

ON A SCALE OF  
**1 to 10**  
HOW MUCH  
DOES IT HURT?

A Book for Teens and Young Adults with Cancer  
by Teens and Young Adults with Cancer:

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## DEDICATION



**Jacob (Jake) Wetchler**

This booklet is dedicated to Jacob Wetchler. He was a valuable member of our writing team who enjoyed his life to the fullest. Jake had a wonderful sense of humor and fought his cancer vigorously. Though cancer took his life, it never touched his spirit. Jake was an inspiration to all of us, and we will always remember him.

*Though we did not decide to use direct quotes until after Jake died, he was a major contributor, and his contributions are throughout the work.*

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## On a Scale of One to Ten, How Much Does It Hurt?

**You are not alone.** We are a group of teens who all went through what you are going through right now. We didn't all have the same kind of cancer, but we all know how it feels to be confused and worried, and we have all gone through some kind of cancer treatment. We hope this booklet helps you get through the tough times.

When you are diagnosed with cancer, you are thrown into dealing with a lot of grownup issues very quickly. When we first heard the word "cancer" we were overwhelmed. The first thing that came to our minds was that we were going to die. But we found out that most childhood cancers are curable. Don't be afraid to ask the question. We also thought that this was going to be the worst thing that could happen. There were times that dealing with cancer and treatment was very hard, but there were also times when it was very different from what we expected. Sometimes it was not so bad. We also learned that there were good things that came from it.

### WHAT IS CANCER?

All parts of our bodies are made of cells. Cancer is what happens when cells somewhere in the body begin to grow abnormally and cannot do the job they are meant to do. Our bodies produce billions of cells a day. Some of these cells are abnormal and are destroyed. However, sometimes these abnormal cells avoid being destroyed and continue to grow abnormally and reproduce. This is called cancer. Usually cancer cells reproduce faster than healthy cells.

Scientists do not know what causes most cancers. They know that exposure to very high levels of radiation can cause cancer. Smoking is known to cause lung cancer in some adults. However, most cancers do not have a clear known cause. **There is nothing you did to cause this to happen and nothing you could have done to prevent it.** If you are worrying that you might have done something to cause your cancer, talk to your doctor.

**Categories of cancer:** Types of cancer fall into 2 major categories.

**Solid cancer:** This is an abnormal mass (tumor) that contains malignant (cancer) cells. The type of cells found gives a particular cancer its name. These cancers can be in many places in the body.

**Systemic (liquid) cancer:** This type of cancer is in a system in the body. There are two main kinds.

A. **Leukemia.** Blood cells are produced in the bone marrow, which is found throughout the body in the center of our bones. Leukemia happens when one of the white blood cells develops as a cancer. There are several types of leukemia.

B. **Lymphomas** (again there are several types) are cancers of the lymph system, which is part of the immune system that helps fight infections. A solid mass is frequently found in lymphomas.

## TESTS & PROCEDURES

You have probably had a lot of tests leading up to your diagnosis. You will probably have more tests and procedures during your treatment. This section gives a brief overview of what some of these tests are for. The tests and procedures that you have depend on what diagnosis is suspected. You will not have all of the things described.

**Blood Tests.** A lot of information can be gotten from blood. Blood tests are done to see how various organs of the body are working. Blood cell production is affected by chemotherapy and must be checked frequently. Blood is removed from a vein or through a finger prick.

Some of us liked a finger stick better than taking blood from the arm, and others preferred the arm draw. If you have a central line, blood may be taken from it. Blood tests are also done to check how other organs in your body are functioning.

**Hannah:** “I didn’t like that thing (tourniquet) they put around your arm. Sometimes they miss the vein, but they can always get blood from the finger. And I think it hurts more.”

**Libby:** “Well, I have really crappy veins in my arm, so I like the finger stick better.”

There are times when you have a choice of how the blood is drawn and others when you do not have a choice.

**Biopsy.** When doctors suspect cancer, they may perform a

biopsy. A biopsy is when a small piece of tissue is removed from a place where it is suspected cancer may be and examined under the microscope to confirm or disprove a diagnosis of cancer. If cancer is found, it will determine what kind of cancer you have. A biopsy is sometimes done with general anesthesia but may be done with a local anesthesia (numbing medicine) if the tissue being removed is close to the surface.

**Bone Marrow Aspirate and Biopsy.** Bone marrow is the sponge like substance inside the bone that produces blood cells. For the bone marrow aspirate, you are usually sedated, and a special needle is put into the bone (usually the hip bone but can be in the front of the pelvic bone or the breast bone) and a small amount of bone marrow is pulled out through a syringe. The bone marrow biopsy uses a different kind of needle that can remove a small piece of bone. Both of these procedures are used to see if there are cancer cells present. This test is usually done when leukemia is suspected and often when lymphoma is suspected.

**Spinal tap (also called a lumbar puncture or LP).** For this procedure, a special needle is inserted into the space between the bones of the spine, and spinal fluid is removed and examined for cancer cells. Your back must be curved for this procedure, so you may be lying curled up on your side or sitting up bent over. If required, chemotherapy is administered through the same needle. In cancer, spinal taps are done for those cancers in which cancer cells can go to the central nervous system or those in which the cancer involves the central nervous system. Many patients receive sedation for this test.

**Sedation.** Sedation uses medicines that relax you or make you sleepy. Conscious sedation helps you feel very relaxed but does not usually put you to sleep. It may be used in combination with another medicine that helps you forget the procedure.

General anesthesia is sedation that puts you completely to sleep. You will not feel or remember anything and will wake when the procedure is over. A mask or IV medication may be used to get you to sleep.

Conscious sedation is often used for spinal taps.

**Hannah:** “I remember the first time I got a spinal tap and I was fighting all the sleeping stuff. I remember being loopy with the

pulse monitor on my finger. I kept looking at the light and my dad said: 'She's not asleep yet.', and they said, 'It's all right. She's too out of it. Don't worry.' "

**Kevin:** "I remember when I was having a spinal tap and they didn't give me enough stuff. I was too awake when they were doing it, and I was freaking out because I was awake. I still remember that moment. All I remember is squeezing my dad's hand. That's the only time I remember it.

## SCANS

Scans use different methods to take pictures of parts of the body. In oncology, they are used to determine if cancer is evident, its location, and whether it involves surrounding tissue. Sometimes contrast (dye) is used, given by IV or swallowed, to improve the view. Other times it is not needed. Scans can also be used to detect other medical problems, like infection.

### **The most common scans are:**

**CT (computerized axial tomography) scan.** A CT (pronounced cat) scan uses x-rays to take cross-sectional pictures of the body... You are on a narrow table that goes through what looks like a donut. It is like going through a large donut hole while you are lying on a bed. The test is not painful, but lying still for a long time can be uncomfortable.

**Rebecca:** I didn't like the contrast. The one you had to drink was gross, and there was a lot of it. The one that goes in the IV made me feel like I had peed myself.

**Kevin:** I had to drink the contrast. I was out in front of my house for a half hour trying to get the confidence to drink the thing down because I took a sip and spit it out. My mom was, like, if you spit it out, you'll just have to drink it again. So we went outside so I wouldn't make a mess. I kept trying, and it took me a half hour to drink it.

**Richie:** "They give you some stuff, and you feel like, 'Oh my god, I peed myself'. They tell you it will feel that way, but I really thought I peed." "First you drink this stuff that tastes terrible. Whatever you mix it with, you'll never want to drink that again. Then they lay you on the table and tell you you'll feel a little warm sensation. It feels like you peed 3 gallons all over yourself."

**Rebecca:** "It's the contrast. You feel it warm, then it stops, and

you feel like you peed. But nothing really happened.”

**Richie:** “They do a terrible job of telling you what’s going to happen. ‘It’s going to be a little warm.’ Yeah, right, then you get that feeling.”

**MRI (magnetic resonance imaging).** You are also lying down on a narrow, hard platform for the MRI and, again, may need contrast. The platform goes into a tube like a tunnel. You may go part way or all the way in. You hear loud banging noises. The MRI can take a long time (from 30 minutes to several hours, and you cannot move. Sometimes headphones are available, so bring cd’s you like. Some of us had no problem with it, and some of us got claustrophobic because the tube is not very big. If that’s a problem, you can be given something to relax.

**Hannah:** “If you weren’t claustrophobic before an MRI, you will be after. It’s like trying to fit a size 24 person into size 2 pants.

**Libby:** “Well, they suck. I really hated them, but they’re not scary. They’re just not fun. The noise really bothered me, and having to stay still for so long was hard.

**Kevin:** They’re just annoying. I hate being confined. It’s hard just laying there and not being able to move. It’s boring.

**Bone Scan.** This test takes pictures of the bones to see if a tumor or infection is present. A radioactive dye is administered through your IV. The dye goes to parts of the bones that are not normal. This dye has about as much radiation as an x-ray. Again you will lie on a table and must lie still, but this time the scanner moves over your body. This test can take up to an hour. It does not hurt but, again, lying still for a long time can be uncomfortable.

Other scans that use dyes with a small amount of radiation , though not exactly the same dye, are Gallium scans, MIBG scans, and the **PET scan** (positron emission tomography). The PET scan is similar to a CT scan, but uses a small amount of radioactive glucose in your IV. The dye goes to the parts of the body that has cancer cells. You will wait a while before the test begins. This, too, requires that you lie still on a table that slides you into a “donut hole.”

**Ultrasound.** This test uses a clear gel put on the part of the body being tested. A transducer, which looks like a microphone, is placed on the gel and moved around to conduct sound waves that

create a picture of the tissue or organ. Sometimes the transducer already has the gel on it.

**Libby:** “It’s cold!”

**Hannah:** Sometimes, some of the pressure points they do, they push hard, and it hurts.”

**Libby:** Yeah, one time it hurt pretty bad. I thought I was going to have oozing.”

**Hannah:** “If they go really hard, they kind of dig in.”

**Echocardiogram.** This is like an ultrasound of the heart that measures the strength and function of the heart. It may use dye and requires that you take off all clothes above the waist. You will lie down on a table. A transducer is used like for an ultrasound, but this one is measuring heart function and strength. It is done on patients prior to their receiving chemotherapy that can have an effect on heart function, and again from time to time over the course of the chemotherapy treatment.

Some of us found the situation uncomfortable and/or embarrassing.

**Libby:** “If they do one (ultrasound or echocardiogram) on your chest, where there’s no fat, it hurts.”

**Hannah:** “I was getting one in Cardiology, and they told me to take off my bra and my shirt, and I’m sitting there with a towel on, and this dude’s –like-feeling up on my chest, and I’m going, ‘Ah hah, oh my.’”

**Libby:** “I would not have a guy do it. I’m very modest, and you’re very exposed when you have it done. I would find that very awkward.”

**Hannah:** “It’s just awkward, especially when you’re a teenage girl. I don’t know. Some parts of me are weirded out by having a guy and sometimes I’m weirded out having a girl. I just don’t like any of it!”

**Libby:** “I feel uncomfortable even with female nurses or female doctors seeing me, but when it’s a guy, it’s harder.”

**Hannah:** “They’re probably not even noticing anything.”

**Rebecca:** “I didn’t care. Whatever.”

**Richie:** “I don’t know. Maybe it’s because I’m a guy, but I lost all sense of dignity really fast when I was in the hospital.”

**X-ray:** A picture taken of the inside of part of the body. It is often used to determine if a bone is broken or if there is fluid or infection in the lungs.

**Libby:** “It was so annoying. When they were trying to figure out what was wrong, they wouldn’t let me stand (because Libby had fainted prior to her diagnosis due to a very low hemoglobin), but they made me stand for the x-ray.”

Other than that, nobody had any problem with x-rays.

**Pulmonary Function Test:** This test measures how well the lungs are working. You’re in a booth, and you blow into a mouth piece connected to a machine that measures the amount of air breathed in and the force of air breathed out.

**Rebecca:** “It was really hard to do. You think it would be easy to breathe into a tube, but it wasn’t. I didn’t do it “good enough” the first time, so I had to do it again. I didn’t expect it to be that hard. It wasn’t that bad. It was just annoying.

There are a number of other tests you may have but these are the most common. **When you are scheduled for any tests, you should ask what they are, how they are done, and why they are being done (what will the results show)**

## CANCER TREATMENT

There are three ways cancer can be treated. They are:

1. **Surgery.** For some solid cancers, surgeons remove as much of the tumor as possible. Sometimes this is the only treatment necessary. Sometimes it is used in combination with another kind of treatment, such as radiation and/or chemotherapy.
2. **Radiation.** For this treatment, very powerful x-rays are aimed at specific areas of the body where there is cancer to kill the cancer cells. Radiation is sometimes used in combination with chemotherapy.
3. **Chemotherapy.** Chemotherapy is medicine designed to kill cancer cells and prevent new cancer cells from growing. The different types of chemotherapy work in different ways to damage and/or destroy cancer cells. Chemotherapy can be oral (swallowed), given into a vein (IV), into a muscle (IM), or under the skin (sub-Q). If you have leukemia or non-Hodgkin lymphoma, you may also have chemotherapy put into your spine

to treat your central nervous system.

**Richie:** talking about PEG (Peg asparaginase – a chemotherapy for leukemia that is sometimes given in the muscle but may be given through an IV. If a patient is has a reaction to the PEG, they may have to get another form of the drug that is given in the muscle.) “The first time I ever got PEG , 5 nurses came in. Three of them had needles, and two of them held my legs down. I was joking and asked, ‘Is this going to be like Pulp Fiction? (where they give a woman an adrenaline shot)’ and the one nurse is like, ‘Kinda,’ and then they say ‘Ready? One, two, three,’” and they all gave me needles at once. I was like, ‘Whoa.’ It felt violent. It didn’t really hurt that much. I was just shocked.”

**Hannah:** “You know what really burned? The Ara-C shots. I hated those.”

**Kevin:** “Are those the ones you get at home? They are bad.”

**Libby:** “I hated them, too. I had to get blood thinners after a surgery, and it reminded of the Ara-C shots. It didn’t burn or anything, but the needles looked the same, and I had flashbacks to the Ara-C. I had really blocked it out, but that brought it back.”

**Hannah:** “It was bad. When the (home care) nurse did it, I thought it would be fine; I got needles so many times, it was like – all right. Just do it. Then I’m freaking. She was doing it slow and then pulling it back, and I’m, like, ‘Just do it. Come on.’ My dad would have to hold me down for those.”

**Kevin:** “The only thing that kept me from doing that was cause a neighbor would come down the street and do it, and I didn’t want to look like a little wussy.”

There’s one medicine we took that wasn’t chemo. It was an antibiotic to prevent us from getting a certain kind of pneumonia when our white blood cell counts were real low. Some of us couldn’t take the medicine and had breathing treatments instead.

**Hannah:** Oh my gosh. It was horrible. It really tasted bad.

**Kevin:** You breathe it in, and it’s just disgusting. You can suck on Jolly Ranchers or something like that to make the taste better.

**Hannah:** I can’t eat Jolly Ranchers any more.

## WHAT DOES GETTING CHEMOTHERAPY FEEL LIKE?

Sometimes chemotherapy feels like nothing, sometimes it feels cold going in. Ara-C, which is a shot, can be painful going in. Some chemo pills have a bad taste. You can ask if you can put them into a capsule so you don't taste them. Some IV medicine actually has a taste, too.

## SIDE EFFECTS OF CHEMOTHERAPY

Along with doing the job it's supposed to do, chemotherapy may have some side effects. You should be given information sheets about all the side effects of chemotherapy that are possible, including some very rare ones that can be pretty scary. The side effects listed as "common" on these sheets are the ones that most frequently happen. Not everyone's the same, so not everyone gets the same side effects. You may not get all of them, or even any of them, but pretty much everyone has some side effects.

Sometimes your body has an allergic reaction to some chemotherapy, scan preparations, or transfusions. This is not a side effect. We have listed some common side effects.

**Steroids.** These are not the kind of steroids athletes sometimes use to build muscles. These are another kind that help fight cancer. They can cause extreme hunger and obsession with food.

**Hannah:** "I felt like an oompa loompa. I hated eating everything in sight. I would get up, have breakfast, and be thinking about what was for lunch at 11:30, but I just ate, like 2 hours ago."

**Richie:** "I would just eat at an alarming rate. Like, one day, in 24 hours, I put on 4 pounds. I ate tacos all the time, and I can't eat them now."

**Rebecca:** "I lost weight on steroids."

You may be obsessed with certain types of food. Salt is a common craving. Our cravings included hot dogs, hamburgers, chicken fingers, cheese fries, potato chips, pretzels, and pizza.

Steroids also make your body retain fluids. We got puffy cheeks and a big belly. Some of us got a "buffalo hump," a swelling at the back of the neck, which is normal with steroids and does go away.

Some of us peed a lot. And steroids can upset your stomach or make you feel nauseated.

Some of us had trouble sleeping, and some of us sweated when we slept.

Steroids can also give you heartburn. The doctor will have given you a prescription for something that helps with that.

One of the hardest side effects is the mood swings. You can get really irritable, angry, sad, or giggly and change moods quickly.

**Kevin:** “I wouldn’t go out with my friends when I was on steroids because they were so annoying to me.”

**Hannah:** “I remember I was getting an EKG done. I got those things put on my head, and I’m just sitting there, and I started crying. I’m like ‘all right.’”

You can suddenly get angry or sad (or happy) about nothing.

**Libby:** “I went to the shore with a friend when I was on steroids, and it was not good.”

**Hannah:** “When I was playing soccer, one day I’d be, like, ‘Yeah,’ then the next it was, like, ‘Ugh.’”

**Richie:** “Steroids suck. They were easily my least favorite drug I got.”

**Rebecca:** “And the taste of it. I threw it up. I couldn’t take it. We had to crush it up and put it into little capsules.”

**The most important thing to remember is that there is nothing wrong with you.** It is steroids that make you feel a little crazy. The side effects stop pretty quickly when you stop taking the steroids.

Large doses of some steroids over a long period of time can cause something called AVN (avascular necrosis) in which the blood supply to the joint or bone is so blocked that the bone or joint tissue dies, causing pain in the affected area. Several of us have AVN and have had treatment for it.

#### **GENERAL SIDE EFFECTS:**

**Hair Loss.** The chemo cannot tell the difference between healthy fast dividing cells and unhealthy cancer cells, so it gets rid of both kinds. Almost everyone has their hair fall out – some or all of it. It may happen soon after you start your chemo or take a long time. A number of the chemo medicines cause hair loss. Chemo that kills or prevents fast growing cells from dividing is responsible for the hair loss because healthy hair cells develop and divide rapidly, too.

Losing your hair can be hard. It is a visible sign that something is wrong, and you are reminded about your cancer every time you look in a mirror. It's particularly hard for us as teenagers because our appearance is very important to us. Not everyone reacts the same way when their hair comes out. We do suggest that you get a short cut before it starts to come out. Long hair gets knots in it when it begins to fall out. Some of us just shaved our heads when we didn't have much hair left and some of us hung on to every last hair we had. That's one of the decisions you have control of.

**Libby:** "I was not one who hung onto every hair on my head. I cut my hair, but I still had a little pouf going on. Then I died it blonde, but it was half green and there was like a purple heart on one side. They had a beef and beer fund raiser for me, and my mother didn't want me to go with my hair green and purple and black. So I went to the hairdresser, and my mom spent all this money to get my hair colored nicely. Four days later I shaved it off."

**Rebecca:** "I hung on to every last hair. I remember going to class and my hair was coming out and there would be clumps of hair on the desk. I took a shower one night, and all this hair was in the drain. My mom saw it and she started to cry. She called her friend from New York to cut my hair, and she cut it in a fringe in the back, and I kept that the whole time. When it grew back, I still had that, and that stuff was disgusting when it started to grow back. I thought my hair was going to be this disgusting texture. I got a haircut and I was like, 'whoa, this is kind of nice now.'"

**Hannah:** I had these three stragglers that wouldn't go away. So I was like 'Can we just cut these please?' I don't remember my hair ever falling out in chunks, though."

**Richie:** "I tortured my parents. I was in the hospital for the first month, and I remember taking a shower one day. It had started coming out a little bit at a time. I'd wake up with a little on my pillow. Then one day I took a shower, and it was falling off me. I was freaking out. So then I cut it short. When I got home, I was sitting on my couch one day just kind of pinching my hair and I put it on my empty plate from dinner. My dad asked what I was doing, and I just kept pulling it out. Then I handed him the plate."

**Libby:** "Mine didn't totally fall out until I had radiation."

**Richie:** “Yeah, I shaved mine at one point because I didn’t want to deal with waking up every morning with hair on the pillow, and I hated going places leaving a trail. So I shaved it, but then it would always come back. I never lost it until radiation; then I was shiny bald.”

There are a number of good places to get wigs if you want one. Sometimes insurance will pay for part of the cost. Some financial aid organizations will also help pay for it. Some of us just wore scarves or hats and made that our “look.” And some of us just went bald.

**Hannah:** “I got really annoyed at being taken for a boy. One day I went to the bakery with my father. I was wearing a head band, skirt, and earrings, and an older guy said, ‘Oh, it’s father and son day, isn’t it?’”

**Rebecca:** “I wore a beanie to sleep because I was cold. I wore Hip-Hats, too.”

**Richie:** “I wore beanies. My aunt went out – I don’t know what she was thinking – went out and bought me a wig. It was like \$1200.00. I was, like, ‘Thank you so much.’ I was waiting for it to sprout wings and start running around. It was the weirdest thing, but I put it on and I looked like Ringo Starr. I wore it once just to show my aunt I wore it. I mean, I used to have long hair, and I miss it, and I loved it, but I’m a guy, it’s fine.”

**Libby:** “I wore a wig for about 4 days, and then I was ‘Oh, my God, I hate this,’ and I would never use it again. I used to wear a bandanna sometimes, and then sometimes I’d just go bald.”

**Hannah:** When I had no hair, I put a bandanna on and made the bandanna into a pony tail.

Some of us knew we were being stared at, and it made us uncomfortable, but after a while it didn’t bother us. It may or may not bother you. Your hair **will** grow back. It is very soft when it is growing in. Sometimes it comes back a different color and/or texture. It may come in lighter or darker, curly or straight, thick or fine.

**Neurologic side effects.** One of the IV chemos, Vincristine, can have neurologic side effects, which means it affects the nerves. You may feel tingling or numbness in your fingers and/or toes. Sometimes you can feel pain in your jaw or other places in

your body. Vincristine can make you clumsier, so you may have trouble with handwriting or holding on to things. You may also have some trouble climbing stairs. Sometimes you walk on your tiptoes. And sometimes your knees “give out.” If you have any trouble with any of these things, you should talk to your doctor about it.

**Hannah:** “I lost feeling in my arms and legs. Like, I went to stand up, and I just fell over. That sent me to the hospital Christmas day. I also had pins and needles.”

Vincristine can also cause constipation. There are medicines to help with that, and your doctor will prescribe them for you.

**Nausea and Vomiting.** Some of the chemotherapy can make you nauseated or make you throw up. The doctors will give you medicines to help with that. It’s important to take the anti-nausea medicine the way the doctor or nurse tells you to. It can decrease or even prevent nausea. Some of us thought it helped if we ate something before we got the chemo, and some of us thought it was better not to eat. You will figure out what is best for you.

**Richie:** “Who didn’t throw up?”

**Libby:** “I didn’t.”

**Rebecca:** “I felt better after I threw up. I’d rather throw up than be nauseated.”

**Richie:** “I remember the first day I wasn’t nauseous, I’m like, What is this? It felt strange.”

We all know it sucks to be nauseated. Sometimes it seems like none of the medicines you are given help. If one is not working, talk to your doctor. There are a lot of anti-nausea medicines and you can usually find one that works for you.

We found out that it is important to drink fluids even if you can’t eat much. If you don’t drink enough, you can get dehydrated, which can make you nauseated as well as give you other problems.

Sometimes you get nauseated from other things. Your sense of smell or taste can be affected by chemotherapy. Some smells in the hospital or clinic can make you nauseated. Some of us felt sick when our IV’s got flushed, and we tasted the flush in the back of our throats. Sometimes it is psychological. You can think something is going to make you throw up, and then you

actually throw up. Some of us started to feel nauseated when we were in the parking lot of the clinic or when we walked in and reacted to certain smells (like alcohol wipes or hand sanitizer). There are things you can do to deal with this. Talk to your medical team for some help.

Radiation to some areas of the body can also cause nausea. If you are going to get radiation, ask about the side effects.

**Most important to remember is that it will get better and it will end.**

### **Your Blood Counts**

Because healthy blood cells grow and divide quickly, some of them will be affected by chemotherapy. Red cells carry oxygen throughout your body. If your red cell count (hemoglobin) is low, you may get tired, weak, and have headaches. You may need a red blood cell transfusion.

Platelets help stop bleeding. If your platelets are too low, you may bruise and/or bleed more easily. If it gets below a certain number, you will need a platelet transfusion.

White blood cells fight infections and allergies. Neutrophils are white cells that fight bacterial infections. If your absolute neutrophil count (ANC) is low, your activities may be restricted. You may not be permitted to be in crowds (school, religious services, the mall, restaurants, movies, or anywhere there are large groups of people). Sometimes you can go to certain places when they are less likely to be crowded or if you wear a mask. Your doctor will talk to you about this.

There are times when your blood counts affect your treatment. For instance, some treatment plans call for your platelets and ANC to be at a certain level before you can move on with a treatment. You may be scheduled to receive chemotherapy, but it gets postponed because your counts aren't high enough. You may be scheduled for a "lab only" appointment but then find you need a transfusion. It helps to keep in mind that what you are expecting at an appointment may not be what actually happens.

White cell transfusions are not usually given. Donated white cells last a very short time, so it is impractical to use them. In addition, they can cause a severe reaction.

**Sun Sensitivity.** The chemotherapy can make your skin more sensitive to the sun, which means your skin burns more easily. Use sunscreen whenever you will be in the sun. When your hair

does fall out, either use sunscreen on your head or wear a head covering (hat, bandana, etc). If you go swimming, be sure to re-apply the sunscreen and recover your head when you come out of the water.

**Fatigue and Weakness.** One of the things we all noticed when we were getting chemotherapy is that it can make you tired and weak. You probably will not have the same energy you did before. If you are in school, you might not have the energy to stay the whole day. Your ability to do physical exercise might be affected, and you might not have the stamina you used to have. Although this can be really upsetting, try to do what you can do. When you are finished with your treatment or in a phase of treatment that isn't as intense, your stamina and strength will come back gradually as you also work to rebuild them.

**Mouth Sores.** Because the mucous membranes that line your mouth, esophagus, and stomach are fast growing, some chemotherapy can cause break down of those tissues. This can lead to mouth sores (mucositis), which are exactly what they sound like. They are little sores in your mouth and, sometimes, in your esophagus and intestinal tract. They can be very painful and cause you a lot of difficulty with eating and swallowing. Call your doctor as soon as you think you have mouth sores. There are treatments that can help make it a lot less painful.

Mouth sores usually happen when your white blood cell count is very low and stays low for a while. Once your bone marrow starts making a good amount of white blood cells, the mouth sores will heal.

### Some Other Things To Know

**Depression.** This is not really a side effect, but when you are really tired and weak and having other side effects from chemotherapy, it is not unusual for you to become depressed. You should talk to your medical team about that because there are people that can help you.

**Fertility:** It is possible for chemotherapy to have an effect on fertility. If you are a young man who has gone through puberty, you will probably be asked if you want to donate sperm to be used later in life in case the treatment makes you infertile.

**Richie:** “So here’s how it goes. First I’m told that I have cancer. Then they ask if I want to donate sperm in case the chemo makes

me infertile. ‘Yeah, of course I do.’ So at 6:00 in the morning the day after I’m diagnosed, they wake me up and take me to this fertility center. I walk in, and there’s this woman who looks just like my grandmother, and she hands me a bottle and gives me instructions before she takes me to this room filled with pornographic magazines and videos. Then she tells me to call her if I need help. Anyhow, I do what I need to, and when I open the door, she’s standing right outside ‘in case (I) needed anything.’ It’s funny now, but it was nerve wracking then.”

Studies are being done to determine whether eggs can be removed from girls before they have gone into puberty. If successful, this would allow for the eggs to be fertilized later and save them from the effects of chemotherapy. At this time, it takes too long to harvest and remove eggs in post pubertal young women and would delay treatment, so it is not being done in most cases.

## HOSPITAL LIFE

### HOSPITAL STAFF

While you’re being diagnosed and going through treatment, you will meet a lot of different staff members. You might meet some or all of them at some point. These are some of the people involved in your care:

#### The Doctors:

1. **Oncologist (sometimes called the attending):** This is a doctor whose specialty is cancer and who supervises your medical care.
2. **Oncology Fellow:** The fellow completed medical school and a residency in pediatrics. The fellow is now completing training in pediatric oncology. He is getting further training in the subspecialty of oncology.
3. **Resident:** A resident is a doctor who has finished medical school and is now training to be a pediatric specialist.
4. **Medical Student:** Medical students have finished college and are in medical school.
5. **Nurse Practitioner:** A nurse practitioner has a master’s degree in nursing and has training in the care of children with cancer. The nurse practitioner in oncology works in collaboration with the oncology physicians and nurses.
6. **Nurse:** Nurses provide your daily care and work in

collaboration with the physicians and nurse practitioner.

7. **Social Worker:** The social worker usually has a master's degree and helps you and your family adjust to the diagnosis and treatment, providing education, counseling and other support. The social worker also provides information about community resources for support and financial aid, if needed. The social worker also works with your school to make sure you receive the accommodations you need at home and at school to help you maintain academic progress.

8. **Child Life Specialist:** The child life specialist has completed college with training in child development. They provide education and help reduce the stress associated with being in the hospital. They help prepare patients for procedures so they know what is going to happen and may accompany patients to procedures to provide support.

9. **Teacher:** Many hospitals have teachers who can help you keep up with school work while you are in the hospital. They may get assignments from your school to go over with you.

10. **Chaplain:** The chaplain is trained to provide spiritual care and/or prayer while you are in the hospital.

11. **IV Team:** These people specialize in placing IV's and may be called if there is difficulty getting an IV placed.

12. **Art and Music Therapists:** These are people who are trained to use art or music to help you when you are in the hospital.

13. **Pharmacist:** The pharmacist prepares the medications you receive and is knowledgeable about what over the counter medications may be taken with the various types of chemotherapy.

14. **Nutritionist:** A nutritionist may help with your food choices if you have difficulty maintaining good nutrition while on chemotherapy or suggest foods that are more palatable for you.

15. **Psychiatrist or Psychologist:** These professionals can help you deal with your diagnosis and the feelings you may have as a result. The psychiatrist can also prescribe medications to help with those feelings when necessary. The psychologist is also trained in testing for learning problems.

16. **Physical therapist/Occupational therapist:** The chemotherapy may affect your strength or ability to do certain tasks. The physical therapist helps you with issues of strength and fitness. The occupational therapist helps with the activities of daily living (eating, dressing, etc.)

17. **Volunteer:** Volunteers are trained by the hospital to provide non-medical help and activities.

18. **Other Staff:** There are many other people you will meet, from technicians to housekeeping staff to cafeteria workers. All of these staff people can be helpful to you and make a difference in your hospital stay.

**Anyone who comes into your room should tell you who they are and what they are there for. If they don't, just ask them.**

## Inpatient Issues

Obviously being in the hospital would not be our first choice of fun things to do. The most important thing to do is **cure** you. Everyone on the staff is working hard to do that. There are some things that can be frustrating, and some of them are harder than others. This section is about the things we found hard and some suggestions for dealing with them.

**Lack of control.** There are some things that happen when you are diagnosed with cancer that you have no control over. You have to have certain tests. You have to stay in the hospital. You have to get your chemotherapy or surgery or radiation. Once you are discharged home, there are times you won't be able to be where there are large groups of people, including school, movies, the mall, restaurants, etc.

But there are some things you do have control over, and you should take it. If you feel strongly about something, speak up. If someone is trying to start an IV and has missed your vein a couple of times, you may want someone else to try. Just make that request and stick to it. There are many times you may feel something would work better for you or feel more comfortable if it were done in a certain way. Don't hesitate to ask. Sometimes there is no choice, but if there is no reason something cannot be done the way you would like, the staff should accommodate you.

**Hannah:** "I didn't feel like they were taking control away from me. I was just there to get better, and they were helping me do that."

**Richie:** "Exactly. I didn't care what I had to do. If anything, I felt more comfortable in the hospital for a long time. If I had to go back in the hospital because I was sick, I was cool with it. I felt better being there than at home when I was sick."

**Hannah:** “I remember hating the finger prick. I wanted them to take blood from my PICC line, but they wouldn’t do it. So I gave up.”

**Richie:** “I had to have a couple of MRI’s. I was on Dilaudid for pain, so I asked them to give me a little extra Dilaudid just before the MRI so I’d be out of it and it would be a lot easier. They agreed to do it, and it was much better.”

**Taylor:** “I know they have to flush the IV before doing another procedure, and the flush always made me throw up. So I was having scans one day and had just finished the CT scan. They wanted to flush after that, and I told them they didn’t need to flush because that was the last procedure and the flush really made me sick. But they didn’t believe me, so they gave me the flush, and I threw up all over the machine.”

**Waiting.** One of the toughest things about being in the hospital is waiting. Hospital time seems to be different from human time. You may be told that something related to your treatment (i.e., tests, test results, procedures, appointments, chemotherapy, other treatment, seeing other specialists, even being discharged from the hospital) will happen at a certain time. There are often delays – sometimes very long ones.

**Hannah:** “No matter what the circumstances are, expect to wait. Even if they tell you you’ll be in and out in 5 minutes, expect to wait. Even if there’s nobody else in the waiting area, expect to wait.”

**Richie:** “I was scheduled for an MRI that was supposed to be at 6:00 PM, so I decided to eat right before that. I’m waiting, and it’s 7:00; then 8:00 comes, and I’m hungry again. It just didn’t happen, and I got into the MRI machine around 11:30 at night. Then I was supposed to get another MRI that they said would be at 8:00 at night. They came in the room at 4:00 in the morning to take me down.”

**Libby:** “When I was getting my port put in, I was also being admitted for high dose Methotrexate after the surgery. The surgery was scheduled for 8:00 in the morning, and then I’d be admitted. We didn’t go in until 6:00 PM, and then when I got to my room, they said, ‘Oh, we don’t start chemo this late, so it will have to wait until tomorrow.’ Ordinarily I wouldn’t even have minded, but it pissed me off because I had a record of short stays for the Methotrexate, and that spoiled it.”

**Hannah:** “I was supposed to get a test done at 8:00 in the morning, so I had to be there by 8:00. I wasn’t allowed to eat or drink since the night before. So then it’s like 10:00 AM now, and I’m starving. It was a little longer before they took me.”

**Kevin:** “Once I was scheduled for outpatient anesthesia for a bone marrow, and they have to measure your oxygen level before they can put you under. I was on Dapsone, which lowered my oxygen level, so it was 94, and it had to be 95 before they’d give me anesthesia. I had to wait a long time, til the oxygen level came up.

How can you make the waiting less stressful? Have things (and people) with you that you enjoy, like games, iPod, laptop, iPad, books, art projects, or other distractions. But the best thing you can do is prepare yourself for the wait. Don’t expect things to happen when you are told they will and be pleasantly surprised if they do. No one is deliberately trying to frustrate you. It is a large system and things don’t always go as planned.

**Communication.** How do you ask questions? How do you answer questions? How do you express yourself when you are angry, worried, or sad? The staff is on your side and wants to help you. If you tell them what you need, it helps both you and them in the end. If you’re embarrassed or afraid to talk or ask about something, make yourself do it anyway because, no matter what it is, they’ve probably heard worse.

Most staff are pleasant and helpful, recognize that you are having a difficult time, and treat you with kindness and sensitivity. They are there to help you. Sometimes there is no connection between you and some staff members, and you may feel they are not sensitive to your issues. Sometimes it feels like they don’t quite understand what you are going through and are not listening to you. Sometimes you feel that you know your own body better than they do, but they won’t listen to your feelings about an issue. It can feel like you are not being respected.

Be a good advocate for yourself. If you feel you aren’t being heard, you can always ask to talk to somebody else. That might be hard to do because you worry that, if you say something negative to someone important to your treatment, they won’t go 100% for you. We were all worried that if we stuck up for ourselves to medical staff, they would treat us differently. Being

dependent on them is hard. The staff will not treat you any differently if you speak up when something is bothering you. When you get to know the staff and the procedures, you might be more comfortable asking if something can be done in a certain way or if a particular person can do it.

**Kevin:** “I really don’t like being touched if it isn’t necessary. I really don’t like to be put into position for a spinal tap by a nurse. I can do it myself. I was encouraged to tell the nurse that I don’t like to be touched. So I talked to the nurse and explained that if she could just tell me what to do, I would do it, but I don’t like to be touched. The nurse said she understood and thanked me for speaking up. She said it helped her to do her job better because she never knew that was an issue for me. Then she put her hand on my chest and pushed me into a flat position! The nurse was appalled when it was pointed out to her what she had done. Now we can laugh about it, but I was angry when it happened.”

Doctors and nurses do not hold grudges because you raise an issue that bothers you. The way you present your opinion is important. If you talk reasonably and not angrily, saying that the communication is not working and you want to talk to someone else, you are likely to have better results. Sometimes, however, you have to be “not so nice” to be heard. You are in a children’s hospital, and sometimes staff treat you like “kids” rather than the teenagers you are. It’s frustrating, but keeping your cool and talking rationally helps staff see you as responsible. Sometimes you need to have your parents help you address an issue.

Some of us felt there were times to keep our opinions to ourselves and other times we needed to speak up. With some things you have to suck it up and deal. Some of us let things go the first time something happened to upset us, but got angry the 2<sup>nd</sup> time the same thing happened. It’s easier to talk to a person who upsets you before you get to the “boiling point.” Often the person who upset you has no idea they did something to make you unhappy and, if you don’t tell them, there is no way to resolve the problem.

**Kevin:** “This one time I was in the hospital and I needed a new IV. They kept digging and tried 3 times. When they were about to try a 4<sup>th</sup> time, I said, ‘All right, no, we’re not doing it again. They listened and got the IV team in to do it.’”

**Rebecca:** “Yeah, the IV team starts it, but then they hook you

up to a pump to pump the chemo or fluid through. I had a really bad experience with that one time because it went in too fast and really hurt. So the next time, I told them about that experience and they said they would drip it in real slow – like they do for babies. And I thought, ‘Okay. I’ll give it a try.’ It hurt so much that I screamed, so he finished it by hand. The next time I went, they said they would do it real slow – like they do it for babies, and I said, ‘No. You’re not doing that to me. Do it by hand.’ And he said it would be fine and that it worked for the babies. But I said, ‘No. You’re not doing this to me again.’ They all thought I was crazy, but they did what I needed.

**Libby:** “When I had an MRI once, I got sedation, but it really didn’t work out because I was still conscious, and when I’m conscious with sedation, I get emotional. So I just cried. So they didn’t want to do it under sedation again, but I said, ‘No, we’re trying it.’ For me, with my AVN, if I have to lay on that table for a long time, it’s misery. So without sedation, I end up flexing my muscles to try to get comfortable without moving, and they have to do it again anyway.

**Kevin:** “It’s important to be comfortable with ourselves, realizing that, without being inflexible, we should be in control as much as we can. The doctors and nurses – the whole staff - are there to help you, so you have to help them help you.”

**Rebecca:** “You should never feel weird asking for something. Most likely you’re not the only one; even though it feels like nobody’s ever had this particular problem before, probably you’re not the only one. Nobody ever told you because how many other people do you know that had cancer that had that problem, too? So you can feel weird speaking up, but chances are other people have had that issue.”

Other problems with communication happen when the medical staff uses words or phrases you don’t understand. Just stop them and ask them to explain what they said in language you can understand. After all, you don’t speak “medicalese.” Even more maddening can be when medical staff speak to your parents while you are in the room and don’t address you directly. You can ask them to talk directly to you or at least include you in the conversation.

**Kevin:** “It really made me mad when I was in the room with my parents, and the doctor would come in and talk to them

and not to me. It was my body it was happening to. That was disrespectful.”

Sometimes different doctors give you different information about the same thing. Something may happen, and a doctor comes in and tells you one thing about it. Then someone else comes in and gives you different information. You might have a lot of questions, especially in the beginning when you are trying to learn about your cancer and everything that comes along with it. You can get very confused if you ask different people the same questions. Even if the answers are similar, they may explain it in a different way. This can be not only confusing, but sometimes scary as well. It is a good idea to have a couple of people on the medical team that you trust to go to with your questions. If one isn't available, you will have a second person you trust to talk to.

### **Being asked to repeat information over and over again.**

Sometimes it seems like everyone who walks into your room asks the same questions. It can get very irritating. But there are a lot of people involved in your care, and this is how they make sure they have the correct information. Also, sometimes you are dealing with medical staff from another department, like Infectious Diseases or Surgery, etc. While it annoys you, it also protects you from having any of the medical staff assume they know your medical information or confuse you with someone else. You can ask why they are asking for this information again when it is in your chart or you have given it to them before. There may be a good reason (and there may not).

Having to rate your pain on the pain scale can also be frustrating. It can be difficult to say just how much your pain is on such a scale. As Hannah said, “It hurts. Just fix it!”

**Getting stuck multiple times to get an IV in without success.** Sometimes when you are having an IV put in or having blood drawn, it can take more than one try. There are different reasons this can happen, but it is always frustrating. Even the best people can have an “off” day. If someone is having a hard time getting your IV in, after the 1<sup>st</sup> or 2<sup>nd</sup> try, ask that someone else try or ask that the IV team be called. (The IV team is made up of people whose job is to start IV's, and they tend to be more skilled because they do it so often.) The person working with you may ask to try one more time. That's up to you, but if you don't want to do that, you can repeat your request that someone else try. “I really

would prefer that you get somebody else (or the IV team).”

There are some things that might help if you have a problem with IV's. If you are allowed to eat or drink before getting stuck, drink fluids so you are not dehydrated. Hot packs are often available to help your veins show better. If getting IVs is difficult for you for any reason, talk to your doctor about other options.

**Rebecca:** “They (IVs) hurt, but I never really got a good one. My first one was awful. The guy dug around there for about 3 minutes, and I'm sitting there, like ‘Oh, my God, what's happening?’ And then, after that, we used the IV team because apparently I'm a really hard stick.”

**Libby:** “I have a port now, but I used to have to go over to the hospital for my spinal taps, so when I was here (outpatient center) the day before to have my chemo, we would leave the IV in overnight so it would be there when I got to Philly. I went back and forth about getting a port. It is a really hard decision to make, but I would do it again in a heartbeat.”

**Kevin:** “I didn't have a port. I didn't like the IVs, but I didn't want to go to the hospital if I got a fever and my counts were good, so I didn't get one.”

**Libby:** “I didn't mind going to the hospital if I had to.”

**Functioning with IVs.** Daily tasks can be challenging when you have an IV. It's hard to get comfortable because you have to be careful of it. If you sleep on the IV line, it can hurt or cause the monitor alarm to start beeping. There's no real solution for this. Sometimes you just have to adjust your sleeping position to accommodate the IV.

Showering with an IV is a pain in the neck, but staying clean is important. You are unhooked from the pole for your shower, so you may need to wait for your infusion to be done before you can be unhooked. The IV is covered to protect it so you can shower. You may need help from your parents or a nurse, which can be awkward. Some of us were too sick to shower ourselves, but others could manage without help.

IVs can be annoying when you have to do things like go to the bathroom. You will probably be getting a lot of fluids and will have to pee often. Dragging the IV pole across the room to use the bathroom is another annoying issue, especially in the middle

of the night. As a guy, you may be able to use a urinal, but girls generally use the toilet in the bathroom if they are able to walk.

**Rebecca:** “The night after I had surgery, I woke up and had to go to the bathroom. I wasn’t fully awake so I woke my mom up, and she unplugged my IV. We had to get the nurse because I never had an IV before, and we weren’t sure how to get to the bathroom. I almost fell into the toilet because I was really out of it and was dragging a pole with me.”

**Kevin:** “It’s good for guys because sometimes you don’t have to go all the way to the bathroom.”

**Libby:** “Yeah, don’t you pee in a bucket on the side of your bed or something?”

**Kevin:** “A bucket? It’s a little container jar. Sometimes they had to measure my pee, so I had to use that (urinal)”

**Noises in the hospital.** When you’re sleeping, being disturbed for vital signs (temperature and blood pressure) or to adjust tubing or monitors can be very annoying, especially when it can be so hard to get to sleep. The alarm on the IV monitors makes an annoying beeping sound when treatment is completed or something needs to be adjusted. It can be even more irritating when it takes a while for someone to respond to your call button and come in to deal with it. There are other bothersome noises in the hospital, too, including people talking outside your room, loud music, or noise from other patients, buffing the floors, etc. , that can make it difficult for you to rest.

Sleeping with music or white noise (like a fan or a television tuned to a nonworking channel that just makes a steady noise) can help.

**Hospital Food.** Although hospital food often has a bad reputation, some hospitals have decent food. Some hospitals offer other options for meals, like the hospital cafeteria. Many hospitals have storage for food that can be used to keep food you didn’t finish or food people bring in for you. You may also have access to snacks.

**Being Confined to Your Room.** Sometimes being in the hospital is just plain boring, especially when you can’t leave the room. There are different reasons why you may have to stay in your room. This can happen if your ANC is very low. Sometimes every patient must stay in his/her room to prevent

the spread of easily acquired infections, whether you have the infection or others on the floor have it.

**Kevin:** “The hardest thing for me was not being able to be alone. There was always someone in there, and I wanted to be by myself. Then when they left, I was like – ‘I don’t want to be alone.’”

**Hannah:** “It’s just boring, boring, boring.”

**Richie:** “I used to work out all the time, and I hated being in there and not able to do that. So I asked them if they could bring in an elliptical or a bike, and they did bring a bike in. So that was good, but I still hated isolation.”

The child life specialist may have some things of interest for you to do. The hospital may be able to provide books, movies, or other entertainment options. You can bring your own laptop, iPod, DS or DSi, games, etc. to the hospital. Friends and family can usually come visit you in the hospital. Check with your nurse about rules regarding how many visitors are allowed and when they can come.

## BEFORE YOU LEAVE THE HOSPITAL

There are some things you might want to know before you leave the hospital. These are questions that we asked.

1. What kind of cancer do I have? What is it?
2. Do you know what caused it?
3. What is the treatment plan?
4. What kind of treatment(s) will I get?
5. How long will I get treatment?
6. Where will I get my treatment?
7. What is the success rate for this kind of cancer with treatment?
8. What are the side effects of treatment?
9. What can and can’t I do while getting treatment? Physical activities? School? Food restrictions? Go to the mall? Movies?

These are important questions, but you might not want to get all this information before you leave the hospital. Just ask about the things you want to know.

## OUTPATIENT TREATMENT

Some cancers are treated primarily on an outpatient basis. You may go there once a week or several times a week, for anywhere from an hour to many hours, depending on what you need.

Many things can be done as an outpatient, including lab tests, some chemotherapy, physical examinations, and procedures that don't require you to be in the hospital.

You may have gotten to know other patients in the hospital. When you're an outpatient, you may see those patients there or get to know other patients who come to the clinic on the same day you do. Sometimes it helps to talk to someone else who is going through the same kind of thing. But it's up to you whether or not you want to do that. If you want to meet other teenagers getting chemotherapy, someone on the medical team can set that up. There are also web sites that connect cancer patients with each other. Your hospital team should be able to tell you what those web sites are.

**Hannah:** "I never wanted to meet anyone there. I always blocked myself from meeting any other people. Everybody wanted me to talk to other patients, but I didn't want to. I didn't like the way I looked, and I didn't want to be comfortable here (the clinic)."

The outpatient spaces have various activities available. They have televisions, movies, and video games. You can bring your own movies or laptop to use while you are there. There will probably be crafts, puzzles, and games available that may interest you.

## THE EMERGENCY DEPARTMENT (E.D.)

The Emergency Department is not always for an emergency. There are a number of reasons you may have to go there. Most common are if you have a fever or you get dehydrated. If you have a central line (port or Broviac) and get a fever, you may have to go to the emergency department to make sure you do not have an infection. Even if you don't have a central line, if you have a fever above a certain level, especially if your ANC is low, you may still have to go to the emergency department to have blood cultures drawn. Don't try to figure out if you should go to the ED. If you have a fever or just aren't feeling right, call either the center where you are treated during regular

hours or the hospital after hours. Don't try to decide whether it's serious or not. Let the doctor make that call. Don't worry about "bothering" the doctor. Their job is to keep you as safe as possible, and they want to know about any problem you have. It is always better to be safe than to be sorry.

The Emergency Department can be a tough place to be and may feel chaotic and hectic. It is often very crowded. You may be taken into an exam room pretty quickly because patients receiving chemotherapy should not be with large groups of sick people because their immune system is compromised. But once you're in the exam room, you might have a long – or a very long – wait. Children come to the Emergency Department for many different reasons and some may require more immediate attention than you do. When you are seen, the doctor will decide whether or not you need to be admitted.

In summary, though the staff was great, we thought the beds were uncomfortable, the wait was hard to take, and it was not a great experience. It's not a place you want to be, but we were glad that it was there to help when we needed it.

## HOME LIFE

We couldn't wait to get out of the hospital, but when we got home, we realized that things were not back to "normal." When we got diagnosed with cancer, we knew our health had changed, but we didn't realize how many other parts of our lives would change, too. All we wanted was to be treated normally, but we soon realized life wasn't like it was before the diagnosis. And we wouldn't be treated like we were before because we had an experience that wasn't like our friends' and affected many of parts of our lives. This was part of the adjustment to cancer we had to make.

**Friends and Classmates.** One of the biggest concerns we had was whether to tell people about our diagnosis. Many of us wanted our information to be kept private, but we realized that this is not something that you can keep secret very long. It's up to you to decide who to tell and when, but be aware that the choice may not be yours. You will probably want to tell your friends yourself, but the news generally gets out quickly. If you want to be sure that your classmates and teachers have correct information, someone from the medical team may be able to go

to the school to explain the diagnosis and treatment and answer questions. This is important to think about because it helps stop rumors and incorrect information from spreading.

**There's no right or wrong way of handling this issue. You need to decide what works for you.**

We found that most people knew about the diagnosis by the time we got home from the hospital. People can find out in ways you don't expect.

**Hannah:** "My teacher wrote it on the board of her classroom. Nobody told her she could do that; she just did it."

**Kevin:** "My math teacher announced it to the class. It wasn't his right to do that."

**Libby:** "I was at band camp. I fainted and was helicoptered to the hospital because my hemoglobin was so low before I was diagnosed. So everyone knew it was something bad."

People may know about your diagnosis or have information you wanted to keep private before you've had a chance to decide how you want to handle it. Hair loss or very short hair can lead to questions before you figure out how you want to tell people.

Some people are uncomfortable when you tell them.

**Hannah:** "I had a friend who told me that, the first time we got together after the diagnosis, she was scared because she didn't know how I was going to act, what I was going to be like, or how I might have changed since the diagnosis. She was happy that I hadn't changed at all and was the same goofy person I always was."

"I had another friend I felt close to who said a lot of times that she would come to see me. But she never came to the hospital and never called. Now I realize that it was probably awkward for her, and she just didn't know how to handle it. "

**Richie:** "I hated that people, when they heard I had cancer, were all so nice to me. I hated that people before I got sick - like, we did not like each other one bit - started being nice to me once I got sick. If you told me you still didn't like me, I'd probably love you. You don't really know who you should trust. It's weird."

**Libby:** "There was one girl who wrote me a 3 page message on my facebook because we had gotten into a really bad fight

before (I was diagnosed). We weren't even good friends. It was just drama. She messaged me and said that she just wanted to apologize. She said, 'God forbid that anything would have happened to you worse. I wouldn't want to end things like that.' It was kind of selfish of her, but, at the same time, I can respect that it opened her eyes to how she had been. We became friends after that. She didn't just act like nothing happened. She actually apologized."

Some friends may feel awkward and need time to get used to your diagnosis. You may have to help them deal with it. You may expect friends to "be there" for you, and it turns out they don't know what to say and are upset themselves. You can avoid a lot of problems by just raising it yourself and opening communication.

Other people often don't understand what it's like. Unless they've been through it, it's hard for them to understand. You hope they don't make a big deal of it, but most people don't know how to react.

**Libby:** "I've been on both sides of this issue. I was really uncomfortable and didn't know what to say when a friend told me she had cancer, and then I was diagnosed with it and had to talk to other people about it."

**Richie:** "My good friends were scared to be around me because they didn't want to make me sick. The first time they came to visit me I forgot to tell them that I was swollen up like the Michelin tire man, and they were, like, 'Oooh.'"

**Taylor:** "I remember I walked in and saw my friends for the first time and they all started crying. And I'm thinking, 'Okay everyone.'"

**Richie:** "After a while you just can't cry any more, and you see them crying, and you're like, 'Stop. Just stop.'"

**Libby:** "I just told everyone they weren't allowed to cry. If I don't cry, you don't cry."

Sometimes people you would expect to be there to support you aren't and people you don't think would help are the ones that do. Some people are really wonderful, and you see how much they care about you. All of us had experiences with lots of people caring about us and being upset that we were sick. We found out who our real friends were, too. Some were afraid

to get too close to us. Some good friends couldn't handle it. Others who hadn't been friendly with us and hadn't been friendly before the diagnosis suddenly wanted to be our friends. Sometimes in school other students called us by name, and we didn't know them. It was strange sometimes. We just wanted people to treat us normally.

Sometimes you find that, when your friends complain about stuff, you get annoyed because it is nothing compared to what you are dealing with. It may help to remember that you were probably the same way before your diagnosis.

You may have someone unexpectedly say or do something really insensitive, and you may be surprised at your own reaction. Taylor experienced it after her treatment was over, and her hair was growing back, as was her confidence.

**Taylor:** "I was out with friends and feeling great when someone asked about me, because my hair was so short, 'Is she a lesbian?' I got really angry and upset. My friends reacted, too, and the person who said it left."

**Libby:** "I didn't have a lot of friends when I was going through this. I had one friend who stuck with me during my treatment. Recently we kind of came to an understanding and don't really hang out any more. He had another friend who got really mad at me and said 'It was okay when he was the only one there for you during your entire treatment, but now you're too good for him or something.' I told him it wasn't like that. It was like I grew up during that time, and he stayed where he was. We have different values. He goes out and drinks and smokes and has to do that all the time to have fun. I can't relate to that. That isn't what I want to do. I have more friends now that have the same kind of values I do."

**Richie:** "I got sick right before I was going to start college, so all my friends weren't around. The only person I saw was my girlfriend because she was a year younger than me. She hasn't changed at all, but I definitely have. It's caused issues because she's so young. I've always been older than her, but now it's a completely different level because we don't see eye to eye on so many things."

We all found that this experience changed our perspective. You grow up real fast. A lot of our friends seem shallow now, and

it's hard to fit. We don't see having fun the same way, even though we still have fun. It's kind of like we lost some of our "childhood." We lost our innocence.

**Hannah:** "It's kind of weird. People and things change. Me and my friends were inseparable (during my treatment), but now we've gotten into arguments more and more. I've been best friends with them for years, but now we get on each others' nerves. We're all going away to college, and all we do is argue."

**Libby:** "In a lot of ways, I'm glad it happened when it did. I lost a year of school and had to repeat it. I was hanging out with people going down the wrong path before I got sick. If I hadn't met some other people, either going through this or just more mature, I really think I would not be the person I am. I'm comfortable with who I am. I want to lose weight, but not for other people, but for myself. I'm comfortable with who I am, and I think that's something most people don't ever feel."

**Hannah:** "I love my classmates. They're so dumb but great at the same time. They don't even remember that I was sick, which I love. It takes them a minute to remember. I'm thankful for it at the same time, but now they don't really know me. I used to be friends with all of them, but they just forgot. They just know me as the quiet one. In school I just sit there and wait until the day is done. I don't want them to perceive me as the sick one, but on the other hand, I liked the attention I got then."

**Rebecca:** "I tell people at certain times because it was natural at that moment, and then they say, 'Why didn't you tell me earlier?' I'm, like, 'what am I supposed to do? Hi, I'm Rebecca, I had cancer.'"

**We think it is very important to talk to someone else who has been through this.** Even when you have family and good friends to talk to, nobody understands like another person who is going through the same thing or went through it. Sometimes you just meet someone in the hospital or the clinic. You can also ask someone on your medical team to help connect you with someone if you think it would help.

Getting to know other patients can be extremely helpful. They can relate to you and you to them. It is important to have friends in all parts of your life, and this is an important part of your life. It really does help. The only people who really "get it" are those

that have been through it. Even if you don't respond to things that happen the same way, you can relate on a level others can't. But the possibility exists that you become friends with someone who does not make it and dies from their cancer.

**Hannah:** "You can be talking with someone, and they talk about something that happened, and you're, like, 'Yeah, that happened to me, too.' But I don't feel exactly what someone else feels. I can relate on some levels but not all."

**Richie:** "Nobody's experience is exactly the same, but there are going to be things we can relate to that you can't relate with people who haven't had cancer."

**Kevin:** "Getting to know other patients showed me that what I went through wasn't as bad as what other people have been through. There are always others who had it worse."

**Richie:** "There were a few people (other patients) that I talked to a lot during treatment. There were two people I talked to the most. One of them I'm still friends with, but the other one died. That was as bad as being told I had leukemia, but I wouldn't trade that 6 months I was good friends with her for anything. Being friends with her helped me so much. That friendship was really important to me."

**Hannah:** "My mom had to force me to come to these meetings. I'm glad she pushed me, but I didn't want to come. I'm glad I came, even though it was really hard when Jake died."

Sometimes you will get to know another patient that doesn't survive. Just because this can happen doesn't mean you shouldn't seek those relationships. We don't regret it at all; those friendships were really important and added a lot to our lives.

## School

When you have cancer, you will miss time from school. How much depends on your diagnosis and treatment plan. Some of us missed very little time from school, but others missed a lot. The school will make accommodations for you which will most likely include home tutoring. Whether you miss a little or a lot, you will probably be going back to school while you are still in treatment. You may have an abbreviated day, meaning that you won't have a full day of classes, but will have some classes and continue tutoring for others.

After your diagnosis, you may feel like a different person. Going

back to school sometimes reinforces this feeling. Things will be different from how they were before you were diagnosed. You'll have some people who are really nice about it and others who aren't. We all had different experiences with going back to school.

**Kevin:** "I got sick, but I still had hair and all. But then the summer hit, and I lost it all. When I came back to school, I had a little hair. People gave me weird looks."

**Rebecca:** "I went to school one day on the last day before I went to my biopsy. My hair was very thin, and it was falling out. The next time they saw me, I didn't have my wig yet, so it was just me and my hat. And then the next week my wig came and then my science teacher goes, 'Your hair grows very quickly,' sort of sarcastically. He was cracking himself up. Another thing that was intimidating was that I would come in to school in the middle of the day because I was half in school and half not. I would come in for the 4<sup>th</sup> period and stay through the 7<sup>th</sup>. When I got to the classroom door, there's people already in there. It was the most intimidating thing ever. I would just stand out there for 5 minutes trying to open the door."

**Hannah:** I went through 1<sup>st</sup> period through 4<sup>th</sup> period in school. There would be this huge bus that would just take me home. That's awkward – there's this bus waiting out front just for me. It was weird. The bus driver would be like 'so how are you doing today?' I'm like 'all right.' I don't like that. I don't like special treatment – well, it depends."

**Libby:** When I went back to school, I was there the whole day, although, when I would go to clinic and stuff, and then I would come back to school, then I'd have to eat my lunch in the middle of third period. Luckily I had the coolest math teacher ever. He told [another patient] that I was like the daughter he never had."

**Kevin:** "You're not used to seeing your peers for all that time (that you missed school), like weeks or months. Your body went through so many changes in that time that it's a big step to just make yourself vulnerable with all that. Some kids are mean or stupid – like, if I touch them, they'll get cancer."

**Taylor:** "I think the biggest thing in school was people just staring. You, yourself, are more used to how you look; you don't really see things as weird. You're around your family a

lot, and when you have no hair, it doesn't seem so different, and then someone will walk in the room and be, 'Oh, my gosh,' and you're like, 'oh yeah, I don't have hair.' ”

**Hannah:** “We were all tutored when we missed school. I had a tutor, and when I did go back to school, I still felt like I was lost. All the stuff I learned, I didn't learn with my teacher. My tutor and I were so far ahead, it was hard.”

**Rebecca:** “The worst thing is that you have to catch up with what you missed, and then when you go back to school, you have to catch up with the work they're doing next, so you have double and don't know where to start.”

We know there are a lot of issues going back to school. You're not where anybody else is emotionally. You're not where everyone else is academically. And you're not where everybody else is physically. If you miss a couple weeks of school, the “social circles” might have changed and you have to catch up. It might seem like everyone else's life is better than yours, that everybody else is out all the time – not sitting at home. All the differences and restrictions can magnify the issues you're dealing with.

Going back to school while you're still getting treatment doesn't feel like that's the most important thing on your mind. The first thing on your mind is getting back to not being “cancerish” (a new word coined by Hannah). Most of the time we were more concerned with staying away from people with colds, worrying about getting nauseated, cleaning our desks to get rid of germs, etc. Sometimes this isolated us from other people because our focus was different from theirs.

Going back to school wasn't necessarily good or bad; it was just different. Some parts were good; others were not, and we had to adjust to the “new normal.”

## SOCIAL LIFE

Your social life can be affected by low blood counts, so we think it's important to be with your friends whenever you can. Sometimes, if your ANC is low, you can't go out. Wearing a mask when you go out may be an option. You may be reluctant to go out because of what people might say or how they look at you. It can be hard to make yourself go to parties or large group

get-togethers, but you don't want to miss out on something just because someone might say something.

**Taylor:** "I did go to parties when some people made rude comments to me, and I got upset, but then I just left and did something else."

Yes, it's hard to do some of the "normal" things, but it is worth forcing yourself to do them. Most important, remember that it does get better. You have a choice about how you handle your situation. You can sit and wallow in misery or you can participate in your life. None of us were happy to have cancer, but we found that if we focused only on the cancer and how hard it was, we were miserable. If we forced ourselves to go out and do "normal" things, we felt better. It's tough, but lots of people are going through it every day.

It is common to feel "out of the loop" sometimes because, in some parts of your life, your experience is so much different from what other people your age are doing. While you still have a lot of things in common with your friends, it can be difficult when you feel like you don't "fit" anywhere. You are still adjusting to your new "normal," and eventually you do get more comfortable being with other people.

When you feel like you look different, it can be tough to have your picture taken. Some of us were uncomfortable getting our driver's license picture taken, and some of us used old photos for our Facebook page. Some of us didn't want any pictures taken while we were in treatment.

Others felt it was important to have some pictures of how we looked at the time. These photos are important because they document an important part of our lives that influences the rest of our lives.

**Taylor:** "I have a scrapbook that was made for me of the time I was in treatment, and I'm very glad I have it."

## **FAMILY**

**Parents.** Parents may feel a lot like you do. They may be scared and feeling out of control. You have to realize that they are frightened and worried as well. Whatever they can be in control of, they want to be. And often that affects you. Some parents may be overprotective. Having your parents hover over you can be tough. One parent may be less protective than another, but

when you are a teenager, you sometimes don't want your parents to always be around. When you're an inpatient, you can suggest that they go for a walk or sit in the parents' lounge for a while.

After you get home from the hospital, your parents may want to oversee your activities and make decisions about who you can see, where you can go, and what you can do. Some of us felt that they treated us as if we were 5-years-old again. Sometimes the doctor may say you can go somewhere or do something, but your parents veto it. If you disagree with some of their decisions, you might want to ask a staff person (doctor, nurse, social worker) to meet with you and your parents to help figure things out and decide what restrictions are reasonable. You may feel that your parents don't understand your perspective, but it's also hard for you to understand theirs.

**Kevin:** "You wouldn't be allowed near me without being squirted with Lysol and using hand sanitizer, and that was just the first day I was home from the hospital. But it pays off in the end, in my opinion. Parents are just trying to make sure you're okay even if they're a little over the top sometimes."

**Libby:** "Me and my mom just used to fight all the time."

**Rebecca:** "My mom was protective but not overprotective. She would not go up to random people, but we were in the grocery store, and this guy was staring at me, and she starts talking to him about my cancer. I didn't even tell half my friends, so why's my mom telling random people?"

**Libby:** "My dad was the worst at that. He would tell people 'My daughter.....' and then come home and tell me that he told people at work about me. I was like, 'My god, first of all, I don't want you to be talking about that in the first place. Don't come back and brag that you were doing it.'"

**Rebecca:** "My mom got more lenient in the end because of it. Now she lets me do things she would never let me do before."

**Kevin:** "My mom and I were always around each other. We got on each others' nerves sometimes."

The way parents deal with their feelings may differ a lot, but all parents are affected by this diagnosis. It is common for teenagers and their parents to have arguments in the normal course of events. Having cancer can increase the tension between you and your parents.

**Libby:** “My parents acted like they hated each other. It was horrible. They fought over stuff that you knew wasn’t really what they were fighting about. Now they’re really close”

**Hannah:** “I think my parents got closer. My whole family got closer.”

**Libby:** “My family’s a whole lot closer now. Going through it we were all on different ends of the earth, but after we went through it, we’re closer than we’ve ever been.”

**Kevin:** “My parents are complete opposites. My Dad was like ‘You wash your hands and make sure you’re clean before you touch him.’ My mom would take me out for McDonald’s. They clashed so many times because they didn’t agree on certain things. They both wanted to make sure I was okay, and each one thought their decisions were the best, so they argued.”

**Rebecca:** “I felt bad for my mom. As much as we’re in control of the situation, our parents are not at all. They just want to do whatever they can to help, and at the same time you don’t want them doing anything. It’s hard for them.”

**Kevin:** When I was first diagnosed, my father would just, like, cry. I’d never seen him cry before. I felt guilty.”

**Hannah:** “Oh, that was the worst. It was terrible. I never saw my dad cry before either.”

**Kevin:** “My dad would stay at the hospital with me, and I had to tell him that it was okay for him to leave the hospital – that I’d be fine there by myself. All he wanted to do was protect me, but I’m not a little kid anymore.”

**Richie:** “My parents were a wreck about it. My mom was pretty good about it, but my dad was not. If I ever felt sick or something, I would never tell them. I feel like they had too much to worry about. I’d tell my sisters or my brothers-in-law.”

Sometimes parents argue more – about money, about what you should and shouldn’t be able to do, and sometimes about nothing. What has happened can create a lot more stress for parents, which can make arguments happen more often. It is sometimes easier to be angry than to be sad or feel out of control. Any tension that already existed can get worse. On the other hand, sometimes this brings families closer.

You might feel responsible for the increased tension or problems

in the family because you are the one with cancer. **It is the cancer that caused the problems – not you, and it's important to remember that.** It's not like you decided to have cancer to cause problems or did anything to cause it. You had no more control over it than anybody else. The cancer is not your fault. It causes problems for everyone, including you.

**Siblings.** Dealing with cancer is also a difficult time for your siblings. The diagnosis of cancer changes the way people in the family relate to each other. There is a shift. Parents may pay so much attention to you that they are not paying as much attention to your brothers and sisters. This can make your siblings feel less important. How they react may vary. They can get angry if they were used to getting more attention and suddenly get less. Sometimes siblings act out to get attention. Other times they withdraw and may appear depressed.

**Libby:** “My brother and I never got along. If you had asked me before this, I would have told you we wouldn't be speaking to each other now, but we actually got much closer, and now we're like, really good friends.”

**Kevin:** “I feel like the relationship between my brother and my sister got a little rocky. They were always together because my sister had to watch my brother. My brother is young, and my sister is older, and they were on each other a lot. Whatever I told my little brother to do, he would do.

**Taylor:** “I don't think my siblings were striving for attention, but they definitely got less attention. I don't think they minded that much because there were 3 of them and they had each other.

**Richie:** “My sisters are both married and not living at home, but like I said, if I needed to talk about something, I talked to them and their husbands – not my parents.”

**Libby:** “My brother had a really hard time with it. He was just going into his senior year, and he had a horrible year. When my mom wasn't in the hospital, she was working. He and my dad didn't have a good relationship, so it was really hard for him.”

**Hannah:** “My sister had a boyfriend, and he lives in Southampton. She was always with them (the boyfriend and his family). He had a stepsister, and it seemed like my sister and the stepsister felt close, but when I got sick, she realized, ‘Hey, I have a sister, too.’ But then I felt bad because the attention was on me,

and there were times when it should have been on her and not on me. I even bought her a Coach purse – you know, from all the people that gave me money.”

**Taylor:** ”I felt bad because when I was first diagnosed, it was right around one of my sister’s birthday, and then when I finished treatment and had that scare that my Hodgkin’s might be back (it wasn’t), it was her birthday again! So for two years in a row, her birthday kind of got completely overshadowed.”

It can be very scary for your brothers and sisters. Things have happened very quickly. They also have no control over what has happened. How they feel about it can be expressed in many ways, but it will come out. They may be afraid they could get cancer, too. They may be afraid to go to school for fear that you and your parents won’t be home when they get back if you have to go to the hospital. They may worry that you are going to die.

Good communication is important. If you see that your siblings are upset or unhappy at a particular time, you might want to talk to them. But if they are in a good place, you may not want to bring up the cancer. You have to play it by ear.

### **CAMPS & WISH GROUPS**

There are a number of camps for young people who have or have had cancer. Some of these camps are only for the patients, but some include siblings and one is for the entire family. Camp is one place where nobody sees you as different. Everyone there knows what having cancer is all about. They understand and support you. The best thing about these camps is that they are regular camps that do normal “camp things,” with the exception that all the campers (and many counselors) are dealing with cancer or have dealt with it in the past.

Wish organizations provide special opportunities to people who have a serious medical issue by granting a (reasonable) wish. These wishes have included meeting famous people, traveling, going on a shopping spree, getting a computer, laptop, plasma tv, etc., and many other things. Your social worker or child life specialist can help you apply for a wish. The volunteers from the wish organization will give you information about how it works. It is a bright spot in the middle of a difficult time.

## END OF TREATMENT

No matter how long your treatment is, at some point it will be finished. Instead of focusing on waiting for that day to come, just live your life day by day. Looking back, we realize that the hardest part of this journey was not the physical part but the emotional piece. The diagnosis of cancer changed our lives quickly and dramatically. It made our lives and our experiences very different from the people around us. It was difficult to see how much this affected our family and friends.

**Libby:** “I blocked most of it out. I don’t know if it’s normal, but I never, ever think about this stuff. I probably wouldn’t remember it if nobody brought it up. I just never think about it.

When I was going through it, it was just part of my life.”

**Hannah:** “I kind of feel like that, too. It was something I had to do. Did I want to live or not live?”

**Kevin:** “I went to a party the other day, and everyone was, like ‘you’re such an inspiration.’ What do you say to that? It’s something you have to do, so you might as well suck it up. Then it’s over and hard to remember. That was a few years of your life where it’s all you were focused on. It’s weird not to remember a lot of it. I like thinking about it. I mean, not thinking about it but remembering it. When I’m having a bad day, knowing what I’ve done and what I’ve been through, I know it’s not that bad of a day.

**Hannah:** “I can’t remember a lot of it. All through chemo, I just wanted to be done. Now, in a way, I’d like to go back and see what I missed – who was there, who wasn’t there. I don’t remember any of that. Sometimes when I do something like the Light the Night Walk (an annual event of The Leukemia and Lymphoma Society), all this stuff comes back, but then I never think about it, and sometimes I even forget. I don’t want to forget because it’s what I’ve been through that makes me me, but, at the same time, I’ve moved on. Now I’m thinking about college, and it’s hard for me to remember everything. I don’t remember most of it. It’s like two years of my life is just gone. I remember certain specific bad things, but I don’t remember the good things.”

**Libby:** “I think it’s different for me because I’m reminded of it

because of what I go through (AVN treatment). But at the same time, it's like that was a different time in my life. It was just a different part of my life. I have a different perspective on it – like that's the way it had to be.”

I remember that me and Kevin and Ellie and Megan were always here on the same day, but I just remember that we were here, not any details. I know what we were here for. It's not like there's no emotions. There's just no memory. I know that it happened, but I don't really remember it. It's kind of blur.”

**Rebecca:** “I don't remember a lot of it. My mom remembers it all better than me.”

**Hannah:** “I remember when I first started getting back to soccer, I was horrible. I was flat out horrible. I didn't have any strength; I had no muscle, and I would throw fits because I knew I sucked. I used to be a starting player every single time. Everyone would look up to me, and then it was like, ‘Oh, you need to sit down.’ That really ticked me off.’ Sometimes I wonder who I would have been if I didn't go through this. Would I have been the hottest soccer kid or would I have dropped out?”

**Libby:** “I know this is a cliché, but I wouldn't be where I am today if not for this. It changed my life in so many ways, more than just emotionally and maturity. I was going down a bad path. My mother was working very long hours; my dad was never home. Things were so bad. I can't even imagine how I would have turned out if this hadn't happened. I would never be doing this good in school. I wouldn't be this involved in school. I wouldn't have the friends I have now. My life would have been so much worse if I never got sick.

We said, at the beginning, that good things come out of this. We learned how strong we are and that we were able to overcome tough obstacles. We hope this booklet helped you understand that you're not alone and that it helps you get through your experience with cancer. Take it seriously, of course, but don't let it ruin your life. Once you beat cancer, nothing can stop you.

“Some days there won't be a song in your heart. Sing anyway.”

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