

Indiana State Department of Health (ISDH)

The ISDH Perinatal Hospice and Palliative Care Information Center provides links to organizations providing perinatal hospice and palliative care resources and services and a list of perinatal hospice and palliative care providers in Indiana. The Information Center is found at:
www.in.gov/isdh/27241.htm.

Indiana Providers:

Perinatal Hospice Agencies

- Center for Hospice Care, *Life Transition Center*, Mishawaka, Elkhart, and Plymouth. Contact: Bereavement Coordinator, (574) 255-1064.
- Community Health Network, Indianapolis, Indiana. Hospice and palliative care programs. Contact: (800) 404-4852.

Perinatal Palliative Care Services

- St. Vincent Indianapolis Hospital, *Center for Perinatal Loss*, Indianapolis. Contact: (317) 415-7494.
- Deaconess Health System, *Hand in Hand Perinatal Palliative Care Program*, The Women's Hospital, Newburgh, IN. Contact: (812) 842-4200.
- Riley Hospital for Children, Perinatal-Fetal Center; Indiana University Health Maternity Center; *Pathways Support Program*, Indianapolis. Contact: (317) 962-8153.

References:

- (1) Perinatal Hospice.org: www.perinatalhospice.org
- (2) Charlotte Lozier Institute:
<https://lozierinstitute.org/the-perinatal-hospice>
- (3) Cope, H., Garrett, M.E., Gregory, S., and Ashley-Koch, A. (2015) *Pregnancy continuation and organizationalreligious activity following prenatal diagnosis of a lethal fetal defect are association with improved psychological outcome*. *Prenatal Diagnosis*, 35: 761-768. doi:
<http://onlinelibrary.wiley.com/doi/10.1002/pd.4603/abstract>



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To promote and provide essential public health services.

Perinatal Hospice

*There is no footprint too small
to leave an imprint on this
world*



What is perinatal loss?

Perinatal refers to the time before, during and immediately after the birth of a child. Perinatal loss is any loss of an infant's life any time from conception up to one year of age, regardless of the reason.

What is perinatal hospice and palliative care?

Perinatal hospice and palliative care is care and support given to families when the baby is diagnosed with a condition that will most likely be fatal either prior to birth or shortly after. Hospice and palliative care provides medical, nursing, spiritual, emotional, social, and bereavement care to families experiencing consequences of a perinatal loss.

Our baby has been given a fatal diagnosis, now what?

When a fatal diagnosis is received, you should immediately seek support to include care planning and counseling. A perinatal hospice or palliative care provider is available to assist you through this difficult time. Each situation is different based upon the diagnosis and other medical factors. You should discuss your particular situation with your physician.

In making the decision to continue the pregnancy, know that you are not alone and you will not be the first mother choosing to do so. "Parents who have traveled this path before you have found that it can be a beautiful, profoundly meaningful, and healing journey." [from www.perinatalhospice.org]



Would parents who have used Perinatal Hospice recommend it to others?

Absolutely! Studies show that 80% of parents experiencing a prenatal diagnosis chose to carry their baby to term, and those parents reported that they were glad that they did so, and would encourage other parents in a similar situation to do the same.

What services may be available through perinatal hospice or palliative care?

- Prenatal support – emotional, spiritual, and medical
- Support groups for parents, siblings and others
- Guidance in working with medical specialists
- Childbirth education and preparation
- Develop individualized personalized birth plans
- Coordinate discharge from hospital
- Assist in creating memories, keepsakes, mementos, and treasures
- Assist with memorial service and funerals
- Emotional and bereavement support
- Pain management for baby, if necessary

Is perinatal hospice safe for the mother and the baby?

The answer is YES! Studies show that there is no increased risk to the mother or the baby from carrying a baby with a prenatal diagnosis to term. Consequently, many diagnosis are made at 21 weeks of pregnancy or later.

If an abortion is performed this late in the pregnancy, it significantly increases the risk of death or complication. Mothers may also risk complications with future pregnancies, including premature birth and low birthweight after an abortion.

Is perinatal hospice psychologically safe for the mother?

Again, the answer is resoundingly yes. Grief is a natural response experienced by all parents who have lost a baby due to a medical condition. However, studies show that mothers who chose to carry their baby to term recover to baseline mental health more quickly than those who aborted due to fetal anomaly. Terminating the pregnancy does not shorten the grieving process or allow parents to "put it behind them"; on the contrary, abortion is a complicating factor in healing.

How do I find a Perinatal Hospice provider?

Most hospitals can provide resources for perinatal hospice, and community-based hospice programs in your community can offer the support you need.

Indiana 211

2-1-1 is a free and confidential service that helps Hoosiers across Indiana find the local resources they need such as grief counseling and other human services. The service is available 24 hours a day, seven days per week. To reach assistance, dial 211 from a phone or visit www.IN211.org