

## [TRACK 8: SURVIVOR STORIES: ADVOCATING FOR OTHERS]

### Brian, his mother and his father

[Brian]

When I first noticed the swelling in my testicle, I thought it was from a tackle during football practice. I thought it would go away in a few days, but instead it got bigger and I got really scared.

[Father]

When Brian first showed me the swelling in his testicle, my heart started racing. But I didn't want Brian to see how scared I was. I told him I thought we should get it checked out, just in case there was some internal damage. Our family doctor sent us to the university hospital right away and that night they were talking about surgery and all kinds of tests. Things were happening very fast.

[Brian]

As soon as the surgery was done and they had the results of the biopsy, the doctors told me I had to start chemotherapy right away. The night before they were going to start the chemotherapy, I had a lot of trouble sleeping. The nurse came in and saw that I couldn't sleep. She sat down next to me and asked me if I was in any pain. Then she asked if I was worried about anything. I got all choked up and it was hard to talk at first. But I just started telling her how I felt. Was my hair going to fall out? Would my friends still be my friends? Was I going to feel sick all the time? Could I still play sports? Would I still be able to have a girlfriend? Would I be able to graduate with my class? Once I got started all these questions just kept coming up.

[Nurse]

Once Brian was admitted to the hospital, things had been happening to him very fast. As his oncology nurse, I could see that there had not been enough time for him to process all the changes in his life and the things that were going to happen in the next few months. The doctors and his parents were trying to save his life. He realized that. But he also needed to know how his life was going to be different-not just physically but socially, emotionally, and with respect to his sports teams.

[Brian]

The nurse asked me if I had ever thought about having children some day. She said the chemotherapy might affect my ability to produce sperm. She told me I could save my sperm in a sperm bank before my first chemotherapy treatment.

[Father]

The day Brian was supposed to start his chemotherapy, he told his mom and me that his nurse had talked to him about sperm banking. He said he needed to do this before he started his chemotherapy. He did not want to start his chemotherapy right away. His mom and I were afraid that if we delayed his chemotherapy, it might affect his chance of being cured. At first we tried to change his mind, but when Brian got angry, we realized how important this was to him. He called for his nurse. She suggested we all talk to the doctor before making any decision. We told Brian that we would support his decision, whatever it would be.

[Brian]

When the doctor came in, I told him I didn't want to have the chemotherapy that day. I told him I

wanted to save my sperm in a sperm bank first. The doctor told me he was sorry he had not talked to me about sperm banking yesterday. He said that it would be OK to delay the chemotherapy for a week or two while I banked my sperm.

[Narrator]

As we just heard, the nurse raised an issue related to Brian's treatment that the doctor had not yet discussed. Brian wanted to delay his treatment to take a step that would preserve his ability to have children some day. With the support of his parents, he was able to advocate for his position with the doctor. Stated simply, advocacy means standing up for yourself or for someone else.

[Narrator]

An issue such as preserving the ability to have children may not seem important to everyone. Some people believe that treating the cancer is the most important thing to consider. They may believe that concerns about side effects, such as losing one's hair, facing an amputation, or losing the ability to have children, come second. To cancer survivors and the people who care for them, however, these issues can be just as important as treating the cancer itself. Learning that one may lose a limb or lose the ability to have children could be the reason for a cancer survivor to "give up" or refuse to have treatment.

[Linda]

There are many ways to advocate for someone else or for yourself. In Brian's case, his parents can advocate for him in many ways:

- They can contact the insurance company and negotiate for payment for the sperm banking.
- They can contact his football coach and advocate for keeping Brian on the team while he goes through treatment.
- They can contact Brian's high school and make arrangements for tutoring, homeschooling, or some other arrangements so that Brian will be able to graduate with his class.
- They can work with the social worker and the oncology nurse to arrange for banking Brian's sperm.
- They can let Brian's friends know that it is okay to visit him in the hospital while he is going through treatment.
- They can look for information and resources for Brian related to his cancer. An example would be an online Internet support group for young adults with testicular cancer.

Katie

[Narrator]

Let's hear from Katie, who is 7 months pregnant and raising 5-year-old twins, David and Anthony, and an 8-year-old daughter, Jessica. Katie's husband, Tony, travels for his job and has been in Japan for the past two weeks. One of the twins, Anthony, has just been diagnosed with a brain tumor and will need immediate surgery at a university hospital 90 miles from the family's home.

[Katie]

When the doctor told me that little Anthony needed surgery right away, I just started to cry. How was I going to take care of Jessica and David, get Anthony to the university hospital, get in touch with Tony and tell him one of our babies has cancer ... I felt so overwhelmed. The doctor sat down with me and handed me a box of tissues from her desk. When I had calmed down a bit, she said she would make a phone call and arrange for the oncology social worker at the university hospital to meet with me and help me plan for Anthony's admission. She held my hands in hers and asked me to look at her. "Katie," she said, "I want to be sure you understand this. I am very hopeful that most of the tumor can be removed with surgery. What is left can be treated with radiation therapy. I want you to be hopeful, too. It is important that we take care of Anthony, but it is also important that you take care of yourself. There are many people here to help you. Just tell us what you need." I will always be grateful for what she told me, and the way she said it. It made me feel like I could go on, that I could get through this crisis. I felt like I was not alone in this.

[Katie]

Before I left the doctor's office, I talked on the phone with the oncology social worker. Together we made a list of things I needed to do. There was a column for things that needed to be done right away and another column for things that could wait. When I got home, I called Tony in Japan, and he made arrangements to come home right away. He told me to call his mother to come and stay with David and Jessica until he got home.

[Katie]

Our faith is an important part of our family's life. I called my pastor and told him what was happening. He came to the house right away and he helped me talk to Jessica, David, and Anthony about what was happening. Then we all prayed together for God to take care of our family. Father John said that families from the parish would bring meals to the house for the next couple of weeks and would drive Jessica and David to school. He asked if I wanted someone to go with me to the university hospital so that I wouldn't be alone. I felt so much love and support from everyone - Anthony's doctor, Tony for dropping everything and coming home, Father John, and the people in my parish. Making the list with the social worker and then taking action right away made me feel like I was in control again. I was moving forward - doing what had to be done. And I was not alone. All I had to do was ask for help and there were people ready and willing to help me.

[Narrator]

When one child in a family is diagnosed with cancer, it can easily become overwhelming for the parents to deal with everyone's needs. It is important to ask for help from family and friends. Asking for help is a form of advocacy. It is a sign of strength to ask for what you need to help you and your loved ones deal with cancer in the family. Family and friends can help you to strike a healthy balance between caring for the child who is ill and preserving as much of a normal family life as possible under the circumstances. Members of your place of worship can also help you and your family to deal with the daily demands of caring for a child with cancer.

[Narrator]

If you need help in advocating for the needs of a loved one or if you just want to learn more about advocacy, you can contact the National Family Caregivers Association which is in Kensington, Maryland or the National Patient Advocacy Foundation in Washington, D.C. Their number is in the reference booklet that accompanies this audio program.