

## THE YOUNG PATIENT (PART III)

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Anything connected to her physical being had been problematic so far. She had the stitches removed from the biopsy seven days later; however, she couldn't help but notice a slight swelling at the site of the incision. That night she again had a fever, and pain at the site. In the morning she showed it to her mom who made a face, reminiscent of the same reaction with the lumps. Her mother looked at it, gently touched and pressed against it and as Jennifer grimaced, she announced with a grave voice, "I think the area is infected. It is red, warm and tender."

Jennifer had a complication from the procedure. She now remembered that on the consent form, infection being mentioned as one. Her mom called the surgeon, and he told them to come right over. After an exam he looked at both. "This is most unusual. I haven't had such a complication in the past ten years. You do have a slight infection of the incision site. I will write a prescription for an antibiotic for the next seven days."

Jennifer couldn't help but think that as luck went, were it not for a bad one, she would not have any at all. This infection set the start of the chemo back till it cleared completely. In the throes of a personal maelstrom, she returned to classes. She immediately could tell that the rumor mills had the tongues wagging by the behavior of the cheerleaders. They averted their eyes and when they must, they greeted her wryly. They asked no questions about her absence from the squad, a very telling sign as chatty as they usually are. Although she resented the possibility of answering the same question too many times, it grated on her that nobody asked even once. Alarming it was as if they were either following a consign or had a tacit covenant not to broach a subject they would rather not touch with a ten-foot pole. That left her at times disappointed and occasionally cloyed. At least asking the question meant a minimum of caring. That was just the tip of the iceberg. There was an elephant in the room that she needed to confront.

She most fretted meeting Rich. She was fighting the yin to see him again for the first time since their date and the yen to run away from him because of his cowardice and flippancy since. She kept thinking that that two hearts went on a date and clicked but since then never shall the twain meet and sizzle. It happened far sooner than expected, in the hallway. He was standing there with a few other jocks, "Hi, Jen," he said with a forced smile. He approached her and swiftly landed a kiss on her cheek.

"Sorry, I am in a hurry," she said. The phony peck mixed with a contrived disposition mortified her and left her in a dour mood the rest of the day. The whole episode gifted her with a bitter taste in the mouth. She did not have a STD, nor did she choose to have cancer. It did hurt, no matter how she spun the narrative or pretended his response didn't matter. This buffeted her more than she anticipated. This carried on even when she reached home. She barely ate her dinner. At 9:30 p.m., she hit the sack. What normally turns into a simple and restful matter was anything but. Instead, she visited a tunnel named insomnia, a state of a shower of addled water that sluices the glow off one's aura and splays a mist of dark thoughts. She was on her back in bed, with the lights off except for the luminescent digital clock on the dresser across from her. The stillness of the night coexisted with ho-hum nocturnal sounds inside and outside.

The low-pitch thrum of the refrigerator, that stalls and restarts intermittently, the occasional wispy or loud noise of a fart, the humming sleepers' breathing sounds formed a polyphonous medley. Her siblings were sharing a bunk bed in her bedroom. Their sounds were faint and regular. In the next room, her mom's groaning in bed, louder and somewhat irregular, reminded her of the loud snoring of her late dad. In her younger days and impish way, she used to cleverly describe it

as “the cadence of the release of the fluttering and droning flies in his chest.” Nonetheless, her dad’s snoring meant the presence of an adult male, a sign of security still sorely missed. Her mom’s sonorous rhythm was of higher pitch but not as loud as his ever was. Like a violin versus a tuba. It dawned on her that each person’s breathing pattern and pitch was characteristic.

Various nighttime critters joined in this aural exercise, no matter its contribution to noise pollution. The intermittent revving of car engines would participate in the scrum as it were. Such a motley menu of sound-making actors was there for the taking and offered without any request. This gratis performance came with the proviso of wakefulness, a show not bargained for. As a doldrums participant, she twisted and turned in bed but would not fall asleep. The clock seemed to take forever to change the hour hand. Boredom set in, listlessness amplified, misery conquered. A sleep-deprived brain, bereft of its quotidian succor, snivels, becomes irascible, and the rest of the body bears the brunt of its deficit, a real torture. The last hour she recalled seeing in the clock was 1:30 AM. The whole time being awake, the thought of her relationship or lack of with Rich kept coming to the fore. She decided to take care of and not feel sorry for herself, to disengage from one direction so she can focus on another one.

From then on if Jennifer and Rich crossed paths again, they did not make eye contact. No more phone calls or texts were exchanged. Jennifer went full speed into her treatment for she had her dignity and wanted nobody’s pity. The infection had delayed the start of the chemotherapy but also had given her additional time to confront her situation, ponder about her future. She was a senior and going to college was the next step. Applying to schools was supposed to be a major priority on her scholastic agenda. The circumstances were turning the whole plan upside down. She had to go to talk to her guidance counselor about her options: should she apply now and delay the start of college, or should she wait till after the treatment was finished? She went into the guidance’s office, but her counselor was out on sick leave (word had it she had a serious illness, maybe cancer).

They assigned her to a different counselor, and she had to return the day after. The next day when she came in, she faced a grouchy lady who gave the impression she had awakened from the wrong side of the bed. She listened to Jennifer’s story about her illness and the impending start of treatment and the decision she needed to make about applying now versus later. The counselor sat pensive for a minute and then suddenly after reading her grades, a smile brightened her face.

“You have very good grades, and any college would be happy to have you as a student. I think it is OK to apply now and if the situation arises, you can delay the start of school. At least you will have been accepted and you will have gone through the motion of applying and getting into school. Often when students delay applying, it takes forever to get into the groove of getting back to school. My recommendation to you my dear, do apply now. As a matter of fact, on your application essay, do mention the fact that you are going through this illness.”

Jennifer felt reassured; she wondered why the counselor had that initial demeanor. Her advice did make sense. As a student she needed letters of recommendation from her teachers and getting them while in school was the best time to get it done. She felt optimistic and started considering her major in college only to have a dark reminder that she was a sick person and may not even last to go to college. She rushed to the bathroom to sob. She couldn’t help it. Every now and then the notion of being sick was overwhelming and took over. It was a strange feeling and one she couldn’t get used to. She was crying and her best friend, Arlene, who was in the bathroom approached her and gave her a hug.

“Oh, I am sorry, I did not know you were here,” said Jennifer.

“What is going on, Jen, you don’t talk much lately. Exactly what is going on with you?”

“What do you care?”

“This is mean. I am your friend, why can't you tell me what is going on? I try to call but you don't pick up. You can trust me. You should know that.”

Jennifer thought for an instant. In fact, she and Arlene have always been the best of friends and the one person she could confide to. She let out a sigh.

“OK, this is the story. After I found out that I have the cancer called Hodgkin's disease, the fact that I hadn't heard from Rich and having a complication from the biopsy have been very depressing. So, for the past few days, I stopped calling and talking to people. This disease involves my lymph nodes. I am supposed to start chemotherapy followed by radiation. The whole thing bugs me, and I can't cope with it at times. Most of the students have given me the cold shoulder and I have decided to be by myself.”

“Oh my, this is horrible. But you know what, a second cousin of mine had the same thing and he was treated, and he has been doing fine since. This was 5 years ago. I am sure you will be alright also. OK, Jen, remember we are supposed to be here for one another.” These words of encouragement meant the world to her. At least someone else had this and has been doing OK. Maybe she will also be fine.

“OK, 'Lene, you are right. But do me a favor. Do not let the world know about this, promised?”

“Of course, it is a promise. You do know I do not discuss our personal matters with other people.”

They hugged each other and left the bathroom together. Jennifer felt relieved to have someone else to share the tragedy with. Arlene was someone she could count on. People were not all mean and this was a good thing. This was day seven of her antibiotic treatment and the swelling, pain and redness have all gone away. The next and main hurdle was to go back to the oncologist and then get the chemotherapy started. The word itself was dreadful. An appointment was set with him in one week. Her chest turned into a racetrack just thinking about the condition, the treatment, the possible complications, and the fact she seemed to be prone to have them. Every now and then she still felt misty. The crying spells occurred less frequently but they did recur all the same. Jennifer went back to read about the disease and by now she was familiar with the main features: it was staged, and the more nodes found, the more severe the condition. Hers was pretty much localized to one area, one side above the diaphragm. The next step was to go over the agents for chemotherapy and review the side effects and take the time to discuss them with the oncologist. She has made up her mind to not start the chemotherapy until she was comfortable with the plan in place. She has come up with evidence in the literature that the treatment can cause cancer down the road as well as other damage. This was cause for second thought. She had a lot on her plate, and she still had to get used to the idea that she had cancer.

She went to sleep early that night and she cried and cried incessantly; the same thought kept coming back: “why me?” Her mom had to work late to make up for the time she had taken off. Jennifer had no immediate support but the softness of her pillow against her face to console her. Her siblings were hard sleepers and would keep on sleeping at the sound of thunder. Moral support from a boyfriend would be very helpful. She had no such luck. Rich begged off. He was just a jock, and she probably was one more conquest, good riddance. A hollow sensation ran through her body; she had a headache. She finally fell asleep. A few hours later, she awoke with a nightmare: she saw herself falling off a cliff and screaming all the way down. By then her mom had come in from work and she heard the shrill sound and came over. Jennifer was not having an easy time with this condition. She liked to be in control and so far it was slipping. Then again how

was she supposed to feel about being sick with cancer? Her mom wrapped her arms around her and they both prayed. This seemed to calm her down. She went back to sleep and this time for good, till she woke up in the morning. Jennifer resumed her regular phone conversations with Arlene. She found her to be a good support. Psychologically it made it that much easier for her to deal with the condition. The day of the appointment with the oncologist, Dr. Gregory, she felt jumpy, not quite sure what to expect. What she did have were lot of questions for him.

“Dr. Gregory, I am concerned about infertility, secondary cancer and any untoward reactions of the treatment.”

“Well, this is perfectly understandable. Considering your age, it is a factor one needs to consider. Radiation therapy is a necessary evil. If chemotherapy is given alone, then the chances of recurrence of the disease are higher. As it stands, the only way to avoid it is if you absolutely refuse it. However, each approach has its plus and down sides. If you get a very intense treatment, it reduces your risk of recurrence, but it increases potential side effects. Avoiding radiation is milder treatment but carries the higher risk of recurrence. I will give you the list of the agents, their known complications and I will also give you a list of recommended measures to be taken to minimize complications. Bear in mind that some complications can occur out of the blue. Before we start the chemotherapy, a special tubing needs to be inserted so it will be used as access site to administer the drugs. Veins on the forearms will be destroyed if used for infusion. Also remember that the patient directed support group meets once a week. It operates without interference on my part. I strongly suggest you join it for your own good.”

Jennifer found out the special tubing was to be inserted by the same surgeon who did the biopsy. At first this sent shivers down her spine. Words of reassurance, from her mom came.

“I checked the surgeon out and everybody calls him outstanding. I don't have any doubt about his ability to do the procedure.”

Since her mom always had her back covered, that settled the issue. From time to time she wondered whether the disease could spontaneously regress and go away, never to come back. She knew she would not be so lucky. Still the idea kept coming back to her. It never hurts to hope; losing hope was like the kiss of death. A sinking feeling in her chest accompanied the idea of death. She was most definitely not ready, capable, comfortable with entertaining the possibility of the notion of death. It was bad enough she had to get accustomed to being sick, but death!

While in the car with her mom on the way back home, she was not paying attention to the radio, the news or the music being played even though her mom had it set on her favorite station. She kept thinking about all of the above and she again felt sad. The same question kept haunting her: why me? In fact, why did people get sick? This million-dollar question made her ponder about life, and our ephemeral tenure on this planet.

She was still in this state of daydreaming when they both arrived at home. Her mom could tell from Jennifer's expression that she was having a down period. She gave her a big smile and a hug. “OK honey bunch, I will make you the best mac and cheese with prime ribs or beef teriyaki. I know you like them. Take your pick,” said her mom with the sweetest tone of the voice. Ordinarily Jennifer would jump at this opportunity of feasting. Today was not one of them. Her heart was not into celebration. In fact, lately she has been feeling tired of living, tired of facing a dreadful disease when all she wanted was to be a happy young teen. In a sense, she did not blame her peers because she was very uncomfortable with her diagnosis. Her mom will not take no for an answer. She knew Jennifer really well. “OK, I will get going and make the macaroni and cheese along with some spicy teriyaki steak. I will make sure we include some dessert either some

cheesecake or peach cobbler with dulce de leche ice cream. Come on, you know you will enjoy it. Let me get going and come and join whenever you are ready.”

The last few words were mom speak to ask her for her participation. She usually didn't ask for help directly but kindly suggested that it would be most welcomed. Jennifer as a rule always felt obligated to chip in. Her mom worked hard, was the sole provider and she as the eldest; *noblesse oblige*, she felt compelled to lighten her mom's load. Her mom also knew from experience this was quality time with Jennifer. This was the time they could chat about anything and everything. Once Jenny got going, there was no stopping her. At least this one time she hoped the trick will work. Jenny was so down that she went straight to her bed. She again began to sob. Her mom was at a loss. She hasn't seen Jenny in this state since the loss of her dad a few years ago. She knew this was a big deal for Jenny to pass up a chance to help with the cooking, especially if it involved her favorite dish. She decided to try anything to cheer up. She opened the door.

“Baby darling, you and I have a lot of living to do. We have to see this through. I am hurting just as much as you. However, we have the other kids to help and we can't give up. Please honey come and join, pretty please, with sugar and lemon on top.”

Jennifer could hardly resist this invitation. She loved her mom a lot and found it hard to say no to her. Besides, her younger sister Anne and brother Art became very sad when Jen their idol was crying, which she has been doing a lot lately. As a matter of fact, Art did ask her yesterday why she cried so often. Thinking about Anne, Art and her mom, she decided to get up with a heavy heart and join her mom. Little by little her mood changed and before long she and her mom were engaged in small talk about the latest gossip at work: a young nurse was found in a compromising position in a room with a young doctor and the news spread like wildfire. They both giggled about it and then they proceeded to have their mom-and-daughter-talkathon.

Jen, her mother, Anne, Art all had a delicious dinner and then had some warm peach cobbler with ice cream for dessert. Jennifer was fast becoming a very good cook, rivaling her mom's skills. Cooking together, sharing a meal evolves into a communion of the minds and souls and seals the bonds among beings as a rule. In this family the kitchen was the center of gravity. It was where everything was debated, where the family got together and where the focal point of attraction resided. The mom decided after the meal to have a powwow.

“As you all know Jennifer has this condition that is making her sick. It is hard on her and hard on me and in fact hard on all of us. She is fortunate in the sense she has all of us to support her. She also has the good luck that the disease seems to have been caught in its early stage and she stands a good chance of being cured. We went to see the doctor today and she will start chemotherapy soon. What it means is that she will be given some powerful medications to destroy the bad cells and unfortunately some good ones in her body. That very fact can take a toll on her body and at times she may feel sick. I expect all of you to be kind and help whenever necessary. Being sick is something a lot of times we can't control. What we can control is how we react to it. Having a good family to support you during an illness can make a big difference. I see it all the time at the hospital where I work. Patients who have relatives who come to visit all the time are treated differently and fare better. We are her backbone. Remember that during your dad's illness I explained to you even though you were much younger that staying together as a unit was most important. Now is no different. Let's all join our hands together in unison and let's bow our heads down and ask the supreme being for his blessing and protection. We must remain strong. Jenny we love you and are with you the whole way.”

With this her mom gives her a hug and they shed tears of love, fear, sadness for they knew all too well that disaster might be looming. Anne and Art joined too and everybody cried together

for a minute. Jennifer then broke the cycle. “This is the last time I will shed tears over this matter. I have resigned myself about the fact I have an illness. I did not choose it. People get sick and that is a fact of life. I thank each one of you for the support offered. I will instead concentrate my efforts on the treatment at hand. I will for sure participate in the patients' support group. I want to give this all I have. If I fail, it will not be because of lack of trying. Now let's play some scrabble.”

And on the family went with the rest of the evening spent playing scrabble, forgetting the illness and concentrating on living, enjoying life to its fullest extent. Try as she might, Jennifer's mind always harkened back to her days of good health; however, she wanted to move forward in a different way. She wanted to have as many days as possible like this one, affording her a positive outlook on her situation. In fact, she was committed to fight the disease so she could go on living, enjoying the company of her loved ones: her mom, her sister and brother. Before going to sleep, she gave a call to her best friend Arlene and they chatted happily. On her way to sleep she made the resolution to remain upbeat and be ready for whatever came her way. She had a good night sleep unencumbered by bad dreams or nightmares.

She did attend a meeting of the support group. She was surprised to see two teens. People ranged in age from the teens to the older set. It was a good experience. The participants talked to each other about their condition, their experience with a given treatment protocol and the result so far. They talked about the side effects of different medications, where to find information to do further research. It was a trove of nuggets from a patient's point of view. The average person attending was very literate and everybody was upbeat about facing their condition. Each one agreed that the simultaneous use of supplements alleviated quite a bit of the unpleasant symptoms of the chemo. Several supplements seemed to come up again and again, the B vitamins to protect the nerves and other cells from the action against DNA by some agents, L-glutamine as a source of nourishment for the GI tract, the use of a diet with plenty of green, leafy vegetables, avoidance of animal fats and sweets.

In fact, sweets were named as a culprit of the highest order; a new fact she learned was that malignant cells fed on sugar a lot. Several patients reminded the group to always check which IV was used during any hospital stay; always avoid D5W which was a solution of sugar. If anything needed to be kept in the back of one's mind, it was the following: do not let sugar into the system as much as possible. She thought immediately about the nice dessert she had not too long ago and realized that she had to make some significant changes in her regimen. A second fact that people in the group reported was that the underlying health of a patient made all the difference in the outcome of the chemo treatment.

Having a baseline of good health, having good habits such as regularly exercising, eating properly made a hell of a difference; finally, having a good mental predisposition did also make a difference. In just one session, Jennifer got an earful of information firsthand. She felt rejuvenated and decided that this meeting was therapeutic at all levels: it was truly a support group from people with similar situations and sharing useful information, it was also psychologically therapeutic and attending a session gave the soul an uplift. Now she realized why the oncologist was so adamant about her attending the session. She began to have a good feeling about his clinical acumen. She was already impressed with his bedside manners. Several of the participants made the same observation: he was a good, attentive clinician and well respected by his peers. Jennifer felt that this could bring good karma. An open-minded, attentive clinician with good bedside manners was what the doctor ordered, so to speak. For the first time since she had received the bad news about her condition, she was feeling upbeat. She couldn't wait to get home and discuss her findings with her mom.

She was on her way home on the bus when her phone rang, and it was the last person on earth she expected to hear from: Rich! (To continue).