Chapter 2: Beyond the Diagnosis

> *A narrative is composed of a unique sequence of events, mental states, happenings… these are its constituents. But these constituents do not as it were have a life or meaning of their own. Their meaning is given by their place in the overall configuration of the sequence as a whole, its plot or fabula. The act of grasping a narrative, then, is a dual one: the interpreter has to grasp the narrative's configuring plot in order to make sense of its constituents, which he must relate to the plot. But the plot configurations must itself be extracted from the succession of events (Bruner, 1993, p. 43).*

In this chapter, I share my experience with cancer and the way in which this unfortunate disease entered my life. I use the notions of dimensionality (Clandinin & Connelly, 2000), wakefulness (Clandinin & Connelly, 2000), wide-awakeness (Greene, 1978) and metaphor (Lakoff & Johnson, 1980), as the lenses to look back upon the events leading up to the diagnosis, the actual diagnosis of cancer, the subsequent treatment and finally, the arrival on the other side of this disease. Through the narration of these events I intend to show that what I initially perceived as an unfortunate event is in fact extremely fortunate because of the insights and new plot line it created for my life's story. Thus, for this narrative, the title *Beyond the Diagnosis,* which gets to the heart of seeing beyond *what is*, came into being.

Part 1: The Journey Begins

The computer room was hot and crowded. There was a mixed mood of interest, curiosity, intensity and anxiety as the Teacher Candidates worked together to become

familiar with the new electronic reporting program that I was demonstrating to them. My role at that time was Course Director for York University's Consecutive Education Program. We were together on a Friday afternoon, in early February, with our goal to become familiar with evaluation and reporting practices used in Ontario schools. We had one afternoon, a mere three hours, in which to review our previous knowledge of assessment and evaluation, learn the reporting program and become prepared for an upcoming assignment– creating a mock report card for one student in their Mentor Teacher's classroom.

As I worked with one of the groups, I could feel a cool trickle at the edge of my nose. I reached up with the back of my hand and much to my surprise discovered there was a drop of blood. How odd, I thought (since I never get nosebleeds). Was it the intense heat in the room? (It was an old building, with an old furnace that had difficulty regulating the temperatures. In this particular room, no windows could be opened to alleviate the extreme heat that was being generated by all of the bodies, as well as the intense heat from all of the computers.) Was this due to the dryness of the cold winter air, I wondered? I went to the washroom to grab a tissue, wash the blood off my hand and try to stop the bleeding. I pinched my nose for a few minutes and it seemed to stop. I went back to the computer room and continued with the seminar. But, my nose still bled, although lightly. As I pinched my nose, concerned Teacher Candidates began to offer up all kinds of methods and suggestions for alleviating this situation. I thanked them for their concern and continued to pinch my nose harder and farther up the bridge, as one of the Teacher Candidates had suggested I do.

Twenty minutes went by and the bleeding persisted, so, it was mutually decided that ice on the back of my neck would be a good thing to try at this stage. One of the Teacher Candidates went to get the ice and we continued with our seminar- ice on the back of my neck and me pinching my nose, all the while trying to keep our focus on the task at hand, to learn this electronic reporting program. An hour passed and my nose was still bleeding. The Teacher Candidates suggested that maybe I had better get to a walk-in- clinic and get it checked out. It wasn't pouring with blood, but I, too, was concerned that it had been a while now and there seemed to be no change. We wrapped up our learning and called it a day. I drove, one- handed (not something I would recommend to anyone) to the nearest walk-in-clinic, which thankfully, was only five minutes away.

The doctor on duty took a look and emphatically stated, "You aren't pinching it hard enough". I explained to him that I had been pinching it on and off for over two hours, but, he insisted that I needed to pinch it with greater force for twenty minutes. While I sat on the exam room table, he grabbed the bridge of my nose with a large towel and said, "Like this. Two hands! " It was excruciatingly hard and painful. He told me to take the towel and pinch it like he did for twenty minutes and indicated that he would come back to check on me when twenty minutes was up. So, there I sat, pushing on my nose with the greatest force I could muster for over twenty minutes until his return. He removed the towel, took a quick look and said with satisfaction in his voice, "There. It has stopped."

I got up from the table, thanked him and headed to the car. I had no sooner sat in the car and my nose started to bleed again only this time with much greater flow. What

was I going to do? I wasn't going back inside the clinic, only to be subjected to some more painful nose grabbing. If this doctor had known what he was doing, then why, I asked myself, was my nose still bleeding? Not only that, why was it significantly worse? I looked at my watch– it was 3:30 pm. Thoughts flooded my brain– I need to get home. Koda (our dog) needs to be let out. He's been cooped up all day and Karl (our son) has jazz band, so he won't be home in time to let Koda out. I should really try to get to our family doctor before they close. I had a plan– get home, let the dog out, and then get to our family doctor's office.

I made it home and thank goodness, the bleeding seemed to have eased off. Maybe the clinic doctor was right after all? Maybe the pinching finally worked? I took Koda down the side of the house and back inside. His feet were wet from the snow so I bent down to dry them off with the towel. All of a sudden, blood started to pour from my nose, dripping onto the floor. I ran to get tissues from the bathroom and then ran to the kitchen to call the family doctor's office. The receptionist said to come in right away, they would fit me in as soon as I got there. So, with keys in hand, a tea towel and tissues clutched to my nose, I headed to the car.

I was just about to start the car when I could see in my peripheral vision, a vehicle pulling into the driveway. Much to my surprise and great relief, it was my husband. He never got home this early. What incredible timing and fate that Paul should be here at this very point in time. We headed off to the doctor's office. We were told that it might be better to get treated in emergency since there is more equipment and access to specialists there. So, off to the hospital we went. It was now 5:00 p.m. and my nose had been

bleeding for four hours. By 10:00 p.m., after having undergone several procedures and attempts to stop the bleeding (bleeding twice through the nasal packing) things were finally under control. The doctor-on-call said to come back to the emergency in three days in order to get the packing removed.

As I think back on this initial experience, I can't help but notice a couple of things about my state of mind amidst all of this excitement. At the time, the nosebleed seemed like a minor disruption, or a slight inconvenience. I also remember feeling somewhat angry about it all. I had other, more important things to do, far more important things than to be disrupted by something as minor and inconvenient as a nosebleed. The events at this stage had no significance as being either major or life altering, neither from my perspective, nor from the perspective of the walk-in-clinic doctor who had dismissed the event as "just a nosebleed". His curt, business-like response reinforced this perspective of the situation- insignificant and "just a nose bleed". Even my desire to keep teaching through the entire event (all the while knowing in the back of my mind that this was a very strange occurrence, as I have never had nosebleeds) showed a lack of wide-awakeness. The doctor and I both shared this state of unconsciousness, a considerable lack of wakefulness to what was actually going on. The clinic doctor did not seek any medical history or show any desire to look in my nose to see if there was something underlying the outward symptom. I did not push or ask any questions of him with regards to it. Even though the desire to ask him about it was nagging at me the entire time instead, I suppressed it into the back recesses of my mind. I now wonder, perhaps I really didn't want to know that something could be wrong?

Three days passed and I returned to the emergency room to have the packing removed. The doctor removed the packing and looked at me with what I would describe as genuine concern in his eyes. He asked about my medical history, seemingly curious about whether I had ever had a nosebleed before. It struck me as interesting that I had three previous doctors interacting with me over this and yet not one of them, not the walk-in-clinic doctor, or the two other doctors who had treated me that night in the emergency, none of them had wanted to probe further into this anomaly. This doctor recommended that I seek a further consultation with an ear, nose and throat (ENT) specialist and immediately made arrangements for me to see an ENT specialist for the next day.

I went to the specialist's office filled with strong apprehension inside of me. What could the specialist possibly discover related to such persistent bleeding? My imagination ran wild, remembering the movie *The Doctor*, with actor William Hurt, who played the unsuspecting lead– a highly successful doctor whose life is drastically altered when he discovers he has laryngeal cancer, detected because he had coughed up some blood. Surely cancer can't be possible; there is no cancer in my family. I reminded myself to put all negative thoughts completely out of my mind. It is not productive to be sitting here considering cancer (I kept repeating this to myself over and over like a mantra). I shouldn't be focusing on such a negative scenario. Besides, it was a complete waste of time and effort to be self-diagnosing, particularly since I have no medical background or knowledge of such things. So, instead, I sat in the waiting room flipping through the magazines, pretending to read, but in reality not paying the slightest bit of attention to

any of the content that flashed before my eyes. All I could feel, see and hear were the cold, glossy pages turning with a flick of anger and impatience underneath my uneasy fingertips.

I was called into the exam room. The doctor looked into my nose and said the words that will forever haunt my mind and soul: “You have a fleshy mass in your nasal vestibule.” I heard the words, but I couldn’t believe what I was hearing. My head flooded with millions of thoughts. “Do you mean like a polyp?” I asked him, for I had heard of polyps and knew that these were nothing to worry about. The doctor responded with very carefully chosen words a second time, “It’s a fleshy mass. We need to do a CT scan to determine if it is growing down from your brain.” Growing down from my brain? Is that why I have had so many severe headaches, I wondered to myself? I kept picturing this octopus-like growth snaking its way from my brain down through my nose. I could hear myself screaming inside my head. I was overwhelmed with a grave sense of dread and yet, relieved all at the same time. Relieved, that I was right to have felt or believed that this nosebleed was unusual and something to be concerned about, but full of dread that this might prove to be something deadly. In that moment of wide-awakeness, I knew that what I had previously viewed as an insignificant, minor, inconvenient incident would ultimately transform and become something much greater in my life. It was for a very brief moment that I was living, in real life, foreshadowing that writers adeptly embed into their novels.

A week later part of the mass was excised and a couple of weeks after that the first biopsy was reported to be inconclusive. The doctor, based on all of his experience

with polyps, and believing that it was more than a mere polyp, sent it to his colleagues at Princess Margaret and Mt Sinai for further analysis. Four weeks later I had an appointment at the University Health Network (Princess Margaret, Mt Sinai and Toronto General) to meet with the oncologists and radiologist. The mass turned out to be cancerous and malignant, something called chondrosarcoma. The fast tracking of my diagnosis, a direct result of the efforts of a couple of diligent professionals became an incredible lesson for me. This was a lesson about the power of intuition and the importance of trusting in the inner, intuitive voices, which *speak* to each of us if we choose to listen. One might call it wide-awakeness or wakefulness, a state where you are aware of things beyond yourself; a space that I believe is built by a desire to care for another beyond one's self and a desire to make sure that one's actions are grounded in the very best of intention.

The young doctor from the emergency had the intuitiveness to ask me about my medical history and to trust in his instincts that something wasn't quite right with my situation. The ENT specialist had drawn from his experience and listened to his own personal concerns regarding the first pathology that had come back as "inconclusive". He had trusted his feelings that the report may not be accurate and was wide-awake enough to seek another medical opinion. I had recognized the signs that something wasn't right, but, because my ego was telling me that I couldn't possibly have cancer and this disease couldn't be happening to me, I chose to push wide-awakeness or wakefulness aside. That is not to say that one should worry about things in the worst possible light, but, perhaps given the series of headaches and ongoing nasal congestion for four years previous to this

event, I could have been a bit more assertive in seeking out the possible cause of these symptoms with my own family doctor.

As I look back on this part of my cancer journey I realize that it has redefined who I am and has reshaped me as an educator. It has reinforced my desire to be responsive to the *other* and to ensure I seek first to understand. I realize that it is vitally important to not dismiss the smaller stories that are going on around us and to not frame these other stories as insignificant. Instead, I realize that I must always strive to take time to hear the other side of things and to hold off on a quick fix or easy end to a problem. I wish to ensure that those individuals who are in the midst of the situation are provided with a chance to make sense of things for themselves and have opportunity voice to their concerns, perspectives and ideas. The importance of working as a team in pursuit of a better alternative is crucial for success, which in Part 2 of this narrative, is addressed in greater depth.

Part 2 Transformations, Creativity, Caring and Accountability

> *Our Vision: Achieving global impact*
> *Our Mission: Exemplary patient care, research and education*
> *Our Purpose: We are a caring, creative and accountable academic hospital, transforming health care for our patients, our community and the world.*
> *Our Values: * Caring * Excellence * Teamwork * Innovation * Integrity * Leadership * Respect (University Health Network)*

It was three days following my cancer surgery. I lay in the hospital bed reflecting on my journey with this frightening disease. This rare form of bone cancer, chondrosarcoma, resulted in the necessary removal of a large portion of my hard palate. The typical course of treatment following the surgery would have involved insertion of an obturator (a prosthesis used to close the opening left as a result of the removal of bone and tissue), but fortunately for me, my course of treatment was not typical. I was under the care of an innovative and talented surgeon who has transformed the level of patient care, particularly for this form of oral cancer. As I lay there, I heard a familiar voice. I looked up and at the open door of my room stood Dr. Gilbert.

He was dressed in shorts and smiling. This was completely unexpected, since it was a holiday (August 1st) and I had been informed that no doctors would be making rounds today. As he entered the room he asked, "How is my patient doing today?"
I was thrilled to see him and so impressed at the degree of caring he showed, taking time during this holiday (his day off) to make an unscheduled visit. We talked about next steps involved in my recovery and then, during our discussion, something quite magical happened. Like a light bulb going off in my head, I could see the connection between this surgeon's unyielding commitment to patient care, his innovative practice and how these beliefs, actions and way of thinking, needed to somehow be captured and transcended into educational reform. What I realized at that very moment was that I needed to understand why this physician desired to revolutionize patient care and understand what pushed him past the resistance of the *status quo*. I wanted to find a way to connect my understanding of how this surgeon's thinking, passion, commitment and drive could lead

to a framework for how we can make a difference in our schools, organizations, educational institutions.

In our dialogue, it became apparent that Dr Gilbert‘s first priority was enhancing the quality of a patient’s life. He was empowered by the belief that the status quo was not good enough. He believed if one really cares about a patient’s quality of life a better solution needs to be pursued and found. His quest for a better solution unfolded over a period of eight years and within the context of over two thousand surgeries. I asked him how he came to develop this radical method of bone and tissue graft (which utilizes the shoulder blade and muscle) as a new standard of reconstructive surgery for this particular form of maxillofacial cancer. He explained that the previous method of treatment involving prosthesis, which was widely accepted and practiced by most doctors around the world as the standard form of care, did not provide the patient with adequate quality of life. In this standard approach, the patient is left with facial abnormalities that are never fully rectified, since without a replacement of the removed bone, the face literally drops when the obturator or prosthesis is removed. Having been in the position of facing this as my possible reality, I recall the emotion that completely overwhelmed me at the thought of the permanent disfigurement that I would have endured if this standard approach had been utilized.

Dr Gilbert went on to explain that in knowing he needed to develop a bone and tissue graft to replace the removed portion of the jaw and palate he had to keep in mind a bone he could use that had a blood supply so that it would continue to be integral to the body and would survive radiation should this be required as a follow up treatment. He

carefully re-examined the human anatomy searching, in particular, for all the bones with a blood supply that could potentially be used for grafting purposes. In his search, he noticed that the shape of the shoulder blade appeared to closely resemble the shape of the bone in the jaw. To be sure, he made an overlay of the two areas and remarkably, as the two images were superimposed on one another, he discovered they were virtually a perfect fit. The challenge now became how to harvest this bone and tissue and to develop surgical procedures and techniques that would ensure success. Many colleagues were wary and skeptical of this new treatment option, warning him that it was too radical and risky. But, convinced that it could be done, he persevered and innovated treatment protocols and developed procedures that are now world-renowned. As he presents this technique in medical conferences around the world, he is still occasionally greeted with skepticism and doubt, but his record of over two thousand surgeries with a 99% success rate speaks for itself.

Now, as I reflect on this conversation, I see that Dr. Gilbert's frame for thinking and his mindset provides great potential and inspiration as a model for innovation in education and for making a difference in our schools. This story offers us a metaphor that is "morally resonant and contributes to our knowing" (Noddings & Witherell, 1991, p. 1). This narrative of medical innovation, when connected to Freire's theories in *Pedagogy of the Oppressed* (1970), I contend, acts as a frame of reference that can effectively guide and support system change and innovation in education. In order to free the oppressed, Freire proposes that one must problematize one's own life in order to realize that a different status is required and can be achieved. Two stages of this transformation are

proposed. The first stage involves becoming conscious of the reality that the individual lives as an oppressed being subject to the decisions that the oppressors impose; the second refers to the initiative of the oppressed to fight and emancipate themselves from the oppressors. He suggests this approach can come across *limiting situations* that block them, and that these situations are the product of resistance on the part of the oppressing classes to any change in the status they protect. Oppressors fall into the naïve thinking that one should adapt to existing conditions, rather than construct the new and appropriate conditions required by critical thought– the kind of thought that builds spaces and opportunities for liberation and the overturning of oppression through conscious action. Dr. Gilbert problematized the issue of the quality of life for the patient and in so doing, realized that a different status was required and could be realized. The oppressor, in this narrative, is represented by the traditional body of knowledge in the medical profession and particular way of dealing with maxillofacial cancers. The doctors who embraced this traditional way, informed by the current body of knowledge, acted as the oppressors in their attempt to block the initiative because they believed the patients (the oppressed) should adapt to existing conditions (accept the prosthesis) rather than experience new conditions (the bone graft innovation) that would actually liberate them (enhance their quality of life). I contend that in order for innovation to occur, individuals within organizations need to examine the realities in existence, thinking critically about how existing procedures might be oppressing others and, with determination, passion, and drive, initiate emancipation from the oppression as demonstrated by Dr Gilbert and his quest for innovation.

To keep moving forward with innovation, Roger Van Oech, President of Creative Think, a California based consulting firm suggests the following tips in his book *A Whack on the Side of the Head: How You Can Be More Creative (1990):*

- **Be Dissatisfied**- Dissatisfaction can be beneficial to the creative process. Otherwise you lose the prod you need to spot potential problems and opportunities.

- **Map Out Your Plans**- Determine your objective, visualize reaching your objective.

- **Take a Whack At It**- You can't hit a home run unless you step up to the plate. Don't wait for your idea to happen, make it happen.

- **Get Rid of Excuses**- It takes more creativity to get rid of excuses we put in the way than it does to come up with the idea in the first place.

- **Have Something At Stake**- Survival, self-esteem, money, reputation, having something at stake will keep you motivated to make your idea successful.

- **Get Support**- It is easier to be creative if your environment both supports and expects new ideas.

- **Sell, Sell, Sell**- It is not creative unless it sells. Identify what benefits does it provide? What does it promise?

- **Be Courageous**- To fight a bull when you are scared requires courage. Determine what gives you courage to act on your idea.

- **Give Yourself a Deadline**- The ultimate inspiration is the deadline. That's when you have to do what needs to be done.

- **Fight For It**- Two basic rules of life are: 1) change is inevitable; and 2) everybody resists change. Much of the world has its defenses up to keep out new ideas. "The human mind likes a strange idea as little as the body likes a strange protein and resists it with a similar energy" (W.I. Beveridge,) Thus you need to become a warrior and do what's necessary to make your idea a reality. Sometimes this means fighting past the obstacles you encounter.

- **Be Persistent-** Once upon a time, two frogs fell into a bucket of cream. The first frog, seeing that there was no way to get any footing in the white fluid, accepted his fate and drowned. The second frog didn't like that approach. He started thrashing around in the cream and doing whatever he could to stay afloat. After awhile, his churning turned the cream into butter, and he was able to hop out. How persistent are you? (*pp. 169-182)*.

As an extremely successful organization in the forefront of cancer research and cure, the hospitals that are part of the University Health Network and the doctors who are part of this organization embrace most (if not all) of Van Oech's mentioned tips. Dr. Gilbert's innovative and comprehensive approach to treating this form of cancer, I contend, embraces these creativity tips from Van Oech (1990). In the narrative interview with Dr. Gilbert (found in Chapter 4) many aspects of these tips are uncovered. The mindset for innovation as described by Van Oech's tips is echoed within the conclusions in Chapter 5 through the Four Directions of Leadership model that I present as a means to transform our educational systems and institutions. The statement of purpose of the University Health Network (as shared at the beginning of Part 2 of this chapter, p. 31) is grounded in the premise of exemplary care and is reliant on the ability to be creative in order to transform patient health. It lays a foundation or condition ideal for innovation to occur. What needs to be integrally linked with the conditions for innovation, is a collective of individuals within the organization who are not constrained by current realities and are open to seeing things in new ways, seeing the potential first rather than only the drawbacks or risks. I argue that the degree to which innovation can occur in an organization is ultimately dependent on the mindsets and desire of empowered

individuals within organizations and when these individuals are supported by clarity of purpose that is focused on improving the human condition then great achievements are possible.

As I look back on this entire journey with cancer, each stage of my journey brings a new level of awareness to my beliefs as an educator. What I initially perceived as an unimportant and an unfortunate event in fact has turned out to be extremely pivotal and must be reframed as fortunate. It has helped to shape and create my future goals and desires as an educator. I am moving beyond the diagnosis into a new place and space in my life's journey. Through the process of narrative inquiry, by looking back on these experiences seeking new insights about them, I am propelled forward into a new space and place in my life. Upon reflection, I can see that a state of the lack of wide-awakeness and lack of desire to determine what is really going on becomes a roadblock to moving beyond one's current reality. The belief that the nosebleed was "just a nosebleed" reinforced the limiting actions that were taken. The limiting power of this belief held by the walk-in- clinic doctor locked him into his decision about how he would proceed with my care. In *Metaphors We Live By*, Lakoff shares that "Our concepts structure what we perceive, how we get around in the world and how we relate to other people" (1980, p. 3). Based on this understanding, I contend that the clinic doctor's inner concepts structured how he related to me in the presenting situation. Blind acceptance of *what is*, kept me and the walk-in-clinic doctor in a state of maintaining the *status quo* and literally relying on actions such as holding one's nose to get by and through the problem. If we are limited by our concepts of *what is* in education, we cannot be responsive to the

students and communities that we work with. By adopting such a limited view of the world we ignore the uniqueness of the needs of others and supplant them with *my way is the right way* framework, or worse, a *father knows best* mindset. This experience has made me consider how I can be more awake in the moment and to not "drift or act on impulses of expediency" (Greene, 1978, p. 43).

In the second stage of my journey, both the young doctor from the emergency department and the ENT specialist demonstrated the importance of wakefulness and the power of intuition. It has reinforced for me the importance of differentiating between what one thinks is happening and carefully deciphering or determining what is really going on, looking beyond the *what is* with curiosity and a burning desire to find out. If we do this we can make a greater difference and perhaps arrive at the correct diagnosis and ultimately the best treatment plan. But how do we get beyond the diagnosis? The answer for me lies in the final stage of my journey, in the events that followed my cancer surgery. It lies within the conversations that I have had with Dr. Gilbert. I realize from these powerful conversations, the significance of a mindset, particularly one that is based on excellence of care, a focus on improvement and a strong desire for innovation. The combination of excellence of care, desire to innovate, and embracing of creativity, enables significant transformation in our lives and the lives of others, in very powerful and positive ways.

As I move beyond the diagnosis, I arrive in a new and exciting space and place where my life story continues to unfold– a space where I am determined to embrace a mindset that is shaped by curiosity, creativity, innovation, caring and wide-awakeness.

This new space propels me towards seeking better ways to transform our educational systems and institutions with renewed passion and hopefulness.

> *We shall not cease from exploration*
> *And the end of all our exploring*
> *Will be to arrive where we started*
> *And know the place for the first time.* (T.S. Eliot, 1942)

Chapter 3: Redefining the Possible

Chapter 3 is divided into two sections. In Part 1, I share the first case study drawn from my own, personal experience as an educational leader of a culturally diverse elementary school. In Part 2, I share my journey as an arts teacher leader within a school charged with the task of transforming the arts programming and experiences within a particular school. These case studies, as well as the narrative interviews in Chapter 4, lay the foundation and basis for my conclusions presented in Chapter 5. The examples represent diverse fields (school administration, music education, medicine, and art). I contend these varied experiences embody perspectives that actually share many commonalities and intersections. These inform my perspectives regarding the spaces and places in organizations where creativity and innovation might flourish and provide us with the opportunity and basis for moving beyond *what is* in educational systems and organizations.