means or other, Sam had been, in a manner of speaking, holding onto the seizure. We all agreed that somehow Sam had timed his convulsions for the most opportune circumstances: when he was certain his mother’s care and comfort were available.

Sam then joined the conversation, adding that currently “if I’m busy or out in town with friends, I can go a whole day” convulsion-free. We called this practice “preventing convulsions,” a clearly definable stage well beyond “delaying convulsions.” Sam’s first thought as to how he went about this was “I don’t have time to think about it . . . I am sidetracked.” We wondered in jest if in fact Sam was sidetracking his convulsions.

We started a very detailed inquiry into Sam’s 4- and 5-year-old “delaying practice.” First of all, Jess had come to the conclusion that “he would wait until he got home . . . I knew he could do it.” But Jess played a part in this in, which we called “prompting”: “Consistently he had them when I was home and I knew he could hold them off with a bit of encouragement.” When we delved in to “prompting” and “encouragement,” Jess concluded that “it had to do with my tone of voice—calm, collected, despite how I felt. It was my reassurance and my affirming of his ability.” Sam, in his turn, concurred that “her tone of voice changes. It becomes calm and soothing.” Jess thought she must have invented this practice as she had not received anything of this kind in the family she grew up in. In fact, she considered that it came from “both my desperation and determination. I had to find some way to deal with this. I can ‘nut off’ so I am not naturally calm, cool, and collected. But when the going gets tough, I have to deal with it.”

Looking back over her childhood, at this metaphorical first glance, she could not find any precedent for this. But then again, at this point in our conversation, she was not considering her history of person/animal relationships. She told me in a matter-of-fact way that “the fear is all there and I swallow it and push it back.” Jess acknowledged a kind of “curiosity” as to “what do I do about it,” which obviously had assisted Sam to “delay” his seizures. Jess became intrigued with herself as well as with Sam. I admit to having been intrigued by them both. Our conversation was “co-research” with Jess and Sam as participant researchers and myself playing a somewhat more conventional research role. But together we were hell bent on tracking what we had described so far as first a practice of

delaying seizures at a young boy to now as a young man preventing seizures. So far, we were able to relate it to Jess's tone of voice. But I suspected that there was a great deal more to come in our inquiry before we reached a satisfactory account of this remarkable history.

It was at this point that Sam rejoined us and expostulated: "That's what I do, I control my seizures." We took this opportunity to do a history of seizure control. In 1990/1991, he had an estimated 10% control, by 1996, an estimated 50% control, and between 1997 and 2002, he estimated that he had gained 70% control of his seizures.²

Over all this period of time, Jess had not spoken to anyone about these matters. When I asked Jess what gave her the heart to pursue these solitary explorations, she attributed it to her "overwhelming love for Sam to have the best possible life he could have" mixed with desperate courage resulting from the urgency she felt that "we had to find some answers before it [epilepsy] destroyed us both." Along the way, there were some who more than ignored their "epilepsy knowledge." At the special school he attended, Jess mentioned the Medical Officer of Health, who "gave me the impression that if Sam controlled his epilepsy, he was faking it and attention-seeking." In this instance, Jess responded by having her general practitioner intervene to establish the validity of Sam's diagnosis of epilepsy and its severity. There were never any doubts expressed again about the legitimacy of Sam's diagnosis of epilepsy.

It didn't take long for Jess to recall where her "soothing voice" came from. But when she did it came as something of a surprise to her. She recalled her career as an animal nurse where she learned what she referred to as "my calming, soothing stuff." In this conversation Sam linked this to the fact that the only other person he knew who could assist him as ably as Jess was a friend who was studying to be a veterinarian.

Soon after this, Sam introduced me to his tigers, which, according to him, became available when required "to protect me from the hallucinations" that preceded every seizure. As he put it, "They stand around me although one is the major ring leader." Tigers had always been Sam's "most favourite creature." He considered it had a lot to do "with their power and colouring." When I enquired as to how they arrived, he replied, "It just happened one day. They just showed up one day unannounced," but from that very moment, Sam realized, "they were there to protect me. They stood in a circle and the leader ripped one of the monsters I hallucinated to bits." Sam approved of their presence and immediately spoke to them: "Thank you very much for being there." It turns out they are of the greatest assistance when Sam is on his own. In addition, Sam can call them up "by thinking about them." And if he needs to, he can be prompted by cell phoning Jess who merely has to say the word "tigers" to him, which seemed to be as

²On reviewing this paper, Sam reassessed his efficacy to 90% (July 7, 2010). This paper was reviewed again in May, 2014.

efficacious. However, there was more to it than that as Jess would also “remind him to do the breathing and remind him to call the Tigers and Nina.” Although we did not have the time to discuss the breathing at length, Jess described it as “deep breathing, like yoga breathing.”

In addition to the tigers, Nina, a very dear friend, also became available to him after her tragic death in a car accident on the eve of her 16th birthday. They had known each other since they were 1 year old. They had attended primary school together and “she always looked after me. She always stopped and helped me.” According to Jess, “they were like brother and sister.” Sam said he retains photos of her and that “everything reminds me of her. She is basically behind me.”

I soon came to understand the significance of that comment when I learned that “the hallucinations come from behind,” which means, in a manner of speaking, Sam has his back turned to them. And I recalled the problem they had spoken about at the very beginning of these conversations, Sam’s continual violent looking over his shoulder. Now I realized why he might seek to urgently see behind himself. The hallucinations themselves take the gruesome forms of snakes, crocodiles, and monsters, “for example cave men with glowy yellow eyes and horns.”

During this meeting, I turned to Sam and enquired if he might possess “body knowledges” and that these might be of a different order than “neurological or medical knowledge.” In reply Sam did not dispute this but said that “I don’t have a name for it. I just learned it as I went along.” Jess mentioned that in addition to the proposition of “body knowledges,” he also has “a special ability to relate to people.” And that he “could make wise choices.” Sam thanked his parents “for encouraging me to think for myself.” Jess mentioned that she always faced “a constant struggle—how much is enough but not too much.”

Meeting 3, 2002

We reviewed our first two meetings and when I asked who turned up first in his mind, Nina or the tigers, Sam told me that Nina arrived first “ever since she died.” In fact, prior to that he had dreamed her death: “The night she died, she appeared in a dream that very night and it followed the sequence of events that happened in real life. It took me a couple of days to find out myself the sequence of events leading up to her death.” Ever since then, Sam takes “a lot more notice of my dreams.” Sam was not haunted by what we called his “dreaming power” but Jess admitted to being “spooked” by it at first.

Sam described his relationship with Nina as “we were basically brother and sister.” Jess mentioned how they had shared the experience of living with disabilities and “they were always there to support each other.” Nina had had spina bifida and a B12 deficiency, poor coordination and a floppy body, and learning difficulties. To some extent, Sam and Nina were what Jess referred to as a “tag team” at school: as Sam put it, “She could read and I could think” and their respective abilities complemented their disabilities. After Nina’s death, Sam was so grief-struck he

was unable to return to school “for weeks.” But 2 or 3 days after her death, “the next time I had a seizure, I could see her like a ghost. In fact, she started appearing when I was having a seizure. She shows up, stands behind me and comforts me. She does what she did when she was alive. She puts her body between my back and the hallucinations.”

In addition, on reviewing the tigers, they also made their first appearance in Sam’s life about 6 months later, although “they walk around in a circle and face the way I am facing.” When I asked Sam if he considered the hallucinations were afraid of Nina, he didn’t know but he assured me that “they never get that close to me but I have to lift my feet” so they can pass beneath his feet on occasions. Knowing Nina is there allows Sam “to turn my back on them. I know they are still there. I have another pair of eyes in the back of my head and I can get a picture of them. I don’t get frightened.” Sam considered that the tigers came about due to a homeopathic remedy that “triggered my imagination.” When I asked Sam how the tigers were already in his imagination, he told me that “I have always been interested in tigers, in fact, fascinated” and considered them “one of the wonders of the world.” During his schooling, he regularly did “tiger assignments,” often with Nina’s assistance, and became something of “an amateur tiger expert.”

When I asked Sam what he thought when Nina and the tigers arrived on the scene, he told me: “I knew straightaway when they appeared that they were there to help.” Over the past few years, the hallucinations have come to respect his defenders and the “tigers no longer have to get aggressive and only the really bad seizures get by the tigers but the hallucinations never get closer than 20 or 30 centimeters.” And on average, Sam has two seizures a day. When I asked how Nina comforts him, he told me that “she never says anything but she is always touching me.” On the other hand, he can “touch the tigers, which is like petting a cat. They sort of purr.” If Nina were able to speak, Sam was of the opinion that she would say: “I am there to protect you” and the tigers would all say in unison: “We are special to him so her memories will be kept alive.” In addition, Sam mentioned that Nina drops by in his dreams and they “chit chat, just how we used to talk, sort of serious young adult talk.”

We then talked about “tiger phone calls,” which Jess had instituted several years before. This is how she described “tiger phone calls”: “I do over the phone exactly what I would do if I was with Sam. I stand behind him and touch him. I got in to the habit of doing so because when he was young he would collapse backwards. But that is where the hallucinations come from.” Sam mentioned that if he were to see the hallucinations, “they would scare the living daylight out of me,” so it is a distinct advantage for them to be behind him.

Meeting 4, 2003

When I asked Jess how she learned to become such an adept “emergency responder,” she said: “Firstly I had to learn to control my own responses of fears and put them to one side and stay focused on the person. Secondly, I needed to recognize parts

of me that connect with him. Thirdly, stay calm, quiet, unhurried and almost repetitive. And get rid of anyone who is panicking or getting upset. I ask him permission to continue to do whatever even if I don't really need to. And I say to myself: 'We can work this out. This will be okay.' My voice gets lower, stronger, and quieter. I use the same voice at work.'

When we traced what Jess and Sam referred again and again as "the voice," Jess recalled that she "always had a love of animals. They were an escape [from a very unpleasant home life] and an alternative family for me. My cat, Softy, and my guinea pigs, Fleur and Penny, in particular. My pets were more important than my people family." I asked Jess: "If Softy had the intelligence of a person and could speak, how would he have described you then?" Jess replied sorrowfully: "Really lonely, unwanted and unhappy." I then if asked Softy thought he had provided happiness for Jess, and she answered with a very emphatic "Yep! And Penny and Fleur knew I needed cuddles." Jess also spent a great deal of time with her neighbor, Kay, an unmarried woman, and her menagerie of "dozens of animals," and in particular, "I spent hours with Jacky the horse." Jess said, "Kay knew I was sad and lonely and just let me spend time with her animals. She just let me be. When I was at Kay's, I didn't have to worry about anything. It was freedom!" On reflection, Jess assumed that "Kay must have been able to talk to animals." She suspected that it was very likely she just picked up many of Kay's person/animal practices from overhearing her.

This was just the beginning of Jess's apprenticeship in the craft of animal care. Jess left school after high school and "did not go to university because it was believed I was too stupid and dumb. My parents told me I couldn't go to that level." She found work first in an animal lab and then moved on to work for the Royal Society for the Prevention of Cruelty to Animals. Here she acquired a reputation for being able to "deal with any animal which was frightened or was losing the plot. I was an animal counselor." Not surprisingly, Jess went on to a tertiary qualification in veterinarian nursing. Jess summed up her formal training as having her "trust my instincts when an animal was unwell." When I asked her if she might consider what she called "my instincts" to be insider knowledges she had gained by apprenticing herself with Kay, Softy, Fleur, and Penny and then applied them both through her paid work and study, she smiled and said this was very apt. She realized that she had learned these so-called "instincts" from the "inside out." When I asked what she had called upon when Sam's cerebral palsy and epilepsy came along, she said something by way of a jest that seemed to hold so much truth in it: "I treated Sam like he was a cat or a dog." Jess considered that "having been with animals in a healing way" was a boon to her and Sam's epilepsy.

Jess continues to have strong commitments to animals in her family: "I love my animals. They are part of our family. I have an absolute commitment to their okayness. Our cat, Nickel, had seizures and I did the same thing as I do with Sam and he seemed to settle." Sam joined us at this point in the conversation and described his mother's emergency responding voice: "calm . . . soothing . . . quiet . . . her tone of voice changes. It is the tone!"

Jess spoke of her struggle in the first years of Sam's life to develop a policy around Sam, his epilepsy, and her family: "We needed to keep things normal. It is better he lives a normal life and not a long one rather than stay at home and live the epilepsy or the disability. I struggled for a long time with that."

Meeting 5, 2003

In this meeting, we all tried, as we put it, to get to the bottom of what Jess had referred to as the "treating Sam like a cat or a dog" practice, a practice that so obviously dignified Sam's life and contributed so much to the fine young person he is turning out to be. As Jess put it, "It doesn't matter what I say, he doesn't hear the words, it's the tone of voice." On further discussion, Jess admitted to being bemused by my interest in her practice as she had "assumed everyone could do it." Sam and I strongly disagreed with Jess on this occasion that her practice was by no means "common garden." With this, Jess returned to the research at hand and told us, "I have always talked to animals. I calm down when I speak. I am gentle and soothing."

We decided to go over the three-step practice Jess had outlined in our previous meeting in some more detail.

1. "I step away from the fear, leaving a part of myself behind. I, in fact, push the fear behind me. I know it's there but my calm voice is calming the brave part of me."
2. "Time has become an instant now. I can feel the internal core of me which I know is strong and capable and I let that strength take me over." Jess considered that this was paralleled by "deep breathing in which I stay fairly still and slow down all my movements. Any movements I make are smooth and unrushed. Nothing is loud; nothing is quick." Jess employs some words and they have to do with: "I'm here to help you, comfort you and love you." She also considered her body language would say: "I am in control. Trust me. I'll support you through this." Jess would also speak under her breath to herself: "It's going to be okay; I can get through this!" At the same time, she described how "everything else goes. I just block everything else out. I just see myself as a mother doing what I need to do for my child. I'm on automatic, sort of programmed in. I believe anyone can do this if they want to. It does not have to do with cleverness but I guess it comes more naturally to some people." We coined the phrase "mothercraft" for such a maternal practice. Sam made the point that this has "to do with the relationship." Jess went on to say that "I shut down my emotions and turn on 'kind and caring' animal nurse! I am moving slowly and calmly, speaking quietly. I stand so close to him that my body touches his. It's exactly the same as stroking an animal." Jess wondered if "someone might say I am doing nothing." I begged to differ, saying that I thought she was doing everything.

3. Jess also asks Sam questions in the format of “Is it okay if . . . ?” And she believes such queries come from “a different part of me, a higher power, a universal something that I haven’t clearly defined.” She laughed when she called it “Jess’s spirituality.” Still, she had no doubt it was a “different level of communication . . . a spiritual connection. Everyone has a spirit whether they are a person or an animal.”

Sometime after these meetings, I rang the pediatrician, whom I had known many years before when we worked together in the child psychiatric public health services. Not surprisingly, he could not remember Jess or Sam by name from their single consultation. However, he found no difficulty whatsoever remembering why he would have considered taking the risk to withdraw Sam from his medication, at the same time offering 24/7 emergency contact. You will recall Jess never rang her medical advisor after the arrangements were made to withdraw the medication. She had been clearly instructed to recontact him for any concern she might have. Despite her concerns, they were insufficient, she felt, to seek further consultation, although she appreciated her consultant’s generosity in offering such a 24/7 service.

He immediately told me a story from his medical studies in neurology as an intern doctor when he was training in Australia. He recalled a discussion he had had with a father, also with a severe seizure disorder, who was the caretaker of his 2-year-old son. When my former colleague spoke with him about his concern that should he have a seizure, the baby might be endangered if he was holding him, the father assured my colleague that he would delay the seizure if that were the case and spoke of having done so on many occasions. Strangely enough, in an instant, I recalled my colleague having told me that very same story 20 years before. I found it so riveting at the time that I can easily recall where we were sitting and who was with us. I had never forgotten it and perhaps that was why I asked Sam the question soon after we met, “Do you have bodily knowledges?,” much as I had to guess my pediatric colleague had assumed about this father.