



*Family  
Ties*

Comforting the parents  
of pediatric cancer patients

*By Tom Schaffner*

*A*s radiologic technologists and radiation therapists proceed through their busy days, they see more than their fair share of emotional patients and their families. For those who work with pediatric cancer patients, emotions tend to run even higher.

Parents' fear that their child will be harmed during radiation therapy or become ill by drinking contrast is ever-present. It is that fear of the unknown that can add more stress to an already tense situation.

Technologists, social workers, nurses and child specialists offer advice on how to talk and offer support to parents as they try to cope with their child's diagnosis and treatments.

### *Education Eases Anxiety*

Ask any technologist or therapist what is the most important part of dealing with patients and their families and many will say that education tops their list.

When supplying patients' families with information on cancer diagnosis, treatment and post-treatment options, medical personnel need to know not only what information to give, but also how to present it.

Tracy Moore, CSW, pediatric oncology social worker and director of patient education and support services at Children's Brain Tumor Foundation, New York City, recommends the parents bring someone — whether it's a friend or another family member — with them to the medical team meetings to act as a "second set of ears."

"In a crisis, it's really difficult to hear everything a physician or educator is explaining," Moore says. "Combine that with the new medical language that's being conveyed and it can be overwhelming for anyone. And this information is critical to their child." She says many hospitals will actually provide additional support such as a social worker, a child life specialist or a nurse practitioner who can re-educate the parents after the meeting.

Moore says most physicians, especially those in pediatrics, are very adept in speaking "at the family's level." She says medical personnel should use terms families can

*"In a crisis, it's really difficult to hear everything a physician or educator is explaining. Combine that with the new medical language that's being conveyed and it can be overwhelming for anyone."*

— Tracy Moore, CSW

understand. For example, a physician probably wouldn't say, "Your child may be suffering from neutropenia." Instead, physicians would say there is a lowering of blood counts and then explain that white blood cells fight infection, while red blood cells carry oxygen and nutrients to the body.

Lara Strickland, MS, child life specialist at Children's Medical Center, Dallas, assists medical staff when working with families of children with cancer. Strickland recommends that clinicians repeat all the important information that clarifies misconceptions — such as the difference between childhood and adult cancers and their cure rates — to the parents.

"Parents often have to hear statements three times before they are able to recall the information," Strickland says. "Discuss the fact that most children treated at pediatric cancer centers are enrolled in Children's Oncology Group national protocols where every child with the same diagnosis anywhere in the country receives the exact same treatment regimen." She says that is often overlooked but comforting information.

Receiving the information is one matter; how the parents react to the news is another. "The explanation of the exam that is given to parents depends on where the child is in the cancer diagnosis," says Joe Zagurski, RT(R), lead MRI imaging specialist for the department of magnetic resonance imaging at Children's Memorial Medical Center, Chicago. "When learning their child has a brain tumor, parents usually react much differently than they will down the line, when the child is already through

the treatments and things are looking better. Parents want to be kept informed, especially when the diagnosis is made, because it's all new to them. They are also looking for reassurance that somebody qualified is doing their child's exam."

Zagurski urges healthcare professionals to be careful when providing families with information and not mislead or make them believe things are better without having a formal diagnosis from the physician.

Since many pediatric patients need to be sedated to image them lying completely still, Zagurski says this is the opportune time to speak with the parents, since their child is being cared for and the parents' attention at that time is not centered on their child.

In addition to sedation, Regina Jackson, RT(R), BS, CMRT, who works in the Clinical Care Center at Texas Children's Hospital, Houston, says parents are also concerned about their children drinking contrast. "We often have to explain why it's important for them to drink the contrast," Jackson says. "We know that they don't want to drink it. It's not the best tasting drink. But in the end, it will give the physicians the results needed to give the child the best treatment." After this is explained to them, she says the parents are usually satisfied.

"You have to take the extra time to explain to the parents exactly what we are going to do to their child," Jackson says. "Always be open and up front. If it's something that's going to hurt, explain that to the parents and the child before it's done."

Medical personnel can also supply

# Little People Facing Big Problems

## Talking to kids about their parents' cancer

**A**s the director of social work services at Fox Chase Cancer Center in Philadelphia, Joan F. Hermann, LSW, helps children of cancer patients cope with and understand what their parents are going through from diagnosis through treatments.

When a parent is first diagnosed and they are asked, "What are you going to tell your kids about this?" the answer is often, "What do you mean? I'm not going to tell them anything." The parent is so overwhelmed in the beginning and worried. Hermann says the first question they think their children will ask them is, "Are you going to die?" That question paralyzes the parent because they have no idea what will happen, so the idea of just talking to their kids is overwhelming, she says.

When parents rationalize to Hermann that their children are too young and don't need to know what is going on, she tells them the kids need to be informed. "Children are much more aware than you think," she says. "They know something's wrong. They may not know what it is, but something is wrong. And that kind of anxiety just exacerbates a situation," she adds. Emotional stress can lead to other problems, such as kids refusing to go to school because they are afraid of what might happen while they are away.

Parents don't have to give their kids an elaborate explanation, she says. In very basic, concrete language, they should explain what the disease is and let their children know that while they are receiving treatment, they may be a little crotchety. Parents should also let the kids know that the emotional change is not their fault. Children often blame themselves if something bad happens, so

reassuring them that they have nothing to do with their parent's cancer is necessary.

"It's a very loaded issue for children and very difficult for parents to address," Hermann says. "We want to protect our children from bad things and misguidedly may think we are protecting them from worrying, when in fact, that is impossible because you can't keep cancer a secret."

Herman says it is also important for parents to let their children know up front in case the kids hear the news from another source first, such as another child at school who heard it from his or her parents. Hearing this information from someone other than the child's parents could create a barrier between parent and child. Not hearing the information directly from the parents could lead the youth to fear the worst.

Fox Chase Cancer Center offers corresponding support groups for both the kids and their parents, since most issues have to be addressed through the parents. "The kids trust their parents more than anyone, and you want to empower the parents to be able to handle things right from the beginning," Hermann says.

"Parents should bring their children to the hospital and show them the radiation therapy area," she continues. "Introduce them to the technologists, show them the machines and walk them around, so that you address their anxieties about where you go and what happens to you when you're gone, so their imagination does not run wild."

— T.S.

additional educational resources to curious parents, but Toni Aiuto, MSW, pediatric social worker in the child and family services department at Sunrise Children's Hospital, Las Vegas, says the information should not be forced on the patient or family if they are not receptive to it.

"Everyone is an individual and must be treated accordingly," Aiuto says. "What one person may want, another may not. Just because they share commonality in diagnosis does not mean that they are one in the same."

Let both patient and family know that they have rights and responsibilities, including participating in the medical decisions, advocacy and a right to express

themselves, she adds. When discussing medical information, Aiuto notes that a hospital room is not always the appropriate place. An alternate private area should be available if needed.

### *Lean on Me*

The reaction of each parent to their child's diagnosis or treatment procedures can differ immensely. Where some parents may be very accepting of information given to them by physicians and technologists, others may not take the news well. In cases of the latter, additional support must be called on to help ease the tension.

Jackson says if she notices a parent is

not coping well with the information presented or the procedure being performed, she will bring in a social worker or child life specialist, an expert in handling pediatric cancer patients and their families.

"Sometimes you get people that, no matter what you say, it's just not good enough," says Jackson. "So we as technologists have to know when to cut it off and seek outside forces to intervene. When the parent gets upset, the child senses the parent's stress and there's a good chance the child will get upset as well. They know this is bad and become fearful. If this happens, you will lose the whole exam."

"But a lot of times, it's therapeutic for the parents if we just listen to them,"

*“Parents often have to hear statements three times before they are able to recall the information.”*

— Lara Strickland, MS

she continues. “By being a good listener, a lot of times [the parents] will want to tell you everything or take things out on you, but we are there for them and just listen.”

Jackson adds that you need to sympathize with a family’s situation, have patience and put yourself in their shoes. “When you’re dealing with a child with a terminal illness, you’re not just treating that child; you’re treating the family as well,” she says. “You really have to be a counselor and a listening ear for the parents and the families that come in with these children.”

At the Children’s Brain Tumor Foundation, Tracy Moore leads support groups for parents whose children have cancer. The foundation sponsors a parent-to-parent network in which people share their own experiences with trained parent volunteers whose children have had brain or spinal cord tumors. The foundation also conducts a parent support group in which families from all over the country can call in weekly to a conference call setting and discuss their concerns and emotions.

“A lot of times the parents are asking us the same questions that they’ve asked the physician to see if they get different answers or hoping for different answers or checking them for trust,” says Moore. “But since we’re not physicians, we don’t give medical information.” She says that in cases where the parent is looking for medical information, her job is to reframe the question and turn it into a therapeutic conversation. For instance, a question about the child’s diagnosis could be reframed to, “It sounds like you’re really nervous about it recurring?”

Moore recommends that medical staff revisit the parents after their initial meetings and ask the families some questions to make sure they understood the barrage of information they received — and revisit

the same conversation as many times as necessary.

“I think some families learn through diagrams, some by hearing the information and others learn really well with seeing the equipment in person and doing a run-through of the procedure,” says Moore.

### *Ties That Bond*

For the children’s trust and the parents’ peace of mind, it is important for the staff to bond with their pediatric patients. Denise Fleig, RN, care manager for Midwest Children’s Brain Tumor Center at Advocate Lutheran General Children’s Hospital, Park Ridge, Ill., has a strategy she uses for both child and parent.

“I start introducing all team members to the patient and their family even before we know if the child needs radiation or not,” Fleig says. “[The families] start to meet everyone so that right from the beginning they get that team approach and get everyone’s input.”

Once the treatment plan has been decided, Fleig says pediatric patients get to stay in a separate waiting area designed just for kids. “The waiting area is like a kids’ wonderland,” she says. “There are art projects, games, toys, snacks and video games — you name it. The staff and physicians go into the play room just to meet the kids and play with them in order to build trust.”

Although Moore encourages the parents to be involved, she notes that in some cases, it is better for the parents to leave the therapists alone to bond with the child. “It’s not even that it’s a distraction,” Moore says. “It’s more that the kids play on their parents more.” However, she notes that there are cases where the kids will be better if their parents are still in the room.

At some point though, it is necessary to

work on separating the parents from the child because when the radiation treatment is actually applied, nobody can be in the room with the child. At that time, the therapist uses videos and the intercom to distract the child while the radiation dose is administered.

If the parents are not comfortable with leaving their child, they can stay with them right up to the time of radiation. The treatment itself only takes 10 to 15 minutes, so they can stand with the physicians and staff behind the partitions. They can talk to their kids through the intercom or they can see them and what’s going on.

“Part of my role is to ‘hand-hold’ for the parents while the technologists spend time with the kids,” Fleig says. “It’s just explaining everything — and explaining it over and over again — because they are so anxious and getting so much information thrown at them.”

Fleig says it’s very frustrating to parents if they have multiple physicians attending to their child. They don’t know which one is in charge or they have to carry the communications between physicians. “To walk in [to the hospital] and know that all of the physicians are on the same page is a big relief to them,” she says. “I spend a lot of my time talking with my counterparts in radiation therapy and the physicians so I can be sure that everybody knows what’s going on with any particular patient.”

Fleig says empowering the parents during their child’s treatment is essential. “The parent needs to be part of the team,” she says. “They will always be the best person to advocate for their child. If the parents have the time, they should do a little research and find a center that has pediatric specialists delivering radiation. It’s very different from adults, and you want the people to work well with your children.”

— Tom Schaffner is the editor in chief of RT Image. Comments on this article are encouraged and can be directed to [tschaffner@rt-image.com](mailto:tschaffner@rt-image.com).

