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PSYCHOLOGICAL ASSOCIATION

When a 25 Year Old Young-Invincible is Diagnosed with Cancer

By Morgan J. Murray, PhD

Introduction to my story:

Being diagnosed with cancer affects everything. As a survivor, I know this personally. One's sense of self and core identity can be called into question. As a psychologist, I work from an existential point of view in which developing an understanding of the experiential world of the patient is central. To understand the experiential world of someone with cancer, it is important to know the person apart from their diagnosis, and then to understand how that vision has been shaken.

I was a 25 years old "young invincible," in 1985 when I was diagnosed with Hodgkin's disease. Young invincible is the label used to describe young healthy people we hope will sign up for Obama Care, so that premiums will remain low, but may not, because, well, they are invincible. Of course "young invincible" is a state of mind, or perspective, not a physical reality. One's state of mind is influenced by who he or she is at a point in time. The point at which a person receives a diagnosis of cancer affects how he or she deals with it. And so it was for me.

As a so called young invincible, I certainly was naïve and immature. I was also optimistic and had drive, and I was something of a risk taker. At age 25, I had a job, I lived with some roommates in Summit, and I was going to graduate school to study psychology at the New

School for Social Research in Manhattan. Things were going well, and it was into this context that I received a cancer diagnosis. Though shaken, my awareness of the life and death reality of my diagnosis was not clear. This limited awareness results from the defensive process of denial. The idea of “being in denial” is often seen in negative terms, but let’s face it, denial helps one manage the sadness and depression that comes with the fear of dying, the fear of not being able to live the life you envisioned for yourself. Mortality is relevant to everyone, but for a patient battling cancer, he or she is confronted with the thing that might end his or her life.

The beginning of the battle and health insurance:

My story actually has a health insurance tie in. You see, by 1985 I had been working at Fair Oaks Hospital (now Summit Oaks) as a mental health associate for three years. I was leaving that job to begin work for a psychiatric day program called Community Psychiatric Institute in Maplewood. Fair Oaks offered to sign me up for COBRA. I learned that COBRA allowed me to pay to extend my health insurance, but it was expensive. I reasoned that my new job had only a three month probationary period before they would provide me with health insurance coverage. Therefore, I could save money by not signing up for COBRA, and just not get sick for three months. Invincibility right?!

So, I started my new job, and one evening I felt a lump near my collar bone. My powers of rationalization and denial can be powerful, but try as I might I could not figure out an “it’s nothing” kind of rational. The lump near my collar bone was a something, and it did not belong. So I made a doctor’s appointment. I did not have a doctor at the time (why would I need one?), so I called the Summit Medical Group and found a doctor that could help me find out what this lump was. The doctor felt the lump and said we need to do a biopsy. “Oh my god,” I remark, “I

have no insurance!” The doctor says, “We are doing the biopsy, we’ll take it as a charity case if we need to.” I left the office and drove across town to Fair Oaks and went into the administrative office and asked if it was too late to sign up for COBRA. No, it is not too late, in fact I had three days to spare!

Biopsy and second opinions:

I had the biopsy and the doctor came to the recovery room and told me, “You have a malignancy.” He called it [Hodgkin’s disease](#). I learned later on that it was a cancer originating from [white blood cells](#) called [lymphocytes](#), and that it was a form of lymphoma that spread through the lymph system moving from lymph node to lymph node. But my immediate reaction was to rationalize. I was in disbelief – my denial went into over-drive. “Is he saying I have cancer or something like cancer?” I mean he called it a “malignancy” and a “disease” but did not use the word cancer. I was waiting for someone to tell me everything was going to be ok.

I was referred to an oncologist at the Summit Medical Group. At the same time, my parents got the name of a doctor at Morristown Memorial Hospital for another opinion, and then a third from someone at Memorial Sloan Kettering in Manhattan. I received optimistic views from each of these three doctors. Current treatments for Hodgkin’s were very successful. They all thought I would be cured. This is what I wanted to hear. It fit the young invincible self-image that I wanted to maintain. There was some disagreement on which chemotherapy regimen would be best, but in the end we went with the recommendation from Sloan Kettering. It was important to me that the treatment take place at the Summit Medical Group, since I lived in Summit and worked in Maplewood. It felt very important to be able to work.

The chemo begins:

The next step was for me to meet with my doctor to learn my treatment plan. I was to receive a cocktail of chemotherapy agents called [MOPP \(Nitrogen Mustard, Oncovin, Prednisone, and Procarbazine\)](#), as well as radiation. I thought that Nitrogen Mustard sounded like a deadly nerve gas. It was scary to think about. I remember that I did not ask many questions, as this made it easier to cope with my fear. I knew others would handle it quite differently, and would need answers to many questions to feel safer. But, given my personality, it was important to try to be stoic. It was the way I coped when so much seemed out of my control.

I learned that treatment would take close to nine months. Chemotherapy would be every other week as long as my blood counts were good, and then I would go through a course of six weeks of radiation, followed by two final months of chemotherapy. My denial weakened as I listened the description of treatment. I steeled myself, “I have to do it.” “Chemo is pretty heavy, but this is curable,” I said to myself.

My doctor continued: people that receive MOPP are at a greater risk for developing leukemia within five years of receiving it. Again, I felt scared, but I remember feeling more numb than scared. Leukemia in my perception was a death sentence. The doctor said it was not a high likelihood but a risk he wanted me to know about. I did not ask for any further details. I held on to his statement, “...not a high likelihood.”

But then he added this (and this was the thing that really got me): “The treatments will make you sterile.” He said, “There is a very high likelihood – a 99% chance that you will be made sterile by this treatment.” My immediate question was, “For how long?” He responded, “Permanently.” He explained to me that chemotherapy had the biggest impact on rapidly dividing cells, like cancer cells, hair, bone marrow, and sperm cells. This really shook me as it

marked the first moment in this whole process when I had to think of a permanent change in my life. I had always planned to have children.

And let's face it, young invincible men are supposed to have sperm! There is a crack in the self-image. It was a direct threat to my masculinity. And by that I mean: What woman was going to want to be in a relationship with someone with no sperm, no fertility, and no genes to pass on to the next generation? What was my status as a man, or as a prospective life partner? I felt devastated. These feelings were flooding my consciousness as I sat in the consultation room discussing the chemotherapy and radiation that would begin by the end of the week.

Now just to be clear, in my mind, it was not a fear of dying at this point – I had been given assurances from some very knowledgeable doctors, so the fear of death was not well formed. The information about being sterile was concrete; it was presented definitely and without a choice, and it affected this sense of youthful invulnerability. I left that meeting with all this swimming in my head. It felt heavy and as though starting chemo would be like crossing a threshold to a life I had never imagined.

I left the meeting with my doctor feeling depressed. I went to visit a friend who was a former oncology nurse. She mentioned cryopreservation of sperm. As simple as that, I felt relief and a way forward. I called my doctor and asked him about it. He said we could delay the treatment for a week, so I would have a chance to store sperm.

My treatment began.

So, I began treatment. There were a lot of things to adjust to, like dealing with nausea on chemo days. The chemotherapy treatments were every other week and I scheduled them for Friday afternoons so it would not conflict with my work schedule. By month 4 of the MOPP

regimen, I began radiation treatment. At first radiation was much easier, but I found the side-effects were cumulative. I did not become nauseous, but it was exhausting.

When I was in the middle of the scheduled course of chemotherapy, the x-ray results indicated that the tumors were responding to treatment. My sense that I would beat this disease was strong. I just had to finish my treatment; that was the major focus for my energy. An equal focus for my energy was keeping my life on track. I wanted to maintain my full time work, my night classes in graduate school, and my social life. At 25 years old, these were all part of establishing my personal independence that was essential to my self-concept.

As I neared the end of my treatment, I began dating Sarah Showalter, who was a friend from college. Having a girlfriend was part of living. And the point of battling cancer is to have time, so we can live.

Remission:

Beating cancer feels good. And life was good. I had a job that I liked, I was in graduate school, and I had a girlfriend.

The CT scan showed that the tumors were gone, with the exception of a small lesion near my heart, but my doctor believed it was scar tissue. I was grateful to my doctors for the successful treatment, and the chance to get on with my life.

Relapse:

Eight weeks after I stopped treatment, I started losing weight. I began having night sweats - soaking sweats. There was so much sweat that not only did I have to change my pj's, but I had to change the sheets as well. I went to see my doctor. He took an x-ray and saw evidence of a large tumor in the center of my chest. I was relapsing.

This was a very traumatic time. My disease was considered more aggressive this time. I remember feeling very frightened, and stunned. I had been in the process of closing this chapter of my life.

I needed to have a biopsy to confirm the disease – to make sure it was Hodgkin's disease and not some other form of cancer. They also wanted to see how close it was to my heart. The surgery this time was much more significant since it was under my rib cage. The biopsy did confirm that it was Hodgkin's, and thankfully that my heart was not involved.

A new round of treatment:

It was very hard to approach the beginning of a new chemotherapy regimen. I learned that these particular medications had the potential to cause heart problems later in life, but I was becoming more accustomed to this kind of trade off. Take something now to beat cancer, even if there are potential long term health consequences.

In the aftermath of my relapse with Hodgkin's disease, I was much more aware of my mortality, and I experienced a low point. The disease was more aggressive now, I had a large tumor in my chest right next to my heart, and I had night sweats that were miserable. I felt sick.

I started to feel the need to withdraw from my relationship. Sarah was supposed to join me to visit my parents, who had rented a place on Nantucket, but I told her I did not think she should come. I would be recuperating from surgery and would not be much fun. What I did not tell her was that I did not think she should be with someone as sick as I was. Internally, I was questioning, who would want to be with me? I questioned my worth in the relationship. I felt like damaged goods. I wanted to retreat.

Psychotherapy:

Luckily, I spoke about this in my own psychotherapy, and thank goodness for good therapists. My therapist told me I could not make such a decision for Sarah. That was her decision. I changed course and asked her to join me on this vacation after all. She was glad that I asked her, and she let me know how hurt she felt when I told her not to come.

Time is Precious:

Up until this time, when I considered my treatment, it was with a sense of, “Let me get the treatment finished, so I can get back to my life.” But now, with the help of therapy and a clearer sense of my mortality, I began to focus on what I wanted in the life I had now, in the uncertain amount of time I had left. This may sound like negative thinking, but it did not feel that way. I had not lost hope, but I could appreciate the stakes of my health crisis more clearly. The time anyone has is uncertain, but with my disease this was brought into sharp focus. Life is that much more precious when we feel the awareness of our mortality. This exchange between David Letterman and Warren Zevon (who at the time had terminal lung cancer) captures a similar feeling:

David Letterman: From your perspective now do you know something about life and death that maybe I don't know?

Warren Zevon: Not unless I know how much you're supposed to enjoy every sandwich. I felt relieved because I knew I wanted Sarah in my life. I loved her, and being with her felt like living. She came with me to Nantucket and we had a great time. I had resolved for myself that I wanted her in my life.

Treatment Round 2:

By the fall of 1986, this second go around of treatment was progressing well and appeared to be working. Treatment was more physically demanding this time around. The

chemotherapy (this time known as [ABVD](#)) and radiation were exhausting, and the impact was cumulative. I was losing my hair.

Integrating the fact of my cancer treatment into my life could be interesting. I remember the first day I wore a wig to work at Community Psychiatric Institute. The patients knew I was getting cancer treatment, but up until now, there had not been much change in me that they could observe (my first time through treatment I did not lose my hair). I sat down at our morning meeting, and several of the patients looked quizzically at me. It was an awkward moment, I was obviously wearing a wig, but we weren't sure what to say to each other. I broke the silence, "I know it's different, I'm still getting used to it also." I felt close to these patients who were also young adults. They were in psychiatric day treatment at crucial times in their lives.

Popping the question:

Finally, the good news started coming that the tumors were shrinking. In spite of all we were going through with my health, my relationship with Sarah was progressing. In October of 1986, I asked her to marry me. I arranged for us to meet with my oncologist first, so he could confirm a positive prognosis. Then I took her to a romantic place and asked her to marry me. She said, "Yes" and we went out to dinner to celebrate our engagement.

Remission again and another second opinion:

I made it through this course of treatment. I had a little bit of hair left, I was physically drained and physically different. I was lighter, not as strong, and I felt very vulnerable. But I was also in remission again and I was engaged to Sarah. Once again the CT scan revealed no tumors, except for that same small lesion near my heart. I was told it was probably left over scar tissue.

My parents wanted me to go for another opinion at Johns Hopkins. I did not see why I should do this. For one thing, I was in remission, but underlying it all, I wanted to feel independent. By now I was 27 years old. My illness had me relying on my parents for the financial resources that enabled me to get second and third opinions. With this reliance, I felt that I was ceding control. In the end, I did agree to go Johns Hopkins, because I was afraid not to take advantage of something that could help me.

I traveled down to the appointment with my parents and Sarah. The meeting was more dramatic than any of us anticipated. The doctor examined me and reviewed my chart and images from recent scans. Then we all met together. The doctor explained that once someone has relapsed, his or her disease is considered resistant to the kind of conventional treatments I had already had. He told me that I would definitely relapse again, and he was recommending that I have a bone marrow transplant right away. It was a very tense consultation room. Sarah left the room for a moment, and my parents looked shell shocked. Surprisingly perhaps, I felt calm. I think the reason was that inside I had already made my decision; I would not have a bone-marrow transplant at this time – not now when I was in remission.

I felt supported in my decision by Sarah. My parents were also supportive, but still wanted another opinion. They wanted to bring me to the University of Pennsylvania to meet with another doctor they had learned about. I told them I did not want another opinion, since I had made my decision. I was adamant, they persisted, but this time they ended up going to this third opinion without me. The doctor told them that my absence from the meeting made it clear I had chosen a course of treatment, so her opinion was not relevant at this point. In this episode, I asserted my right and responsibility to make a decision about my treatment, and my parents were coping with how to help their first born child deal with a life threatening illness. The dance of

independence between children and parents plays out in a multitude of forms in families everywhere. In my case, it was happening in the context of cancer. As much as I valued my independence, there was a part of me that wished that my parents could magically make this all go away.

Planning our wedding:

I was in remission, and we got back into our lives. We were busy planning our August wedding. But then I started feeling pain in my back and in my abdomen. The x-rays and CT scans showed nothing, but the pain increased. It got so bad I could not sleep at night. I would lie for hours in a tub of hot water as the only way I felt relief. My doctor prescribed pain killers, [Demerol](#) at first, and then adding [MS Contin](#). Finally an MRI revealed bulky tumors throughout my lower abdomen and again in my chest. My Hodgkin's was now considered stage 3B, since the tumors were above and below my diaphragm, and I was having what are called B symptoms which are the night sweats. I had advanced Hodgkin's disease. I had never felt so sick and vulnerable in my life.

The doctor at Johns Hopkins had been right. Now I knew I needed the bone marrow transplant. I met with Dr. Subhash Gulati at Sloan Kettering. He had a protocol that was in clinical trial. He currently had 6 patients in the program. I would be the 7th admitted to the trial. Since it appeared there was no disease in my own bone marrow (based on a bone marrow biopsy), I was able to have an autologous bone marrow transplant, that means bone marrow would be harvested from me and stored. Then after a course of intensive chemotherapy, the bone marrow would be put back intravenously to restore my bone marrow function.

But we were in the middle of planning a wedding. The wedding was scheduled for August, but the bone marrow transplant was going to take 6 weeks, from mid-June to the end of

July. We decided to get married in May. I remember our reasoning this way, “If I had the bone marrow transplant in June and July, what kind of shape would I be in for an August wedding?” Unspoken, at least around me, “Would I be alive?” I will always be amazed by Sarah’s courage in this moment, because I knew she was scared. We got married two weeks before I went into the hospital for the bone marrow transplant. Getting married felt like a tremendous victory. I looked like hell (one of my friends said I looked gray), but I was elated.

The Transplant.

The explanation I received going into the bone marrow transplant went something like this: Five percent of people will not survive because of the toxicity of the treatment itself, 5% will not survive due to infection, 5% will not survive because they will not go into remission, the remaining 85% will get through it and be in remission after the procedure. I was scared, as my days of invincibility were long gone. I still had hope, but my two relapses had changed my state of mind. I focused on the task in front of me, quite literally one day at a time. My visitors were limited, because I was so vulnerable to infection. My mother visited often. Sarah came after work. At one point I had to ask my mother to allow more time for Sarah to visit me alone. It was an early, fairly common marital issue playing out in an extraordinary situation.

Over the years I have thought about the level of dependency I experienced over the six weeks of the intensive treatment. I’ll never forget how emotional it felt when I received my bone marrow back. I was skinny and weak. I needed daily blood transfusions of platelets and packed red cells (some donated by siblings), and I required broad spectrum intravenous antibiotics to fight infection when I would get fevers. The bone marrow represented my ability to make my own blood, and to fight infection.

It is now 29 years since my bone marrow transplant, and I have been disease free ever since. I do not believe I survived because of any special personal characteristics or the way I handled things. I know I was fortunate that a medical treatment was found and was available to me that eradicated the cancer from my body. I knew individuals who were going through similar treatment at the same time I was, who did not survive. I remember them and know they wanted more time to live.

Cancer treatment is a very physical experience, but also an emotional and psychological one. I have felt this in myself, and I have witnessed it in others. So much depends on where a person is in life, and how they want to use their time. I have often thought about how different it would be if I became ill now, since death would mean leaving my wife and my young adult children. It would change my focus and priorities away from those of a young man concerned about career, a wedding, and independence.

I realize that time is the most valuable thing we have, and my awareness of this fundamental truth grew over the course of my illness and treatment. It's not that once I was finished with the bone marrow transplant everything was perfect, because life isn't like that. Everyone has ups and downs. In the years since I was in a sustained remission, I would experience the fear of another relapse, such as when I had a sweaty night (which everyone has sometimes). Thankfully, those fears are rare now. But life is never easy, as one balances life's demands. With time, one is given the opportunity to manage all the ups, and downs, and I feel so fortunate to be able to do that. I live with a fuller appreciation of each moment, and this is a gift.

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