

SYMPOSIUM 2015

**Serving Children and Families Facing
Life Threatening Illness**
Support, Care & Spirituality

*A Discussion Brief to Stimulate
Symposium Participants' Thinking and Conversations*



October 16-17, 2015

LifeSource Conference Center
Mississippi River
2225 West River Road North
Minneapolis, Minnesota



*“It will take all of
us to make this happen,
and there are families waiting
to use this home right now!”*

- Melissa Johnston, Audrey's Mom



This 2015 Symposium program is designed for an eclectic group of about 30 community leaders whose experiences and perspectives will shape care for children with limiting or life threatening conditions. Participants know the need for palliative and respite care as recipients or service providers, purchasers or payers of services, or as civic and business leaders who would like a supportive policy framework that will complement the quality of excellence found in the health system of the Upper Midwest.

Goals of symposium

To build awareness and advocacy supporting children and young adults with a shortened life expectancy, and their families, and to gain a greater understanding of the support possible from a variety of therapeutic interventions and venues for children's respite and hospice.

Symposium background

Finding the right child care is challenging for any parent, but when your child has special needs and is facing life limiting health challenges, it can be even more difficult. Sometimes you need to travel out of town on business; you may become sick yourself or just need some personal time.

Where can you turn in the Upper Midwest and Metropolitan Minneapolis-St. Paul to find support to help cope with these challenges? In seeking comfort, how do families and care givers collaborate to navigate through these four overlapping spheres.

- Family frustrations, anxiety, pain and financial loss
- Policy initiatives to fund innovative facilities, services and care giver development
- Advances in diagnostic techniques, pharmacology, palliative care and pain management
- Insights in the growing contributions from all faith communities, spirituality and alternative therapies

This Symposium has been organized by Crescent Cove to stimulate fresh ideas, new partnerships and bold actions and investments in pediatric palliative care, hospice and respite arrangements for people within the Twin Cities and the Upper Midwest.

Understanding of providing whole person and whole family care is still developing for children throughout the world. New insights are surfacing in Europe, North America and Australia. There are a number of emerging themes in the clinical aspects of pediatric palliative care, and the spiritual and emotional support necessary in caring for a family whose child's life may be cut short. Additionally, there are policy changes that can facilitate access to necessary support. These themes will be discussed and explored throughout this symposium.

Four topics will be explored during the symposium sessions, including:

SESSION 1: *The Family: Challenges and Opportunities*

Moderator: Jason Albrecht, MHA, CCLS, University of Minnesota Masonic Children's Hospital

Four families, the Wilson Family, the Goodspeed family, the Martindale Family and the Shu family, will share their diverse experiences caring for a child who is medically fragile. Some of the questions that families will answer to further inform the advances needed within pediatric palliative care include:

1. What are barriers to receiving optimal care for your child and family?
2. How can we bring experienced support and advocate for more support from care providers and payers?
3. What forms of support are or were helpful for you and which are or were not helpful?

SESSION 2: *Policy: Finding Resources and Building Relationships for Supportive Policy*

Keynote: MN State Representative Nick Zerwas

Panelists: Jody Chrastek, DNP, Fairview Home Health, Janet Will, RN Gilchrist Hospice, Lynn Gruber, JD, Summit Solutions Unlimited

Moderator: Richard Forschler, JD, Faegre, Baker, Daniels LLC

1. How has policy changed? How does it need to change to be more supportive of licensure of people and facilities and payment of these initiatives?
2. How might public and private payers best support these respite and hospice initiatives?
3. A primer on "Community Directed Waivers"

In addition to the many physical, emotional and spiritual benefits of accessing palliative care, there are also economic benefits. We know that only a small portion of the children who die each year in Minnesota have adequate coverage for healthcare costs. The costs for hospital-level care are much higher compared to in-home pediatric palliative or hospice care. When a child is at the end-of-life and not at the hospital, research demonstrates the cost savings of supporting families at their home (Fraser, et al, 2013). A local

study reviewing hospital admissions pre and post pediatric palliative care exposure demonstrates that for pediatric cancer patients nearing the end-of-life, support from home-based palliative care reduced the number of stays in the hospital compared with those who were not accessing palliative and home-care (Postier, et al, 2014). Accessing pediatric palliative care services depends on the knowledge of primary physician teams being familiar with and referring children and families for support.

SESSION 3: *Clinical Care: Exploring and Enabling Clinical Care Within the Continuum of Care*

Keynote: Dr. Hal Siden, Canuck Place Children's Hospice, Vancouver, Canada

Panelists: Dr. Scott Schwantes, Gillette Children's Specialty Healthcare, Dr. Naomi Goloff, University of Minnesota Masonic Children's Hospitals/Fairview Home Hospice, Dr. Susan Sencer, Children's Hospitals and Clinics of Minnesota

Moderator: Tamara Schafer, MBA, Pediatric Home Service

1. Canuck Place – How does a community-based pediatric hospice home operate and coordinate care between the hospital and home-care agencies?
2. What happens in a hospital environment vs. a residential, community children's hospice setting?
3. What are the needs that Canuck Place has met?
4. How should we be training health professionals to better understand and support children and their families dealing with respite and end-of-life needs?

There is a great need to further ease the suffering of children at the end-of-life. Access to pediatric palliative care contributes greatly to improved care and comfort (Niswander, et, al, 2014; Schmidt, 2013, Siden, 2015). Additionally, advance care planning and increased collaboration between pediatric palliative care teams and hospital-based clinicians gives families the opportunity to make decisions based on clear information at the right time as well as support with decision making (Bogetz, et. Al, 2014; Mitchell & Dale, 2015; Ullrick & Wolfe, 2013). Pediatric palliative care may take place in several different locations including hospitals, free-standing pediatric hospice and respite facilities, community or home-care and hospice-based programs (Friebert & Williams, 2015, Siden, 2014).

SESSION 4: *Spirituality: Embracing the Contributions of Emotional Support, and Faith Communities for Children, their Families and Staff*

Keynote: Dr. Jan Aldridge, Martin House Children's Hospice

Panelists: Ted Bowman, Grief Counselor and Educator, Dr. Kaci Osenga, Children's Hospitals and Clinics of Minnesota, Tisha Moore, Chaplain, University of Minnesota Masonic Children's Hospital

1. Spiritual care is often an after thought in Pediatric Palliative Care – how can this support be more visible?
2. What is necessary with staff care and development in order to ensure family support is achieved.
3. How can all staff be supported to ensure the sacred place of this home we are building provides quality emotional and spiritual support for families?

Moderator: Theresa Zimanske, Parent Advocate

Emotional and spiritual support for children, youth and their families within the pediatric palliative care setting can offer the benefits of increased relaxation, more energy, decreased pain, a more positive attitude and more 'hope or spiritual strength' (Heath, et al, 2012). Health professionals continue to learn how to best address not only a child's physical pain, but also the emotional and spiritual concerns that arise for the child, young adult and his or her family (Field & Behrman, 2003; O'Quinn & Giambra, 2014; Schwantes & O'Brien, 2014). Support for children, young adults and their families is often best provided by those specially trained to work with children and their unique needs (Linebarger, et. al, 2014; Rapoport, et. al, 2013)

Following-up and following-through

The Symposium 2015 is intended to be more than an exchange of experiences, concerns, ideas and opportunities. We hope it stimulates new relationships that champion innovative and practical actions that advance pediatric palliative care and support resources for families and care givers in the Upper Midwest.

Participants will be encouraged and supported to define actions, keep the dialogue moving and guide activities and investments (over the next 9 weeks, 9 months and 9 years) that benefit children and their families. What do you think are the problems, and what can be done to minimize them and maximize support for children and families dealing with life limiting illness?

*“At its root a parent’s love for his or her child knows no bounds.
It is an impulse that is both primal and transcendent.*

*The same is true of a child’s love for his parents. This kind of love is not volitional. It is who we are.
We belong to one another and that, it seems to me, is the best part of being alive.”*

— Ira Byock, from *The Four Things that Matter Most*

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