



A Guiding Light
By Emilia Hamburg

Cancer is a demon. It strips every teen of their comforts, making them sit alone with themselves trying to figure out who this new person is that stares back at them in the mirror.

Teens lose much more than their hair when they are battling cancer. They lose their ability to play their sport, to attend school, and to hang out with their friends. Many teens begin to worry about their futures; if they will be able to go to a D1 school, or if they even should be planning their future at all. It is very easy for them to spiral downward during this time. To help teens who have been diagnosed with cancer, the [Adolescent and Young Adult \(AYA\) Program](#) at City of Hope was designed to encourage teens and to keep them going when they are sad: to be a guiding light for them when they feel engulfed by darkness. The program provides specialized social and emotional care for this population of patients.

During my interview with City of Hope, I had the pleasure of speaking with [Dr. Jeanelle Folbrecht](#), Chief of the Division of Psychology within the Department of Supportive Care Medicine, who is the head of the Adolescent and Young Adult (AYA) program at City of Hope. This program is made up of leaders from different departments like nursing, rehab, and supportive care. This group of leaders come together to search for ways to address the needs of young adults and adolescents proactively and create programs that address issues such as fertility preservation. They are also trying to gather as much information and as many resources as possible in order to address all questions and concerns that may arise throughout a young patient's battle with cancer.

One of the main parts of the program is a tool called [SupportScreen](#), a software pioneered by [Matthew Loscalzo](#), who is now executive director of City of Hope's Department of Supportive Care Medicine. *SupportScreen* asks patients a series of questions prior to their visit with their doctor in order for their entire care team at City of Hope to be aware of their questions and concerns. This allows for their visit to become tailored and specific to their needs. To come up with relevant questions, City of Hope did research and compiled a list of the most common questions and concerns surrounding areas like finances, social challenges, and physical and emotional symptoms. This tool also allows for them to offer additional resources for patients before physical and emotional problems get out of hand and become bigger issues. They also provide different specialists/resources for patients including psychiatrists, social workers, psychologists, and child life and spiritual care programs.

Moreover, they are in the process of connecting patients in a program called "ConnectU." Their hope with this program is for patients to support each other through their journey with cancer. An example of how this program has really benefited a patient is when a young adult was frightened of her treatment to the point where she was about to refuse her treatment altogether even though it could cure her, Dr. Folbrecht paired her up with another patient who went through the same treatment and they talked. They talked about her worries, about the treatment and she found herself no longer frightened; instead, she was comforted by the knowledge she now had and the fact that she knew someone else who went through the same journey she was about to embark on.

Both *SupportScreen* and "ConnectU" cater to the full age range of the AYA group, which is those ages 15-39. This age range was determined from statistics that showed how new medical treatments were not improving the care of this group of people. There is a huge difference between the needs of a 15-year-old vs.

a 30-year-old, and City of Hope is aware of that. With this in mind, City of Hope offers programs like support groups aimed at specific ages in order to address the issues that a particular group is struggling with. Some of their groups deal with topics of body image, sexuality, and fertility.

Lastly, Dr. Folbrecht is looking to develop a survivorship program targeted to the AYA population for AYA patients in remission who are cancer survivors. As of now, their program is a mix of patients and survivors, and a separate survivorship program would specifically address issues that patients face when they enter survivorship. This will also give survivors the opportunity to serve as mentors for the patients.

Some of the current projects they are working on consist of trying to educate both the nurses and doctors on the specific needs of AYAs. Since teens tend to not want to be told what to do, doctors need to be more creative in their approach when interacting with them. For example, they need to offer their course of treatment as a recommendation, showing them both the upsides and the downsides to their treatment. This allows for a running dialogue to start between the doctor and the patient, but most importantly, it allows the patient to make their own decision. A teenager is different from a child because they have the ability to make their own decisions. They are able to form opinions and choose right from wrong. But, they can only do that when people are open and honest with them. They just have to be allowed the space and the opportunity to make those decisions.

While they are trying to keep teens involved in their care, they are also trying to uplift their spirits. In order to do that, prior to the pandemic, City of Hope held different events for them, like game nights and art showcases. For their game night, they hired a group to set up their lobby with different games; and for their art show, they put together a coffee bar and showcased the different pieces that their teen patients created. Both of these events were extremely captivating and enjoyed by the teens. To battle isolation during the pandemic, City of Hope offers support groups virtually and meets with teens one-on-one. City of Hope also offers in-patient children, adolescents and young adults social events organized for specific age groups so that they can play games and support one another. All participants practice social distancing and wear masks. In addition to these fun events for teens, the support groups provide a way for patients to safely attend to their health during the pandemic. The teens gravitate to these, especially when they are feeling their worst. The teens tend to show up at all events and hang outs hosted by City of Hope when they are doing treatment at the hospital in order to meet the other teens on the floor. Teens tend to not always need structured hang outs, because all they want is to surround themselves with people who understand what they are going through and can support them, and City of Hope provides many ways to meet this need.

Through the AYA program at City of Hope, teens have become more confident with themselves even while dealing with a disease like cancer. Beyond this, they have become willing to embrace all the challenges that come with cancer. Through all of this, the teens allow themselves to recognize friendships and people their diagnosis has brought into their life; instead of focusing on what it took from them.

This article is part of Tower's Teen Corner Blog, a blog that explores the effects that cancer has on children and teens, their treatment, their development, their relationships, and their fears, whether it be a personal battle with cancer or watching their parents or siblings fight cancer. To read more articles, visit: <https://www.towercancer.org/teen-corner/>