

The Dark Side of the Purple Heart

Ring Ring Ring..... The hospital phone calls to me. I have trouble grabbing the phone; I am connected to the Intravenous pole. Finally, I hear a voice on the other end.

"Hello? Simone, guess what's on TV today?" My friend Sarah asked, stressed, to tell me in time.

"I know... the *O.C.*" I said, with little enthusiasm. Sarah, a teenage girl, doesn't know, but I am at the hospital getting a type of chemotherapy for my consolidation phase of my cancer treatment. I cannot watch the *O.C.* in the hospital because in Children's Hospital all possible shows with violence or sexuality are blocked. Instead I am stuck with Sesame Street, Disney or the food channel.

"Oh my gosh, you have to watch it! It is going to be such a good one, I think Melissa and Ryan finally get back together, or something like that." Sarah said excitedly. My eyes focus on the television in front of me. "I am a teenager, and it would be nice to watch the *O.C.*" I think to myself, "I wish I could watch the *O.C.* with my group of friends, huddled up together with popcorn, laughing and crying over the drama." Instead, I am bored, barely able to walk to the bathroom, connected to an I.V. pole, chemotherapy dripping quietly to a steady beat, so perfectly into my veins.

"I'll watch it tonight," I lie, trying not to show my sad emotions. "Thanks for calling."

Why does Children's hospital not have any television programs for teens, so teens

can watch the shows that are popular with their peers? Teens with cancer feel disconnected from the whole teen world because they cannot do simple things such as watch a TV show, spend time with friends or attend a concert. When people visit, they must wash their hands because if the patient catches a cold, their immune system is so low, they could die. Having cancer at any age is hard, but having cancer as a teen is like being a rose bud that can never blossom. Adults with cancer have more support and are often more mature to handle the pressure associated with cancer. Through my experience with cancer I noticed teens with cancer lacked support, and I wondered does support for adults and teens with cancer differ?

Anyone going through cancer treatment must understand the terms and vocabulary associated. Hemoglobin, a word used all the time during cancer treatment, is the red blood cell count that carries oxygen throughout the body (Keene 456). Leukemia is especially based on the blood cells swarming in ones body. The white blood cells fight cells programmed to take away all bad cells that try to enter or have entered the body. For example, if one gets a cold, the white blood cells fight to get rid of bacteria caused by the cold. "The white blood cell count specifically ANC, the absolute neutrophil count, indicates the ability for a child to fight infection" (Keene 215). The ANC is normally in the range of five thousand to ten thousand. However, a cancer patient can fight off infections if their ANC count is between five hundred to one thousand (Keene 216). After treatment, it takes over five years for a patient to get back to a regular ANC count. When the ANC is at a 0 it can be good, because the chemotherapy is doing its job of knocking out all the blood cells, even the good cells, unfortunately it can also be deadly if the patient is exposed to germs, the cold or flu. could be very deadly, which is why it is safer

for the patient to be in an indoor environment as much as possible during treatment.

Chemotherapy is a drug to combat cancer that poisons the inside and outside of the body. Chemo causes severe side effects, such as nausea, tiredness, depression, hair loss, and overall weakness (Keene 173). Leukemia treatment for children takes about two and a half years. "Acute Leukemia is the most common childhood cancer; approximately 3,500 children are diagnosed each year in the United States," (Keene 16). During Leukemia treatment, the first year is overwhelming with many, many chemotherapy treatments. The last year and a half, a patient must take chemo pills everyday, a heavier dose of chemo pills once a week, liquid chemo through I.V once a month, and a spinal tap of chemo therapy once every other month. In-between chemotherapy treatments a patient, must have many blood transfusions because chemo dries the body of all the blood counts (Keene 19). Hemoglobin transfusions take up to four hours while blood platelet transfusions take an hour. The transfusions just add to the long treatment and require more hospital visits. A leukemia patient goes to the hospital at least three to four times a week for a year. To help patients get through all of the trauma and unbearable pain, there are support groups to help teens and families cope (Woznick 23).

The Leukemia Lymphoma Society supports all people with Leukemia and Lymphoma by raising money for research and helping individuals cope with cancer (leukemia-lymphoma.org). The Woman's NIKE marathon is geared toward women who will run a marathon in support of someone they know who has cancer. The Wellness Community Center is another very helpful support group for people who have cancer. The Wellness Community has programs to help patients get a better understanding of

their treatment or who need to talk about their problems, but most of their events are for adults. Support groups are mainly geared toward helping adults return to work and coping with their family lives. (thewellnesscommunity.org). There are so many cancer support groups for adults, but not enough for teenagers. The Wellness Community offers Pilates, Yoga, Chi Kung, Dream Tending and other adult activities. One of the Wellness Community's events is Kids Circle and Teen Talk, for teens and kids whose parents have cancer. "This program is for families with school-age children when a parent has cancer" (wellness community). This is effective for teens and kids who need help with a parent, but what about the actual teen who has an illness? Unfortunately, no programs focus on teenagers going through treatment and the faces of all the people on the website are adults.

The Wellness Community does have Grouploop.org for teenagers. The website has bulletins and chat rooms and features information on the type of cancer one teenager might have. At the top of the Grouploop website, "Teens. Talk. Cancer. Online." is advertised. This means teenagers with cancer can talk online to each other about cancer. The website helps teens to get outside of the parenting world. Parents help the teenager go through the cancer treatment, so parents have a huge responsibility and a bigger role in the teens life while going through the treatment "Parents can help by being understanding and sensitive to a teenager's concerns" (Woznick 69). Parents play a big part in a teenager's cancer treatment and their reactions can affect everything. I know what it is like for a teen to experience cancer, so I interviewed Sally Hirst, an adult survivor, for another perspective. I met Sally in Davis on a cold and cloudy day. When I walked into Mrs. Hirst's house she greeted me with a great big hug and a how are you doing? Mrs.

Hirst has shortish dark brown wavy hair, no shoes, and a bright welcoming smile. We sat at the kitchen counter and talked about her cancer treatment experience. My burning question was what was the worst part of her treatment. Sally quickly responded, "Oh, loosing my hair" Hirst told me. The worst part of her treatment was loosing her hair because she felt she lost her physical beauty, even though she could walk around and do other activities. "I was lucky that I wasn't that sick until the very end, it wasn't until the last doses of chemo that I could really feel it, but for some reason, having no hair made me really self-conscious." Mrs. Hirst's had a hard time getting out of bed and getting ready for the day, but she had to take care of her son who had to get going for school every weekday and fun activites during the weekend. "I had to take care of my son Aaron because he was a little boy." I asked her if there were enough support groups for her breast cancer. She said, "Yes, very much so." Mrs. Hirst mentioned that there was enough cancer support for her. The support group Mrs. Hirst favored the most was the Breast Cancer support group. Mrs. Hirst liked how the Breast Cancer support group had so many activities and walks to support patients to promote breast cancer awareness.

Next interview was with a good friend Kate McGrath, who went through cancer treatment at the same time as myself. We met in downtown Danville at the restaurant *Father Natures*. It was a nice day out, a perfect day for a nice reunion with Kate. She wore a nice skirt and top, her hair was full with curls and her shoes had a little heel. Kate welcomed me with a big smile and hug. Kate is a teen cancer survivor that went through leukemia from the age fifteen to seventeen and is currently attends Stanford University. I asked Kate if there were any support groups for teenagers and she replied, "None for

teens per say, but volunteering for the Leukemia/Lymphoma relay for life and planning for meetings really helped me to change the cancer into a positive experience. This turned my experience into one I could control instead of it controlling me." During Kate's treatment she wanted to be in control of something, so helping out for the Leukemia/Lymphoma society really helped her cope and get through her treatment with a more positive spin. One of the most difficult parts of going through cancer treatment while being a teenager, is simultaneously going through the whole high school experience. "I didn't go to school." Kate was so sick she couldn't go to school for over a year; it was hard for her to get her strength back and to finally have the courage to go back to school. She loves school, so even though she was sick, she was willing to go. "I wanted to take classes that home school teachers didn't offer. One of the reasons why I couldn't go to school was because my blood counts were too low." Kate wanted so badly to go to school and see her friends to experience a "normal" teenage high school experience. "I wore a bandana while I went to classes to cover my bald head, I was tired, nauseous, and couldn't really focus in any of my classes. I even went to school after L.P's, (L.P's are Lumbar Punctures which is a shot up one's spine injected with chemotherapy) I really liked school, and I really wanted to eat lunch with friends." Kate even went to school after getting chemo because she was so desperate to just go out and try to live a normal life. Even with her puffy cheeks and bald head, she kept going strong. Because of her fragility, Kate couldn't do some physical things that she wished she wished she could do. "Cancer affected my ability to do contact sports. I couldn't wear heels for that long, because of a huge amount of joint pain and I really wanted to do exercises and other things." Instead, Kate, like many patients, sat and watched the Food Network Channel.

There are several horrific reasons being a teenager and going through cancer treatment is hell. Kate had no control of her own life and other small things, such as going to the bathroom or being able to write on a piece of paper. "Cancer made me realize I don't have control over what I want to have control over, no matter what the situation. There will always be choices, and choices are what makes you a person."

Taking a walk to burn calories or being comfy and watching T.V are things most people take for granted, but Kate never will. Choices, are what makes a person human. "I just wanted to be normal, but I couldn't remember what it was like, having friends, and going to school. Cancer affected my health because I didn't know and couldn't remember what it felt like to be healthy. Most teens have trouble figuring out life and how to be "normal," but when the teen faces a life threatening illness, a persons perspective on what normal is changes. The perfect image of being normal to cancer patients is going to high school and being able to walk. For normal teens it is to have the perfect body, to get the perfect boyfriend/girlfriend, to get straight A's and to go to a perfect college. Every person and teenager has an image of what is perfect, or what is normal. To help teenagers get through cancer treatment there needs to be support groups to show teens with cancer that they are not alone; there are other teens who understand.

There are only a handful of programs to help teen cancer patients with school and for teens to chat with other teens. Currently, cancer fundraising groups are using the internet to develop internet chat rooms for teenagers so they can share their experiences with each other. The internet is a great source for teenagers in order to have conversations with others during treatment. Leigh Woznick, author of a book to help young people cope with cancer wrote, that Internet chat rooms are a good way for teenagers with cancer to

pass along information, without intruding on "private space" and allowing teens to decide what he or she will do with the information (69). Internet chat rooms are good for teenagers because teens can research good information. AOL Instant Messenger or through email is a common way teenagers chat now a days. Grouploop.org is a good start for teenagers with cancer, to get access to hundreds and hundreds of cancer survivors and many patients still in treatment. Teenagers go through so much in high school and just figuring out life at such an age, having to become dependent at an age where you start to become independent is difficult. Many teenagers meet people across the county with the same cancer and make new life long friends. Support for teens with cancer makes a difference for teen by helping them get though their awful rollercoaster ride.

Another support group that helps teens, but is not specifically for teens is the Leukemia Lymphoma Society. A teenager can be an "Honoree" or be a spokesperson for LLS by speaking at high schools and other public areas to promote cancer awareness. The LLS advertises by hanging posters in cities, hospitals or at fun fundraisers. Yearly, the LLS holds the Light the Night Walk which is a fundraising event held in early October in Walnut Creek. A block of the small town is covered with light up balloons; cancer survivors get white balloons while family and friends get red balloons. The Light the Night Walk is for children and adults, affected by cancer and it promotes awareness to the community. In just an hour, the street looks like a lit up blood stream with a few white blood cells. While this fundraiser is very appropriate, the focus is not on teens, the main focus is on adults and children. There are only a small number of teenagers, and not all teenagers can come because they are so sick. Also, many teens who lack support just want to get through the cancer treatment and forget they ever had cancer. It is unhealthy

to go through something so life threatening which has had such a huge impact on life to just forget about it. The young cancer survivors should show and share their accomplishments; they experience something most people will never understand in a life time.

I walk to the bathroom to see what I look like. I have not had the nerve to face the mirror in several months. I look down and wait until the right moment. I am sad and depressed; this is the worst day of my life. All I really want to do is see a group of my friends at a birthday party. My ANC counts are high enough to go, but my physical and emotional self cannot. I finally take the chance and look in the mirror. There, right in front of me, is a puffy face, that I barely recognize. There are no eyebrows, no eyelashes, and no long auburn curls. The head is completely bald. I stare deeper into the mirror, tears stream down my cheeks; I shouldn't have looked. Why am I punishing myself? With a closer look, I see one eyelash. With a shaking arm, I lift my hand and arm and very carefully put mascara on that one "soldier" eyelash. The blush brush paints my bloated cheeks pink. I try to smile, but I am more depressed. I go to the party with mascara on one eyelash, my friends circle around me wearing make up, showing off their toned legs, arms, and large busts. I am only ugly and weak barely able to stand. I want to be a "normal teenager." Life is unfair.

This paper brought back a plethora of memories and emotions about teenagers with cancer. I have a passion for teenagers with cancer. Teens need to be noticed and need to speak for themselves as loudly as they can. I learned the most in this paper by interviewing Kate McGrath and Sally Hirst. Sally Hirst, the adult cancer survivor did not have much to say about her cancer treatment; her answers were a few words at best, while Kate McGrath,

the teenage cancer survivor, spoke volumes about her experience. Kate was more open than Hirst. She seemed shy and quiet about her experience while Kate understood the importance of the cancer in her life. I feel as though more teens need to speak out about their illness, so there would be more support for teens with cancer. We teens need so much help and understanding to get through this difficult time because cancer is difficult, but just being a teen can sometimes be even more difficult. I learned in my question that there is not enough teen support for teenagers with cancer. There are more cancer support groups for adults than there is for teenagers. With more teen organizations, teens will cope and understand what is happening to their bodies better and become more successful adults. When a teenager finishes their treatment, the doctor will give them a purple heart glass bead to signify the completion of their treatment. This purple heart represents winning the battle against cancer.

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