



California Hospice Foundation



CHOICES

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Fall 2014

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Pediatric Hospice Care Helps Parents Focus on Their Family

When people ask Pam Romias what she does for a living, their first reaction is, “How can you do that?” As a registered nurse and program liaison for the pediatric care programs at Hinds Hospice in Fresno, she’s used to that response. “We’re in a unique situation,” she said. “Hospice is harder and sadder with children because it’s not supposed to be this way, but the truth is, and I’m getting goose bumps just talking about it, it’s always such an honor to be involved in this time of their lives.”

Pediatric hospice care at Hinds

The pediatric team at Hinds takes care of infants, children, and young adults up to the age of 21 who have life-limiting illnesses. Hinds has three pediatric programs: hospice care, concurrent care, and pediatric palliative care waiver program.

The hospice care program focuses on comfort and quality of life care, managing symptoms and anxiety for patients in their last six months. In addition to home health and nursing care for the child, a team of social workers, volunteers, and chaplains provide emotional and spiritual counseling and support for the entire family.

Concurrent care is a relatively new program established with the enactment of the Affordable Care Act. It allows parents to not have to choose between comfort care (hospice) and curative care for their child. If qualified, the patient and family receive the supportive services of hospice alongside palliative care treatments, such as

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If you or anyone you know has a need for Hospice Information and Referral services please call the California Hospice Foundation’s toll free number: 888-252-1010

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radiation, chemotherapy, and specialty physician visits.

“No parent wants to give up on their child,” said Victoria Cruz-Hernandez, MSW, a social worker at Hinds who specializes in working with families of pediatric patients. “Forgoing curative treatment is seen as giving up hope. This program offers hope like a comfort.” Pediatric hospice care is unique in offering concurrent care. Adult hospice patients usually don’t have that option.

Children are referred by the California Children’s Services agency to the pediatric palliative care waiver program. Similar to the concurrent care program, the goal is to let the child receive palliative and hospice care at home, not in the hospital.

Pediatric hospice patients and their families also have access to massage, art, music, and child life (play) therapy to help them deal with and even learn about the child’s condition. Victoria worked with a family whose five year old son, the patient’s brother, always looked forward to the child life specialist’s visits. “The therapy gave him an outlet to express his feelings and cope with his brother being ill.”

Children and parents coping with reality

“Pediatric patients aren’t just little adults,” said Victoria. “They require a unique type of care and training.” Hospice staff works very closely with the parents as well as the child. They make sure parents understand the process of the disease and know how to provide the appropriate care for their child, for example, managing their medications, catheter, and IV. Pam said, “The entire team does a lot of research so we can discuss the disease with parents in laymen’s terms.”

“It’s best to be honest with a child about what’s going on with their body,” said Pam. “Most of the time they know they’re going to die and their parents know, but they don’t talk to each other about it because they’re each trying to protect the other.” With the counseling and support of hospice chaplains and social workers, parents and children begin to have the necessary conversations about what’s happening in their family.

The parents of one of Victoria’s patients, a boy with a brain tumor, hadn’t yet talked openly with him about his condition. “We honored their wishes,” said Victoria. “But one day, he wanted to play doctor and have his mom play the patient.”

He pretended to draw blood from his mom. After a pause, he said, “I got your results.” The mom asked, “Am I okay?” “No,” he said. “It looks like you’re going to die.” The mom was taken aback and thought to herself, “This is our talk.” Her son said, “Don’t worry, it doesn’t hurt. You’re not scared, are you?” She replied, “I don’t want to leave you.” Her son said, “Once you die, you’ll be gone but not really. We’ll always be together.”

Victoria said, “That’s the one constant. Kids always know what’s happening but there’s not usually an open dialogue because it’s so hard, emotionally draining and traumatizing. Our goal is to encourage those talks.”

After a pediatric hospice patient dies, very often the relationship with the family continues. Families keep in touch by sending cards, photos, and news over the years. Pam said, “It might be that way because we helped them through a difficult period by making life more meaningful to them.” In the midst of a devastating experience, pediatric hospice care helps families to focus on each other and, after their child is gone, to heal.

Resources

Caring Connections

www.caringinfo.org
caringinfo@nhpco.org
800.658.8898
877.658.8896 Multilingual

Partnerships for Parents

A Program of the Children’s Hospice and Palliative Care Coalition

www.partnershipforparents.org
www.padrescompadres.org

California Hospice Foundation

www.cahospicefoundation.com
info@calhospice.org
888.252.1010

Talking with Your Child About His or Her Illness

I don't know when the best time is to talk to my child about some of the things I know we need to discuss. I want to make sure she isn't wondering about something and is afraid or having a hard time asking about it.

No matter how young or old a child is, each child handles illness and treatment in unique ways. Reactions can be influenced by past experiences, how the child is treated, how safe he or she feels, how much discomfort he or she has, and other issues.

You can help your child find ways to cope with this life-changing experience in a positive way. As a result, your child may discover important things—about himself or herself, as well as about you—that might otherwise never have become known. Together, you can grow in love, courage, patience, resiliency, strength and hope.

Talk with your child about the illness and treatment.

You may feel like there is so much to talk about with your child that you don't know where to begin. You may also be having difficulty getting your child to open up and share how he or she is feeling and coping with the news about the illness. Perhaps he or she feels too upset to do much talking. Whatever the case, it is important that you and your child keep the lines of communication open. The following are tips that may help you talk with your child:

- Let your child know you will always love him or her no matter what he or she might say or think. Repeat this often.
- If you don't feel completely comfortable talking about goals and hopes, take a few moments to think about how you have talked about other difficult issues with your child and draw upon that experience. Try to use those same ways to engage your child so he or she will feel safe.
- Rather than trying to cover everything all at once, try discussing things in smaller bits, giving your child time to take in the information.
- Trust your instincts to help you determine how much to say and when. The right moments will appear and when they do, you can talk with your child lovingly and confidently.
- If your timing is off, just be patient. Your child will let you in when he or she is both able to talk and needs to do so.
- Young children naturally focus on more concrete information. Make sure your child understands the plan for today and what's going to happen in the next few hours or next couple of days.
- Older kids often try to go it alone. They may find it easier

to talk to peers with similar medical conditions. Talk to your child's medical team about appropriate chat rooms and making contact with other children with similar experiences.

- Reassure your child that you will do whatever you can to prevent pain and help him or her cope with any changes.
- Ask to meet with a child life specialist (at the hospital or clinic), who can help your child talk about feelings and fears, through conversation and/or play therapy.
- Be kind to yourself and to other family members who may be involved. This is a challenging time for all of you and each of you will have your "difficult moments" along the way.
- Keep communication open during health care visits. How much and when to share information regarding your child's condition is an important topic. Ask your doctor and the team caring for your child for guidance as they begin to know and understand your child. Discuss ways to help your child feel in control at a time when so much seems beyond control.
- Use comforting language and a tone of voice that expresses confidence and warmth.
- Be sure your child understands everything that is discussed during doctors appointments or treatments.
- Don't be afraid to give the healthcare team feedback if they are not getting through or are confusing or frightening your child. "Medical talk" confuses most adults, let alone children who may be scared by their doctor and other health care workers.
- Help your child prepare a list of questions for the healthcare team before visits and practice going through the questions to help your child become confident about speaking up when something is not understood.
- Remember, you know and understand your child better than anyone else.

Source: Caring Connections, a Program of the National Hospice and Palliative Care Association



How we help. How you can help.

In a world of the internet and technology, we are able to help tens of thousands of patients and their families each year with our tiny staff of three. We are always updating our hospice listing and adding resources and materials to our website so that they can have information at their fingertips in a matter of seconds.

Still, we know the value of a personal connection. Each day, we receive phone calls from people during the most challenging times of their lives. Our staff provides guidance, information and often, we just just lend an ear. Most importantly, we connect them to end-of-life care that brings comfort to both the patient and their family.

Here's where you come in. **100% of our work is supported by donations.** Our employees, the technology that allows us to reach so many, printed material that we send out, connecting families to hospices... none of it would be possible without you.

We cannot thank you enough for your support, and we hope you will continue to contribute to our work. Whether you can give \$20 or \$200, it all makes a difference.

Please use the enclosed envelope and give today. *Thank you.*

Car Donations

If you have a vehicle that you are thinking of trading in or selling, please consider donating it to the California Hospice Foundation's Donate a Car Program.



When your vehicle is sold, the proceeds will go to the California Hospice Foundation (CHF). You may also be able to deduct the fair market value of your vehicle as a charitable contribution for income tax purposes.

We have partnered with Car Program, which accepts most vehicles, including cars, trucks, trailers, boats and RVs. The donation process is easy by fax or by phone.

If you have questions or would like to learn more, please visit our website at www.cahospicefoundation.com or call us at (888) 252-1010