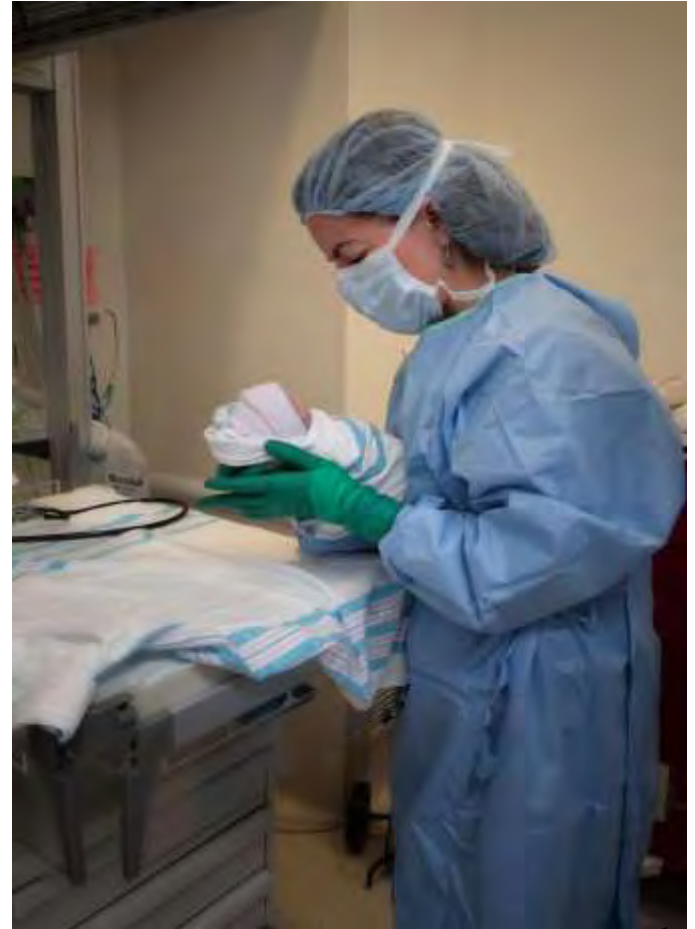


# Reaching the World with Perinatal Palliative Care

Tammy Ruiz Ziegler, RN, CPLC  
Certified in Perinatal Loss Care



I join you today from



Dr Charlotte Wool

RN PhD  
Researcher

Pennsylvania



Amy Kuebelbeck

Author, Speaker

Minnesota

# Research - Practice – Outreach

To tap into resources, go to →

[Perinatalbereavement.com](http://Perinatalbereavement.com)



[Perinatalhospice.org](http://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.

# LIFE AND LOSS

REFLECTIONS OF A NURSE  
APPRECIATING LIFE WHILE CARING FOR  
THE SADDEST DEATHS

## 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.



Follow ...

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](http://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





Some hospitals don't offer PPC because they think it is too complex



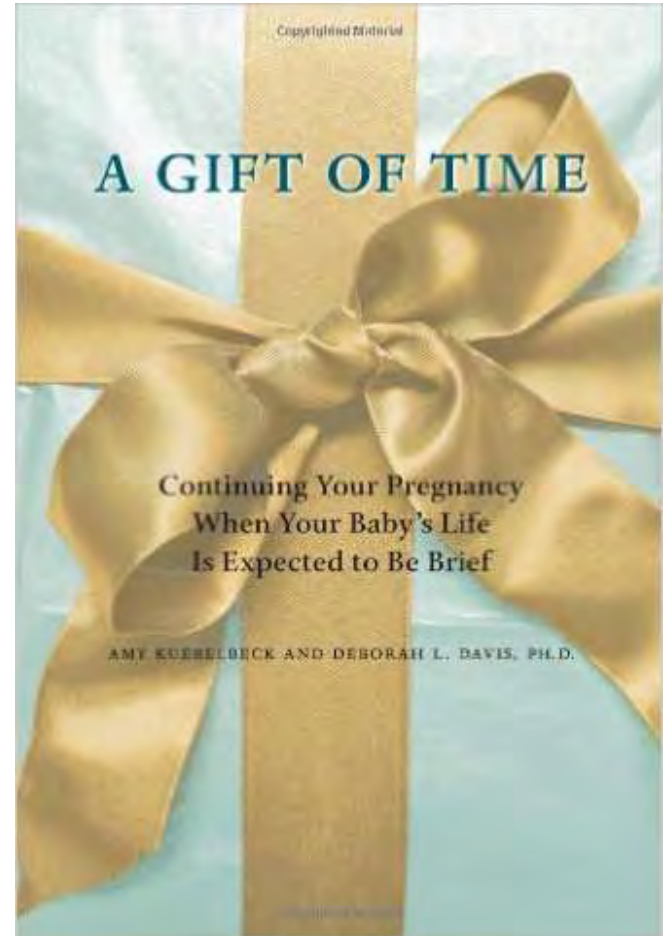
In reality, the care isn't complex, it just connects the dots of services likely already available



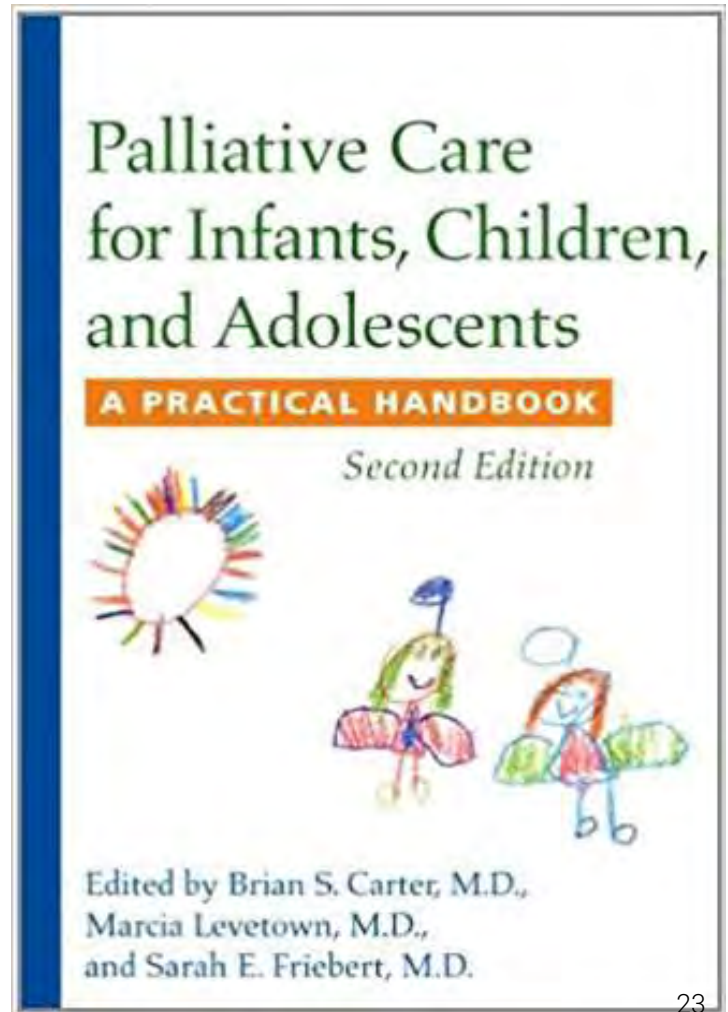
Resources to inform you as you consider offering this model of care:

Book published by  
Johns Hopkins Press

Excellent resource  
for parents

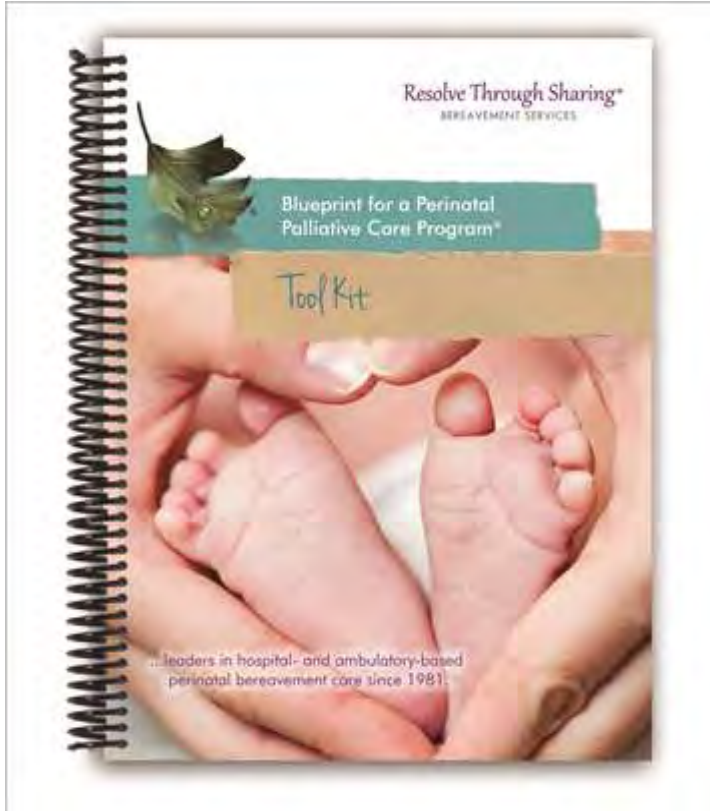


Excellent resource for  
physicians and nurses



# 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 from all over the world to attend





# Certification in Perinatal Loss Care is available through the Hospice and Palliative Credentialing Center



The screenshot shows a Microsoft Edge browser window displaying the website for the Hospice and Palliative Credentialing Center (HPCC). The address bar shows the URL [advancingexpertcare.org](http://advancingexpertcare.org). The page features a blue header with the HPCC logo and navigation links for Education, Certification, Advocacy, Leadership, Research, About, Shop, and Careers. The main content area is titled "Certified in Perinatal Loss Care (CPLC®)" and includes a sidebar with navigation links: Overview, Eligibility and Application Information, Candidate Handbook / Application, Role Delineation Study, and CPLC® Recertification. The main text describes the process of developing a certification examination, starting with a role definition study (RDS) and leading to a computer-based candidate handbook. A sidebar on the right displays a thumbnail for the "CPLC® Candidate Handbook" with the text "What you need to know for the Certified in Perinatal Loss Care® computer based". The browser's taskbar at the bottom shows the Windows Start button, a search bar, and several application icons. The system tray in the bottom right corner displays the time as 10:25 PM on 11/1/2017.