Reaching the World with Perinatal Palliative Care

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Certified in Perinatal Loss Care
I join you today from Fredericksburg, VA.
Research - Practice – Outreach

To tap into resources, go to →

Dr Charlotte Wool
RN PhD
Researcher
Pennsylvania

Amy Kuebelbeck
Author, Speaker
Minnesota
Perinatalbereavement.com

Perinatalhospice.org
I made a video about a case I did in Virginia (USA) which showed what perinatal care can look like

It is available in English, Spanish, French, Italian, Czech, Polish, and Japanese and has been viewed all over the world almost 200,000 times

For a quick find, Google “Perinatal Hospice Video”
PERINATAL HOSPICE & PALLIATIVE CARE
CONTINUING YOUR PREGNANCY WHEN YOUR BABY'S LIFE IS EXPECTED TO BE BRIEF

If you are here because of a prenatal diagnosis that indicates your baby may die before or after birth, we are so sorry. Perhaps you are considering continuing your pregnancy and embracing whatever time you may be able to have with your baby, even if that time is only before birth, while your baby is cradled safely inside of you. Please know that support is available (see the links on this site for perinatal hospice & palliative care programs and other resources) and that you are not alone. Parents who have traveled this path before you have found that it can be a beautiful, profoundly meaningful, and healing journey.
Perinatal Palliative Care Resources

NURSE TAMMY • FEBRUARY 21, 2016 • LEAVE A COMMENT

(Updated May 2018)

Welcome to my Perinatal Hospice/Palliative Care Resource page; this is the most efficient way I can think of to get information out the wide world. After I attend the International Childrens Palliative Care Network Conference in South Africa, I imagine I will add a lot of global resources, stay tuned.

Perinatal Hospice Resources

Disclaimer

I discuss issues of a medical nature here but I give no medical advise, real or implied. If you read something that you feel might be important to you, please discuss it with your licensed Physician or Midwife. My opinions are mine and are not meant to represent that of my employers past or present.
Total website visits:

Perinatalhospice.org  380,000
Perinatalbereavement.com  almost 40,000
Perinatal Hospice Video (8 versions combined) over 200,000

~ 620,000 site visits worldwide
What does Perinatal Palliative Care Look Like to us?

It looks like love

In the US alone, over 20,000 babies who are born alive die each year.

Most effort goes into convincing places to offer palliative care as an option, the care itself is often very simple and primitive.

birth them, hold them, love them
Some people fear that children will be traumatized by this experience,

What I have found is that they see their baby sibling with awe
Some siblings help with care..

The sisters – only 2 & 4 at the time – helped and participated in care and memento making
Some fathers choose to be very active and hands-on, especially if the mother had a cesarean birth.
Photography is so important because time can be very short and there is no earlier life to have pictures of.
Every family is different

I spend a lot of time listening to learn what is important to them

After they feel safe with me and we have spoken for a while I eventually ask them....
“If you had one hour with your child, what do you want to share with him or her in that hour?”
What conditions do I see most?

- Anencephaly
- Trisomy 13 or 18
- Renal agenesis
- Pre-viable prematurity
I get referrals from:

• Obstetric physicians and midwives

• Maternal / Fetal Medicine physicians

• Mothers who find me on the internet

• People in my city know the care is available

• Mother must have a local Obstetrician who oversees her care
Important components of care:

- Explain their options and give them time to think about what they want

- Give them a “Parenting Plan” to fill out
  (examples on perinatalhospice.org)

- Make consultations possible during the pregnancy
  Neonatologist
  Lactation Support
  Home Hospice Service

“Hospice” isn’t a place, it is a philosophy that is offered in the same setting as aggressive therapy
In reality, the care isn’t complex, it just connects the dots of services likely already available.

Some hospitals don’t offer PPC because they think it is too complex.
Resources to inform you as you consider offering this model of care:
Book published by Johns Hopkins Press

Excellent resource for parents
Excellent resource for physicians and nurses
Further Education:

Resources available through Bereavement Services - Gunderson Health

- Position Paper on Palliative Care
  Can be downloaded for free

- Classes

- Blueprint for a Palliative Care Program
  Less than $40, really helpful tool

- Literature for families

  Spanish and English
Professional Networking:

PLIDA - Pregnancy Loss Infant Death Alliance
PLIDA.org

Membership is not limited to North America
International Perinatal Bereavement Conference

participants come form all over the world to attend
Certification in Perinatal Loss Care is available through the Hospice and Palliative Credentialing Center