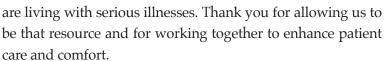
Cultivating Hope

From Our Leadership

In our field of work, having extra hands can make all the difference in the level of care and comfort patients and families receive. Our continued partnership with you and your team allows us to be those "extra hands" for your patients who



This new publication, *Cultivating Hope*, is full of news, resources and stories to keep you informed about how we are working to enhance our partnership with your team now and in the future. We hope that as you read this information, you will share it with your colleagues.

It is our privilege to work with you and your team to ensure the highest level of care and comfort for our patients, their families and the entire community.

Thank you,

Kristen Ma

Dr. Kristen Moyer Pediatric Medical Director Sunflower Pediatric Program







ISSUE HIGHLIGHTS

Preparing for the Conversation Honoring a Patient's Hope & Wish

For more information or to meet our team, visit www.sunflowerpediatric.org



Preparing for the Conversation

We understand that having conversations with families about palliative care may be difficult for you and your team. Children receiving this type of care may live for years. Recommending palliative care is not a sign of giving up on your patient but rather to improve their quality of life. As experts in palliative and hospice care, we are here to help you.

Palliative care is specialized medical care for children with a serious illness that is provided along with treatments aimed at a cure or to control an illness. Palliative care is about helping children overcome barriers to meet their hopes and wishes so they can live life to the fullest while facing serious illness.

As you prepare for the conversation, please ask yourself the following questions:

- Why do you feel the patient would benefit from palliative care?
- What do good days look like? What do hard days look like?
- Does the patient have symptoms or frequent illnesses/hospitalization that may limit their ability to meet their goals or to enjoy activities?

Having the Conversation with Families

- Encourage the patient and family to talk about their hopes and wishes and what quality of life looks like to them.
- Ask the family if there is anything about the child's illness that is interfering with achieving their hopes and wishes or impairing their quality of life.

Be prepared for questions about what palliative care is and is not.

• What are the patient's and family's goals? What does the patient enjoy? What is the family's definition of quality of life for their child/family?

• How does the patient express themselves?

Summarize the conversation.

I know it is important for [insert name of patient] to be able to enjoy [insert the hope, wish, or quality of life]. I am concerned that [insert symptoms/illnesses] are keeping [insert patient name] from doing so.

I would like to refer [insert name of patient] to a palliative care program called the Sunflower Pediatric Program. It consists of physicians, nurse practitioners, nurses, social workers, complimentary massage and music therapists, chaplains, and grief counselors who help support children and families facing serious or complex illnesses. The support is unique to the needs of the child and their family.

Honoring a Patient's Hope & Wish

Hospice & Community Care's Volunteer Services team was contacted to see if they could help fulfill a Sunflower Pediatric patient's hope and wish. Due to disease progression, the two-year-old patient's vision was compromised, so utilizing other senses like touch and sound had become critical for her. Her father mentioned her deep love for sheep and her desire to pet one. The challenge? The family was Amish and didn't have transportation. To make this moment possible, the sheep had to come to her.

Irina Lawrence Mathias and Jeri Robinson-

Lawrence from Flying Fibers are to the rescue! When approached regarding this request, they didn't hesitate to say yes and transported a sheep from their Flying Fibers Farm to the family so our little patient could fulfill her wish. Although she slept through much of the visit, her sisters got to play with the sheep, creating a cherished memory for the entire family.

This story highlights one of the many benefits of early referral to the Sunflower Pediatric Program. Our dedicated team of clinicians is committed to honoring patients' hopes and wishes every day, helping them live life to the fullest, even in the face of illness.

Additional resources:

- 1. Courageous Parents Network (but also great for care providers – lots of conversation tools)
- 2. Pediatric Palliative Care Coalition (Caring Conversations Toolkit, Firefly Chats especially)
- 3. Vital Talk (conversation guide resources)
- If you have further questions or concerns, please call the Sunflower Pediatric Program at (877) 777-5559.

If you would like us to help you honor the hopes and wishes of a child receiving care through the Sunflower Pediatric Program, please contact us at (877) 777-5559.

