

# Completion of Adolescent Cancer Treatment: Excitement, Guilt, and Anxiety

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The completion of cancer treatment in adolescents and young adults (AYAs) is a time that many patients and families approach with hope and excitement but is often tinged with anxiety and fear. In 2005, the Institute of Medicine published a report on navigating and optimizing the transition from active treatment to survivorship in which necessary elements of care for adults completing cancer therapy were defined.<sup>1</sup> Recognizing the unique needs of AYAs with cancer who may struggle with different medical and psychosocial needs at treatment completion, the Institute of Medicine suggested developing new models for transitioning AYAs with cancer to survivorship care.<sup>2</sup> However, many children and AYAs with cancer feel unprepared and unsupported in this transition,<sup>3,4</sup> which may have long-term implications for AYA engagement in survivorship screening and care.<sup>5</sup> Below, we describe a young man's (S.P.) personal experience moving from treatment to survivorship as well as that of his oncologist (K.A.G.), and together we offer recommendations for supporting children and teenagers with serious illness at the completion of therapy. Although many other family members and providers played an integral role in this patient's care and transition to survivorship, in this piece, we focus on our experiences as patient and oncologist.

## PATIENT PERSPECTIVE (MR PEREZ)

The moment your oncologist tells you the date of your final treatment, you

realize that your cancer has an expiration date. Although the excitement and eagerness to finish my treatment kept me restless and energized, what I failed to anticipate were many other challenges and worries that would simultaneously come with finishing treatment. For me, completing treatment and transitioning from weekly chemotherapy to less frequent checkups with my medical team came with mixed emotions. When I went in for my final treatment in March 2016 with my entire family, it was one of the first times I truly felt anxious throughout my 2 years with cancer. My oncologist asked if I wanted to hear the statistics and rates of relapse for my type of cancer, and as usual, I said no. Yet, despite my response, I really was curious about those numbers. The thought of my cancer relapsing had crossed my mind and concerned me. But I did not voice my concerns that day because I did not want my family to see those worries.

In addition to this new anxiety, another unexpected emotion that overcame me was guilt. Being declared a survivor of cancer made me feel proud and accomplished, but it also made me feel guilty. My entire family joined me in clinic on that mid-March Tuesday, overjoyed as they carried signs with my face on it to let everyone know that I had overcome cancer. While there, we saw a friend of mine and fellow patient who was in the waiting room with her mother. As much as they attempted to express their joy for me, I knew that



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she was nowhere near to finishing the treatment that had consumed almost her entire life. On a day that was supposed to be one of the happiest of my life, I could not help but feel confused and guilty as to why the same disease had left us with opposing results.

In addition to the friend I saw in the clinic that day, I have lost 2 other friends from the clinic because of their cancers. To this day, I still struggle with the guilt of trying to understand why our paths were so different. Although I discussed these challenges with my oncologist as they presented themselves, I think it is important for oncologists to be aware of the challenges of survivor's guilt. I believe discussing this topic should be part of the process of transitioning to survivorship, and oncologists should ask their patients about their experiences with survivor's guilt before it becomes a problem. Many times, I felt alone and struggled to articulate these difficult-to-describe feelings to anyone who attempted to have me open up.

Over time, my oncologist helped me to understand that these feelings of anxiety, guilt, and even fear are normal during the transition from being a patient with cancer to a survivor of cancer. It is important to recognize them when they present themselves and not push them aside or allow them to be overshadowed by feelings of excitement and elation that you are finally a survivor of cancer. At the same time, it is imperative to take time to celebrate the unforgettable moment you hear "You are cancer free!" or "You're finally done with treatment!" with family and friends. Although this is well deserved, so is a time of self-reflection to think about all that has occurred during your time with cancer. At times, I did not express my emotions well during my transition to cancer survivorship and felt that I was nearing a place I did not want to be in. I think that by fostering conversations about the

challenges that come with finishing treatment, patients and physicians can help ensure a truly happy life postcancer.

### PHYSICIAN PERSPECTIVE (DR GREENZANG)

I also vividly remember Stephen's last treatment visit in our clinic. Whereas college-aged Stephen typically came to his visits alone or with his mother, for his last planned dose of chemotherapy, he was accompanied by both parents, 2 of his siblings, balloons, congratulatory posters, and high-fiving nurses and medical assistants. Stephen, a young man who approached every part of his diagnosis and treatment with poise and a belief that everything would be okay, wanted to reflect on his cancer journey. He also had questions, although not the ones I anticipated. For example, when could he get a tattoo? He wanted one to signify all he had been through. Halfway through the celebratory visit, as we reviewed the treatment he had received and what came next, his mother began to cry. Her tears, she explained, were tears of relief that her son had completed treatment but also tears of anxiety at the thought of stopping active therapy and reflected her aching fear of relapse.

The visit that comes at the completion of cancer therapy is both one of celebration but also one of uncertainty. Patients and parents often express feelings of vulnerability; up to this point, they have been actively "doing something" to treat the cancer, but now that active treatment has come to an end, the threat of relapse looms large. Patients and families may also worry about losing the reassurance of frequent clinic visits and check-ins with the oncology team they have seen all too regularly throughout treatment. Many survivors of cancer, particularly AYA survivors of cancer, experience uncertainty with completion of treatment and

persistent fears of cancer recurrence.<sup>6,7</sup> As providers, we struggle to balance honoring the momentous occasion of finishing therapy, acknowledging the nervousness that accompanies this milestone, and conveying important information about screening for recurrence and for late effects of treatment. This is made even more challenging because patients and their parents may have different goals for the visit and varied information preferences.<sup>3</sup>

Guidance on approaching the conversation at the completion of therapy suggests creating space for patients and families to set the tone for the visit and express their potentially mixed emotions.<sup>8</sup> Stephen indicated his preference for a celebratory end-of-therapy visit well ahead of time, and we prepared accordingly. Experts also recommend acknowledging the "new normal" that comes after cancer therapy, with its associated potential psychosocial challenges, and providing information about recurrence risk and late effects of cancer in a supportive and age-appropriate manner.<sup>8</sup> In Stephen's situation, his expressed preference to avoid hearing the numeric risk of recurrence was counterbalanced by his mother's desire for this information, and in hindsight, Stephen's ambivalent wish for statistics. We honored Stephen's stated preference for general information about the risk of relapse, both in speaking with the family as a whole and when meeting with Stephen alone, particularly because Stephen was over 18 years old. The optimal way to handle these competing information needs may vary with families with younger children or when each parent has a different preference.

Several months after our end-of-therapy visit, Stephen and I discussed his experience with survivor guilt, which he so thoughtfully describes above. I only fully became cognizant

of this issue with Stephen when he e-mailed to share that he was returning home early from a semester abroad to see one of his friends from clinic one last time. I had previously been unaware of the friendship between Stephen and this other patient, and I had no idea of the guilt Stephen was experiencing. Although feelings of guilt surrounding surviving a cancer diagnosis are extensively chronicled in survivorship blogs, popular press, and patient materials provided in survivorship clinics, there is strikingly limited research describing or studying this phenomenon in survivors of cancer<sup>9</sup> and no information about how best to address this issue in pediatric and AYA survivors of cancers.<sup>10</sup> Pediatric and AYA patients with cancer often develop strong relationships with other patients, partly through attending clinic the same day of the week for years, which are further supported by social events organized by pediatric and AYA cancer centers such as teenager trips and patients' nights out. Providers may be unaware of these friendships and may feel unable to ask about them because of concerns of confidentiality. But these shared experiences and relationships are meaningful and important to patients and families, and they can and should be explored by providers. Despite the dearth of research on survivor guilt, studies reveal that parents and patients in the first several months after completion of treatment express a need and desire for emotional and psychosocial information and support.<sup>3,4</sup> Although psychosocial providers are embedded in our care model and were a part of Stephen's care throughout, Stephen's generosity in sharing his experience with me revealed gaps in my usual support and care. I have now made it a part of my practice to discuss the potential for and normalcy of survivorship guilt and to offer support and further psychosocial resources to those who express a need.

## CONCLUSIONS

The end of pediatric and AYA cancer treatment is an emotionally challenging time in which hopes and fears must both be addressed. From our experiences as a survivor of cancer (S.P.) and pediatric oncologist (K.A.G.), we offer the following suggestions for the end-of-treatment conversation and subsequent discussions to help children and AYAs with cancer successfully transition from patient to survivor:

First, ask what the patient and his or her family are most looking forward to about stopping therapy and what they are most worried about. The answers may surprise and guide the conversation going forward. Second, explore what the patient and family remember about prognosis and risks of late effects and use this as a platform to assess patient and family understanding, preferences for information style and details, and to discuss future screening recommendations. Next, while discussing the emotional challenges that often accompany this time, acknowledge that the survivor and his or her relationships may have changed as a result of the cancer experience and create an opening to discuss survivor guilt. Conclude by reassuring patients that their oncology team will still be available and involved to support them going forward.

Although we all recognize and celebrate the date of treatment completion, the process of transitioning to survivorship begins well before the end of therapy and extends months thereafter. Therefore, we also encourage patients and providers to discuss these aspects of treatment completion over multiple visits and with various members of the care team, including psychosocial providers. The appropriate support surrounding completion of therapy ideally allows children and AYAs with cancer and other serious illnesses to

acknowledge and process the complex emotions surrounding this transition and helps them to thrive in survivorship.

For detailed guidance on survivorship care for children and AYAs with cancer, including psychosocial evaluations and resources, please consult the recently revised Children's Oncology Group Long-Term Follow-Up Guidelines at [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org).

## ABBREVIATION

AYA: adolescent and young adult

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