

views

Simple Talk

Support for families when a parent has cancer

BY SARAH JOHNSON, MSW, LICSW, OSW-C, AND ALI CAIN, MSW, LICSW, OSW-C

Allina Health is a nonprofit healthcare system in Minnesota and western Wisconsin consisting of 13 hospitals, 90 clinics, and various community-based services. The Virginia Piper Cancer Institute embodies whole-person care, one of Allina Health's core values. Our cancer program is dedicated to caring for patients' physical health and their psychosocial well-being.

As oncology social workers, we demonstrate this holistic, patient-centered approach through our Simple Talk Program, which centers on treating the whole patient alongside the whole family. Simple Talk provides an opportunity for parents to meet with social workers, in person or over the phone, to discuss their fears and concerns about cancer, while learning how to best communicate with and support their children.

Our program was inspired by the book *Simple Talk for Tough Times*¹ by social worker Marcia Carlson, MSW. Published in 2013, the book gives practical advice on how to communicate with and support children with a family member who is diagnosed with cancer. Parents in our cancer program are offered the *Simple Talk*¹ book, usually at the time of their initial diagnosis; however, it is available to everyone, at any time. Patients do not need a referral to receive a copy.

Carlson writes, "The diagnosis acts like an 'elephant in the room.' It is something big that everyone is aware of, but no one wants to talk about."

Program Development

Ongoing requests from medical providers wanting resources for their patients with

children made it clear that this was an unfulfilled need in our cancer program. Our social workers also received requests from parents asking for support with these conversations. To meet these unmet needs, our social workers developed the Simple Talk Program, named in honor of Carlson's work. Today, our Simple Talk Program provides families with the tools they can use to communicate with and support one another through a cancer diagnosis and treatment.

When families are referred to Simple Talk, they are connected with an oncology social worker who helps them decide on the resources that will best meet the family's needs. Often these referrals occur at the onset of a new diagnosis, when parents worry about "breaking the news." During this session, patients are provided psycho-education related to child development—for example, children's understanding of illness and information processing, children's normal reactions, coping techniques, and recommended language use, among other supports. As social workers, we spend time answering questions, coaching patients through difficult conversations, and helping them prepare to answer their children's questions. We also make age-appropriate recommendations for education, online resources, books, journals, and drawing materials.

Young children often benefit from picture books. Seeing an animated picture of a radiation machine or where on their parent's body the cancer is located can help children understand and comprehend complex information. We find that teenagers are often interested in online resources, like the riprap "when a parent has cancer"² website

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(riprap.org.uk) or guided journals to help express their thoughts and feelings.

When we meet with parents, we review typical reactions and questions their children may have. For example, younger children (four to seven years old) may ask, “Did I cause the cancer?” and “Can I still hug mommy?” whereas teenagers may not ask questions at all and opt to spend more time with friends. Reviewing child development and cognitive understanding of illness, grief, and loss can be helpful for parents in understanding how their children think, process, and feel.

A distinct component of the Simple Talk Program is the delivery process, as well as who is invited to participate. The program can involve one or both parents but can also include other important adult figures in a child’s life. Sometimes parents choose to involve their children in a follow-up visit with the social worker, as well. Many parents report that face-to-face conversations are more beneficial because they are able to process their own fears and concerns, and they walk away with a plan and strategy for approaching these difficult conversations with their children.


Growing the Program

In 2019 I (Sarah Johnson) created a journal titled *Our Family’s Journey: A Guided Journal for a Child Who Has a Loved One with Cancer* because I recognized that children do better with hands-on materials. This journal provides a colorful, fun, and safe place for children to draw or write their feelings, thoughts, and questions about their loved one’s cancer at their own pace and comfort level. Some of the topics the journal addresses include feelings, emotions, their support circle, the importance of self-care, asking questions, and the idea that it is okay to have fun even during a difficult time. Our social workers educate parents about the journal during their Simple Talk session, demonstrating ways in which parents can use the journal, so they can introduce it to their children at home.

Response from patients about the Simple Talk Program has been incredibly encourag-

ing and positive. Patients have expressed relief in having tools and techniques to share with their children throughout this change in their lives. Parents are comforted in learning that there is not one perfect way to support children; rather, emphasis is placed on acknowledging each child’s uniqueness and a family’s different and varying needs.

In a conversation with her social worker, one parent voiced concern about the eventual hair loss she would experience and how her family would react. We gave this patient take-home tools to help alleviate her children’s worries and answer their questions, including two children’s books about moms experiencing hair loss from chemotherapy to take home and share with her children (*Nowhere Hair* by Sue Glader and *Chemo Cat* by Cathy Nilon).^{3,4}

Virginia Piper Cancer Institute recognizes that a cancer diagnosis extends beyond the patient and affects his or her whole support system. One of the greatest initial fears for parents diagnosed with cancer is the welfare of their children. The Simple Talk Program is our response to these fears and concerns. We believe that delivering effective cancer care needs to include specialized support for parents. Parents and children alike deserve to feel prepared, empowered, and cared for while on their path to healing. 

Sarah Johnson, MSW, LICSW, OSW-C, and Ali Cain, MSW, LICSW, OSW-C, are oncology social workers at the Virginia Piper Cancer Institute, Minneapolis, Minn.

References

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2. Riprap. *When a Parent Has Cancer*. Available online at riprap.org.uk. Last accessed April 13, 2020.
3. Glader S. *Nowhere Hair*. Thousand Words Press; 2014.
4. Nilon C. *Chemo Cat*. Ravenna Press; 2007.



As an oncology social worker for the past 11 years, a common theme I have consistently heard from newly diagnosed parents is “What do I tell my kids about my cancer and how will this impact their childhood?”

Since the development and implementation of the Simple Talk Program, I have seen relief and reassurance when parents learn there is help, support, and guidance in addressing their concerns. For me, one of the great feelings as a member of their cancer team is to witness them finding hope and building confidence to tackle their fears and worries.

Sarah Johnson, MSW, LICSW, OSW-C



I work with families to assess their needs and provide tools in the form of books, online resources, conversation guides, and one-on-one coaching to offer the right

resources, at the right time. This work certainly pulls at the heartstrings, yet it is deeply satisfying to be given an opportunity to remind people of their strengths and capabilities. I help enforce, and sometimes restore, a parent’s confidence by highlighting the position they are in to provide the connection and comfort their children need.

For many parents I work with, their children are both their greatest source of strength and deepest sense of angst when facing a cancer diagnosis. Simple Talk has provided me a more holistic response to the unique challenges parents with cancer face.

Ali Cain, MSW, LICSW, OSW-C