



GROW OLD
TOGETHER



graduation?

FAMILY

Don't forget
At end a
secret squeal

A small yellow sticky note with handwritten text and simple line drawings. The drawings include a person sitting at a desk and a box.

WEARING



Bridging the Gap



A Family Program for Parents with Cancer and their Children

In 2004 oncology social worker Krista Nelson, MSW, LCSW, OSW-C, and several supportive care colleagues at Providence Cancer Center, Portland, Ore., saw that patients with children were struggling to communicate with their families about their illness and realized that there was no real support available to this hidden population. In response to this patient need, these clinicians developed the Providence Family Program, which uses a group model to deliver early and ongoing intervention and support throughout the cancer care journey. Creating a framework to talk about the impact of cancer on the family, the Providence Family Program offers effective communication techniques and coping strategies, as well as practical tips to help families adjust to their “new normal.”

Communication is Key

According to the Institute of Medicine (IOM), 24 percent of parents undergoing cancer treatment have a child 18 years of age or younger at home.¹ Recently, the IOM released a workgroup report about families touched by cancer, and though it focused heavily on pediatric oncology, the report also highlighted the importance of treating the whole family.² Research and experience tells us that parents want support and information on how to talk to their family about a diagnosis of cancer.

For example, one day during clinic, as the oncology social worker, I was seeing a patient who’d just found out she had

The Providence Family Program educates parents on how to use developmentally and age-specific information about cancer when talking to their children.

metastatic breast cancer. I asked her to tell me about her treatment plan. The patient replied, “You know what? I actually did not hear any of that. All I could think about was my kids, how I was going to tell them, and if they were going to remember me.”

Another patient that I saw was a head and neck cancer patient who was going to have a significant surgery in addition to chemotherapy and radiation, and she wanted advice on how to talk about this treatment regimen with her family.

Some of the most important education we can share with patients diagnosed with cancer is how to talk to their children. I remind these parents that they know their children much better than the treatment team does, offering reassurance that the dread of this conversation is often worse than the actual conversation



itself. Perhaps the most important message for these parents to hear is that their cancer will most likely not have any long-term negative impact on their child's functioning.

The Providence Family Program educates parents on how to use developmentally and age-specific information about cancer when talking to their children. Our experience has been that parents coming to the hospital with an older child want them to spend less time in the hospital. Younger kids will sit and play at the bottom of the hospital bed all day, but parents tell us they want a "sense of normalcy" for their teenagers.

Many cancer patients tell me that they worry about their children asking if they are going to die. Conversations around mortality are very emotional, and patients express uncertainty about how to answer that question. I advise patients to tell their children what they know, framing the conversation so the children understand that, for example, while the physicians do not think the parent will die right now, they will let the children know if the situation changes. I urge parents to create a legacy of truth

with the information they share with their children, encouraging parents to use real words—like cancer and chemotherapy—and to explain what these words mean so that their children understand.

As an oncology social worker, I am just one member of the multidisciplinary cancer care team, and it does not fall to only one staff member to have this conversation. Our supportive care staff reminds other cancer care team members that we *all* support our patients and their families and, as such, any one of us can provide needed resources. Speaking with families in our Providence Family Program, I've heard stories about how children found out about their parent's illness from a third party—sometimes overhearing phone calls or conversations among adults. That is not the optimal way for children to learn this news. Bottom line: as healthcare professionals, we should reach out early and often to our patients about any issues with their children and other family members.

Treating the Whole Family

A 2014 literature review article identified three common themes among cancer patients who expressed concerns about the best ways to talk with their children:³

1. Parents try hard to maintain normalcy in their children's lives.
2. Parents strive to be good parents and parenting became a priority.
3. Parents are concerned about the emotional impact their cancer has on their children.

The article also states that it is imperative that the cancer care team provide parents with the support and resources they need to feel confident in preparing their children for this change. While we all do our best to provide great care for our patients and families, this literature review article highlighted an opportunity for clinicians to think outside of the box in terms of the services and resources we provide.

So what exactly can members of the cancer care team do? First, identify the patients in your program or practice who have children at home. If you're seeing a patient under the age of 50, you may want to proactively ask about his or her family life. If you don't have the opportunity to speak personally with patients about their children, at least provide patients with community resources and help educate other staff on ways to talk about this topic with patients. Patients and families who seem to be doing well also want support about how to parent through this challenging time. In other words, do not simply focus on your highly-distressed patients; this type of education and support is beneficial to all patients with children still at home. The Providence Family Program supports families as a unit, with the understanding that cancer does not just affect the patient. By supporting the entire family, we hopefully can improve their everyday life.

After dream room meditation that focused on creating a safe place, an eight-year-old girl made this flag; her mom has stage IV breast cancer.





A photo of Portland's Hawthorne Bridge taken by the author.

Building the Bridge

Today, the Providence Family Program:

- Is free to patients and families in our community
- Accommodates different learning styles and needs
- Uses evidence-based interventions
- Offers peer support
- Includes support around parenting with cancer
- Incorporates art as a modality to communicate about cancer.

The staff that manages and runs the Providence Family Program is a combination of hospital employees and volunteers; it requires about 10 to 11 people to host this monthly event. Most staff are social workers, and volunteers are required to take specialized training. Clinical staff pre-screens all participating families so that we are prepared to support each family and child's needs. If a patient is near death, it may not be appropriate for the family to attend the program, as we do not want to introduce another loss to group members. For these families, our supportive care staff offers monthly telephone support and support groups, which are open and ongoing—anyone can come and go at any time. Each month about 30 percent of Providence Family Program participants are new to the program.

To educate staff about the Providence Family Program, our supportive care team put together a one-page glossy handout, containing tips and education on talking to kids about cancer. View this handout online at: acc-cancer.org/oncology_issues/JA2016. This free handout is available in the hospital and at all

clinic locations. We also share it with other healthcare professionals in the community.

One of our challenges is finding space for the program. Currently, the Providence Family Program requires seven different spaces for activities. However, because the hospital is less busy at night, we can use hallways for high-energy play with the younger kids.

About a week before every meeting of the Providence Family Program, we mail out the planned curriculum—including the research that supports the curriculum—to our volunteers. Today the Providence Family Program meets monthly, with anywhere between 20 to 60 attendees. Hosting this group is similar to throwing a big party. We provide dinner (usually pizza) in a family setting, so families can come together and share a meal. Some of our families come from two hours away to participate in the program. After dinner, we divide the participants into three main groups: children, teenagers, and parents. Sometimes we may have two parent groups, depending on the number of attendees. Each group has at least one masters-level trained social worker to lead the group.

Group Structure & Activities

Families are invited to participate in a free meal 30 minutes prior to group, and the group runs about 90 minutes. After a welcome and the meal, we split into age-specific groups. Typically, the children's group begins with a check-in. We sit together on the floor and have each child say who in their family has cancer, what kind of cancer they have, and how they might be feeling. We end



A mom with stage IV colon cancer creates a flag that communicates her hopes for herself and her family.

The Nuts & Bolts of the Program

The Providence Family Program is free to our community; participants do not have to receive treatment at Providence Cancer Center. The program receives referrals from physicians, nurses, other social workers in the community, or families who know someone with cancer. For our team, the question: “How do I tell my children that I have cancer?” triggers a referral to the Providence Family Program. We have a conversation with the patient about how to talk about death and perform an assessment to learn more about their children. We ask, “Is there anything you think I should know about your child that would help them succeed or be more comfortable in our group?” The first time the family attends the program, we have them complete a consent form.

We know that children do better, in general, if they have some rituals in their life, such as sharing a meal with family. Accordingly, one of our art projects was for children to use a non-toxic paint to decorate the back of a plate with an activity they hoped to do with their parents or a favorite celebration. The bridging activity comes when children then take the plate home and use it during a shared meal.

It is important to have a variety of play available for the younger children. For example, we have a quiet space, dollhouses, board games, art supplies, and dress-up materials.

Two or three times a year, we keep the family together as a unit and do an activity together. Some past family activities have

been a drum circle, memory books, candles, wish flags, or making a coat of arms around a family picture taken that evening.

One year we provided “coping backpacks” before the school year started. Our staff filled the backpacks with iTunes gift cards, stress balls, journals, activity books, tissues, and healthy snacks. The kids decorated the outside of the backpacks and encouraged parents to write letters to their children to include inside.

Fear collages are always a powerful activity. The kids populate collages with moving images that represent their fears about cancer. While this activity can be difficult and emotional for parents to hear, these fears may not have been discussed before, and this activity creates an opportunity for children to share.

The annual budget for the Providence Family Program is modest. Food costs for the program range between \$200 to \$300 a month; art supplies generally run about \$300 a month. Not including staff time, the Providence Family Program costs between \$6,000 and \$7,500 annually. Our medical foundation has helped us partner with community groups to help fund and support this program. We’ve even had children who’ve known someone who has been a part of the group raise money for the Providence Family Program because they understood how important the group was to their friend.

The Providence Family Program is available year round. Since the program has grown in popularity, we’ve made the informal

decision that families no longer dealing with cancer (about two years post-treatment) would no longer benefit from the program. The majority of families opt out of the program on their own. In the rare occurrence when a family is still attending two years post-treatment, we suggest other activities, such as volunteering in the community.

Patient Feedback

Since launching the program in 2004, we have collected some quality outcomes research. Almost all (95 percent) of our families felt their children benefited from being around another child who had a parent with cancer. Other questions we asked Providence Family Program participants:

- Do you feel the art activities we do in the Providence Family Program help your family talk about their feelings about cancer? (84 percent answered yes; 5 percent were unsure.)
- Do you feel like participating in the Providence Family Program increased your family's communication about cancer? (68 percent answered yes; 20 percent were unsure.)
- Has the Providence Family Program changed the way you communicate as a family? (68 percent answered yes; 20 percent were unsure.)
- Has the Providence Family Program reduced your children's anxiety about the cancer? (68 percent answered yes; 20 percent were unsure.)

Overall, 63 percent of respondents felt that participating in the Providence Family Program helped bring them closer together as a family. The box at right showcases first-person testimonials about the program.


Going Forward

For the past 11 years, the Providence Family Program's main themes have been communication, feelings, and coping. As we begin to expand and update our meeting curriculum, we frame those themes into our discussions:

- What are we trying to be thoughtful about?
- What does the research tell us about how kids cope?
- How can we support these children and families?
- How can we integrate the use of creative modalities into our support?

When first developing the program, we assumed most of our parents would be women with early-stage breast cancer; however, about 70 percent of the parents that attend the Providence Family Program have advanced cancer. Since the majority of participants are patients with advanced-stage cancer, many do die. After a parent dies, the family does not come back to the Providence Family Program. Instead, we refer these families to bereavement support services in the community. That said, the Providence Family Program does honor the children of deceased parents by asking the participants in the next group to make wishes on a ceramic heart. This heart is then mailed with a bereavement packet to the families, which includes literature on how to support children when a parent dies, community

bereavement resources for children and adults, and a note from the team.

Today, with the emphasis on patient-centered care, some cancer centers are looking to develop these types of programs and services. The model we used to develop the Providence Family Program is easily replicable and is, in fact, featured in the *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*, a compilation of successful evidence-based interventions.⁴ 

Krista Nelson, MSW, LCSW, OSW-C, is an oncology social worker and program manager of quality and research, cancer support services, Providence Cancer Center, Portland, Ore.

References

1. Semple CJ, McCance T. Parents' experience of cancer who have young children: a literature review. *Cancer Nurs*. 2010 Mar-Apr;33(2):110-118.
2. National Academies of Sciences, Engineering, and Medicine. 2015. *Comprehensive cancer care for children and their families: Summary of a joint workshop by the Institute of Medicine and the American Cancer Society*. Washington, DC: The National Academies Press.
3. Philips F. Adolescents living with a parent with advanced cancer: a review of the literature. *Psycho-oncol*. 2014;23:1323-1339.
4. Christ G, et al. *Handbook of Oncology Social Work: Psychosocial Care for People with Cancer*. Oxford University Press; 2015.

In Their Own Words

"It [the Providence Family Program] is such an incredible and helpful place to be. Cancer is so confusing, as are all the repercussions of cancer on the family. The support and love we receive in this group allows us to find safety and love in very challenging times."

"There is a grief in not being able to control cancer, and the damage it does to everyone. You guys give us renewed hope in this group. Thank you from the bottom of our hearts."

"We were hesitant to come [to the Providence Family Program], but it was the best place for my kids. They loved seeing other kids their age going through the same thing."

"The only thing that would make the group [the Providence Family Program] better is if the group was to meet more often."