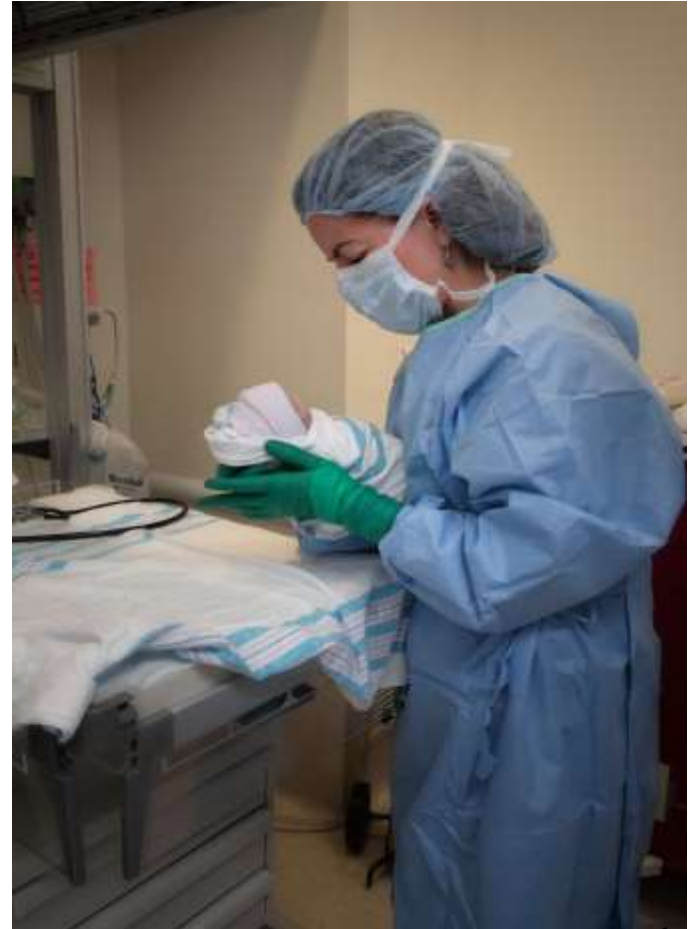


Reaching the World with Perinatal Palliative Care

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



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:

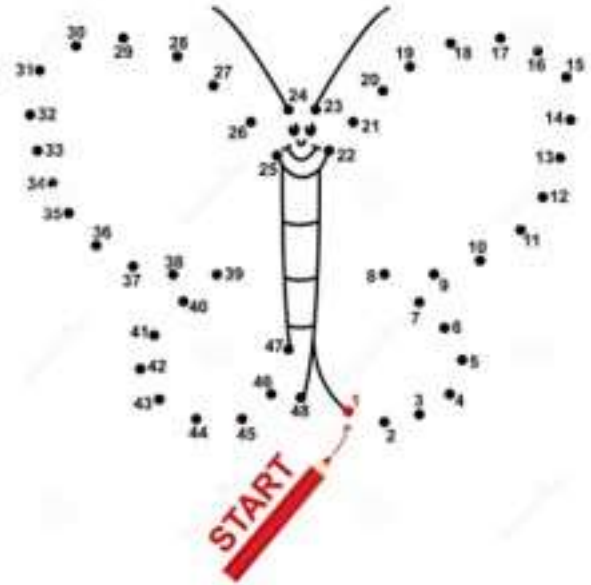
- Explain their options and give them time to think about what they want
- Give them a “Parenting Plan” to fill out
(examples on perinatalhospice.org)
- Make consultations possible during the pregnancy
 - Neonatologist
 - Lactation Support
 - Home Hospice Service

“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

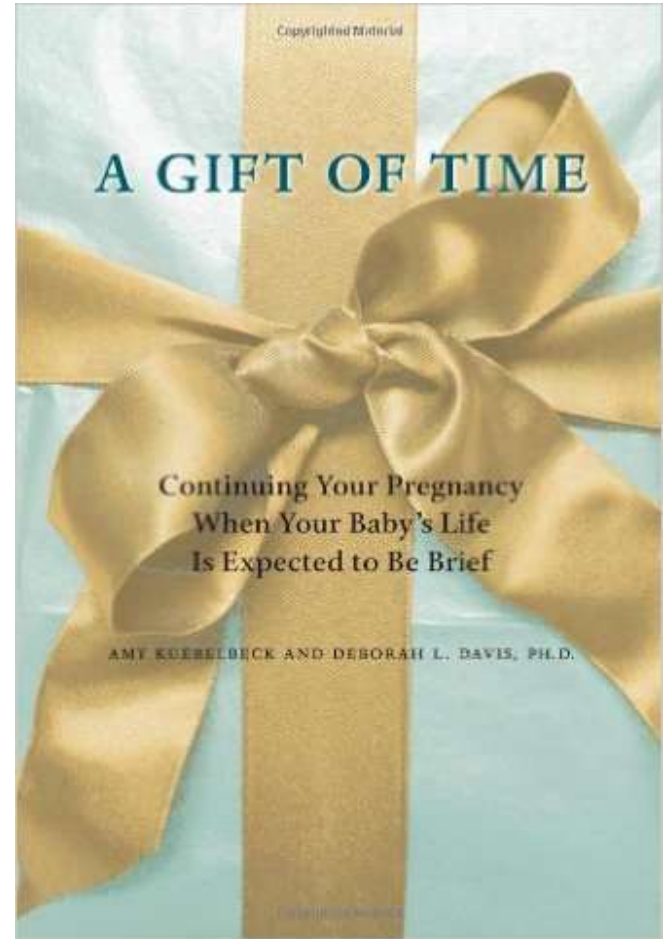


In reality, the care isn't complex, it just connects the dots of services likely already available

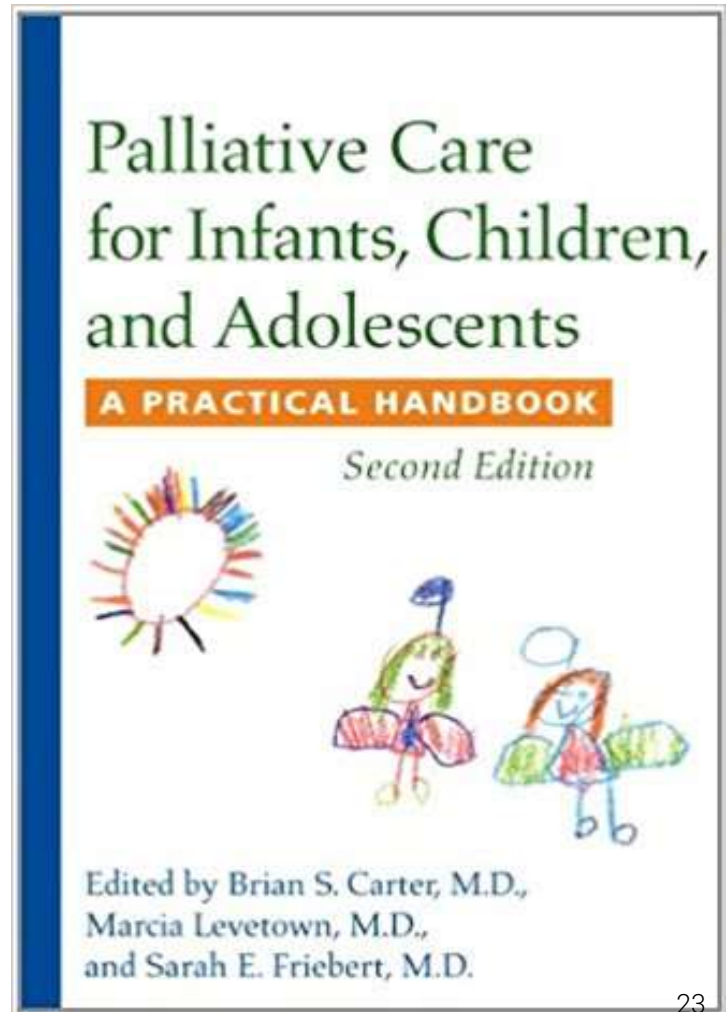
Resources to inform you as
you consider offering this
model of care:

Book published by
Johns Hopkins Press

Excellent resource
for parents

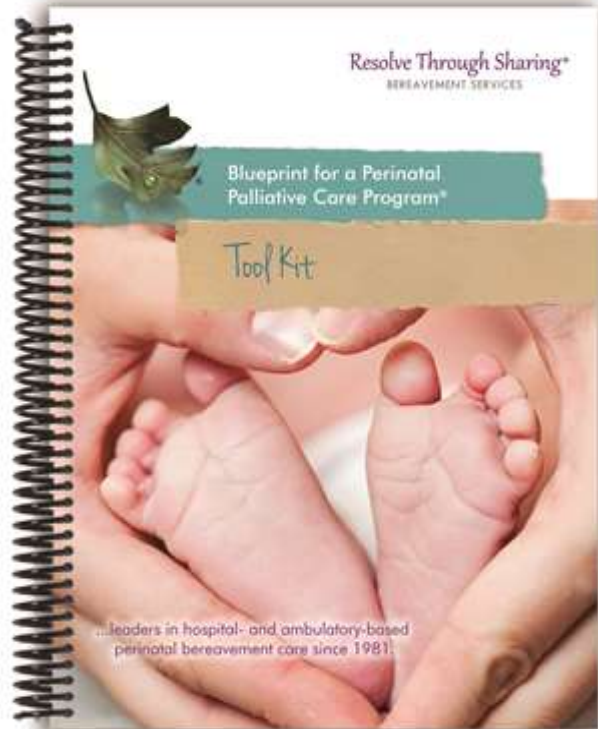


Excellent resource for
physicians and nurses



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



Meet Us in St. Louis
10.24.18 - 10.27.18
The Gateway to New Ideas and Practice
21st International Perinatal Bereavement Conference
Union Station downtown, St. Louis, Missouri
www.plida.org



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

The screenshot shows a Microsoft Edge browser window displaying the HPCC website. The address bar shows advancingexpertcare.org/cplc/. The page features the HPCC logo and navigation menu. The main heading is "Certified in Perinatal Loss Care (CPLC®)". A sidebar on the left contains a table of contents with the following items:

Overview	
Eligibility and Application information	
Candidate Handbook / Application	
Role Delineation Study	
CPLC® Recertification	

The main content area includes the following text:

HPCC begins the development of every certification examination with a role delineation study (RDS), also known as a job analysis. The RDS is a research project that is conducted when initially developing a certification program, and then repeated approximately every five years to ensure that a certification exam is based on current practice.

The objective of an RDS is to define a role in terms of the work behaviors necessary for practitioners to safely and effectively perform the role at a specified level of expertise. The RDS is guided by an advisory committee of subject matter experts who are representative and knowledgeable of the role to be studied. The RDS uses a survey method which verifies the major domains of practice and leading to the development of the content outline. The survey is pilot tested and then nationally disseminated to individuals in the hospice and palliative team serving in the role to be studied.

The advisory committee reviews the survey responses and using decision rules, determines the detailed content outline. Next they decide the

On the right side, there is a "Candidate Handbook" section with a thumbnail image of the handbook cover. The cover text includes: "HPCC Hospice & Palliative Credentialing Center", "CPLC® Candidate Handbook", and "Certified in Perinatal Loss Care (CPLC®) Computer Based Examination". Below the thumbnail, the text reads: "Candidate Handbook 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 on the right indicates the time is 10:25 PM on 11/1/2017.