



Partnering for Children

Because Every Day Is a Gift

By Melissa Gilbert

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Many of you may have watched me grow up on television playing Laura Ingalls Wilder. Thanks to DVDs and broadcasts on television, we can continue to learn values from “Little House on the Prairie” today. I learned those lessons right along with the audience. Two of those lessons; compassion and the importance of community are even more relevant to me now.

Twelve years ago, I watched helplessly as my youngest son struggled to survive after being born a “severely premature” child at 28 weeks (almost three months early). As a result of my journey with my son, Michael, I have a deep connection with families who have a child living with a life-threatening condition.

First the facts; every day, families are faced with the heart-breaking news that their child is seriously ill. In the United States alone, there are more than 300,000 children living with complex, chronic conditions that may lead to death in childhood. Hospice and palliative care bring expert pain and symptom management, emotional, social, and spiritual support to these children and their families.

Most of these children need long term or ongoing care from hospice professionals, yet very few children who need this specialized care can get it. Why?

In some communities hospices aren’t trained to meet the unique needs of children. In others, families in need of this service may have no idea it is available. But most importantly, in all but a few states, in order to qualify for the hospice benefit, a child’s parent must sign a document stating that their child is expected to die in six months. Children are also ineligible for hospice care if they are still receiving any type of treatment that has the possibility of curing their disease and/or prolonging their lives. This is happening in your hometown, your state, your country! This must change and change now!

In an ideal world, children should never need palliative care or hospice, but the truth is, they do. Too many children in this country die in uncontrolled pain because they don't have access to hospice or palliative care. This is inhumane, frightening and wrong. It is our responsibility, as human beings, to ensure that they get this care, the moment they need it.

I am so happy and proud to tell you about a new initiative that is working to ensure that these children get the highest quality healthcare they deserve and that their families get the loving support they need. I serve as president of the board of directors of the Children's Hospice and Palliative Care Coalition. I am also the spokesperson for Partnering for Children, a national effort to give voice to the needs of these children. Partnering for Children is reaching out to parents, healthcare professionals, the media, and funders to raise awareness about the benefits of palliative care and hospice.

Palliative care and hospice are not "places," rather they are specialized forms of healthcare that address the many needs of the child and their family during this gut-wrenchingly difficult time. We believe that palliative care should be available at the time of diagnosis, throughout the course of treatment and to guide the family as they transition back into "normal" life or, through their grief if the child dies. Having early access to this emotional, psychosocial, and spiritual support can also help prevent so much unnecessary pain.

There are too many statistics, too many diseases with long names, but at the heart of it all, there is a child. A child who needs our help. A child who may know that he/she is dying. A child who may be frightened. A child with dreams for a life without sickness and/or relief from pain.

There is also a family. A family facing one of the most difficult experiences any family can face. They deserve the support, care and love of each and every one of us.

We live in such an extraordinary time; an age of unsurpassed connectivity. In an instant, we can speak with a person on the other side of the world. Yet, so often we forget to look at what is happening right next door or just down the street. It seems so easy to turn a blind eye. Easy to assume that someone else is watching out for the sick and vulnerable but that is not so. Each one of us carries that responsibility in our hands and in our hearts. I promise you, if you could spend one moment with a child facing a life threatening condition, it will change you forever.

Please, please, do not turn a blind eye anymore. Please help.

Ms. Gilbert, the actor, director and producer, is board president of Children's Hospice and Palliative Care Coalition. In that capacity, she also serves as spokesperson for Partnering for Children, a collaborative effort between the Children's Hospice and Palliative Care Coalition, the National Hospice and Palliative Care Organization, and the National Hospice Foundation. To learn more about the campaign and how to get involved, visit www.partneringforchildren.org.