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Completion of Therapy Talk

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Neil was 4 years old when he was diagnosed with acute lymphoblastic leukemia, and 7 years old when he completed his treatment. For Neil, there was little he remembered of life at any time other than as a patient with cancer. On the day of his last planned treatment, as with many such visits, we walked into his room with a certificate of completion, a gift bag, and a cheerful song. Much to our surprise, Neil sat quietly in his chair and stared at the corner of the room. We halted our song midsentence and Neil looked at us and asked, "Is it okay if I don't feel like celebrating?" We, the members of the clinic team, were left feeling abashed, wondering how we could have so misconceived the situation and how often we may have committed the same error in the past.

Neil's reaction taught us much about the potential differences in perceptions between patients, families, and health care team members around the completion of planned upfront therapy, and guided us to take a look at how we approached the occasion. We realized that what patients and families really need at this important moment is an opportunity to discuss their fears and hopes and to have their questions answered; as much as on the day they first faced the diagnosis of cancer, they need a conversation.

So much of oncology care occurs in conversations. Not more than a decade ago, the article by Mack and Grier¹ in *Journal of Clinical Oncology* offered a practical and concise approach to delivering the bad news of a cancer diagnosis and supporting families during such a tumultuous time. This early conversation is of paramount

importance in preparing patients and families for their cancer journey and for establishing a therapeutic relationship. It influences much of their upcoming experiences and is often remembered for years to come.

At the other end of the cancer treatment journey is another important conversation but one that receives less structured attention in our mental scripts or in our training programs: the completion of therapy talk, an important conversation in its own right and with its own requirements for individualized structure and content. Our personal approach to this conversation, culled from years of trial and error and encapsulated in three main goals, is presented here. Many of the concepts discussed below are not unique to pediatrics but are relevant to all survivors who reach this significant milestone.

Perspectives

The first goal is to identify the patients' and families' perspective of this important moment, without setting expectations. We now begin the conversation by simply asking, "How do you feel today?" and allowing families to express their emotions, positive or negative. For most families, it is often a moment of mixed emotions, a complicated amalgam of apprehension, uncertainty, relief, and hope.

Families may express the fear that completion of active therapy today may not mean the same thing as end of therapy for good. Indeed, we know that for a proportion of patients, subsequent experience of relapse will unfortunately occur, and the families' worst fears will be realized. It is of utmost importance to acknowledge these fears and



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to place them in the proper context for each patient's circumstance.

Other families may be concerned that ceremony of any sort will build resentment or increase shock if relapse occurs. We try to give families permission to celebrate, to mark the end of a long journey, and, indeed, to try to think of the occasion as good news. We still have the gifts and certificates prepared, but we leave them aside for the latter part of the conversation and bring them in only if appropriate.

We also take this opportunity to emphasize that families are not losing their care team. We recognize that the clinic and hospital ward has become somewhat of a second home and that completing therapy feels, for some, like they are losing that home. We explain that the same team will continue to observe them for a long time, and although these families may be in the clinic less often, we will always be there for them when they need us.

Moving to a New Normal

During active treatment, a plan is available for every detail and is displayed in tangible schedules and roadmaps. Families may fear that the completion of therapy phase will bring about a loss of the structure and routine that they found comforting during active treatment. We usually address four key actions that patients can expect when treatment ends, including removal of their central line, stopping *Pneumocystis jirovecii* pneumonia prophylaxis, resumption of regular immunizations, and change in the management plan for fevers. These four milestones can serve as valuable teaching moments for families and as opportunities to discuss the risk of relapse, the recovery of the immune system, and healthy lifestyle choices.

Changes in a family's and child's routines are an essential step forward in rebuilding normalcy. What this new normal looks like will be different for each patient, depending on the lasting impact the cancer has had on their physical or psychosocial health.² Ideally, a smooth transition occurs when efforts are made to maintain normal routines and relationships throughout active treatment.

We emphasize re-establishing a therapeutic relationship with their pediatrician and reconnecting with friends and classmates. Whenever possible, we also encourage a family vacation, a well-deserved respite from months or years of rigorous therapy, and offer financial support from local charities, such as the Children's Wish Foundation. We inform parents and children that physical and psychological

recovery is a work in progress that takes a long time and does not happen as soon as therapy ends. We also address the possible long-lasting psychological impact of cancer and discuss letting the child find a balance between a return to their old world and the preservation of pieces of their new identity as a survivor of cancer.

Ongoing Monitoring

The third goal is to outline a schedule of off-therapy monitoring, usually composed of radiologic scans, blood tests, and clinic visits. As with active therapy, we find it helpful to provide families with a roadmap that includes the surveillance schedule, making sure to explain the rationale for each item. Even if earlier detection of relapse offers no specific advantage to the patient, most families have told us that they would not be comfortable without some form of surveillance.

Some families ask directly about the risk of the cancer coming back and worry that coming off therapy means that the cancer is more likely to come back. We address these concerns by showing them survival curves that help us convey the important message that coming off active treatment does not increase the child's probability of experiencing recurrence and that this risk decreases with time.

A family may experience the conversation about the late effects of cancer therapy as another bringing bad news. Families may feel like they are hearing about these things for the first time, although they were often introduced to the idea of late effects with the initial disclosure.³ During the day one talk, discussion about late effects seemed like a remote concern or a small price to pay for the chance of cure. At the completion of therapy talk, discussion about late effects increases in its relevance and is an opportune moment to shift focus from cancer care to survivorship care. It is vitally important to talk about the risks of late effects directly with the child and to do this an age-appropriate way. Adolescents, in particular, need to be empowered to take increasing ownership of their health information. Active patient engagement in survivorship care promotes early recognition of late effects and works to strengthen the therapeutic relationship with the care team.

Final Thoughts

Completion of active therapy is a momentous occasion. It is a time to explore what patients and families feel about how far they have come and to discuss their hopes and fears for the future. It is an opportunity to inform them that they will

continue to be supported in both the triumphs and challenges that may follow. Just as the initial investment of time, planning, and compassionate communication on day one affected adjustment to the cancer diagnosis, so will our investment in the conversation here affect adjustment to the process of recovery. And just as with the day-one talk, this conversation typically happens in installments over many days, weeks, and, often, months. The day one talk and the completion of therapy talk are the two shores of the cancer treatment journey. As their oncologists, we recognize the importance of compassionate communication to provide not only information but to convey our support and dedication to our patients, not just while they receive therapy but long after they are done. **JOP**

Acknowledgment

We acknowledge all the patients and families going through the cancer journey. We are forever grateful for the many valuable lessons you have taught us along the way.

Authors' Disclosures of Potential Conflicts of Interest

Disclosures provided by the authors are available with this article at jop.ascopubs.org.

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- **Obesity and Cancer Bundle: Oncology Provider Guides and Patient Booklets** includes practical tips and implementation strategies for weight assessment and weight loss, as well as information about how to be reimbursed for these services.
- Find these and other patient resources for your practice at **Cancer.Net/estore**.


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