Caring for patients after perinatal loss.

Considerations for Providers and Office Staff

Perinatal loss can be an incredibly painful experience so supporting patients through grief requires sensitivity and specialized care.

This document outlines trauma-informed procedures to guide healthcare providers in providing effective and compassionate support for patients following a fetal or infant loss.

Developed by: St. Joseph County Fetal Infant Mortality Review Program

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FETAL-INFANT MORTALITY REVIEW

For more information and to order more copies of provider or patient materials please contact:
Sally Dixon, RN
Maternal Infant Health Coordinator
sadixon@beaconhealthsystem.org

Scan here to find the guide online

Trauma-Informed Considerations for the Follow-Up Visit

Medical appointments following the loss of a baby can be a stressful and anxiety-provoking experience for patients. Below are some suggested procedures for ensuring a trauma-informed approach that supports patient wellbeing. You can also provide the *Coping with the Loss of a Pregnancy or Baby* patient guide that offers ideas and helpful local and online resources for navigating grief.

Universal Mental Health Referrals	Patients who experience perinatal loss are at increased risk for depression and other mental health challenges. Offering a referral for mental health support is a best practice, even if counseling was already discussed during the hospital stay. **Just as specialty referrals are made for physical health concerns, a mental health referral can be an important part of the patient's overall care plan.***
The Follow Up Visit	Follow- up visits after a loss are often emotionally difficult for patients. Try to schedule the patient with the provider with whom they feel the most comfortable. **A pre-appointment call can help reassure patients that it's natural to feel worried about the visit** and can provide an opportunity to explain what to expect and ask if there is anything that could help them feel more comfortable during their appointment.
Timing of the Visit	**Schedule follow-up appointments during quieter times**, like early morning or late afternoon, when office volume is lower. If possible, offer a separate entrance or take the patient to an exam room immediately upon check-in to minimize waiting room time and help patients feel emotionally safe.
Telehealth	I**f available, consider offering a telehealth appointment** so patients can avoid coming to the office in person. This can reduce the re-traumatization of being around other pregnant women or being in the space where they were once identified as a mother.
Sharing patient loss information with staff	Based on current office processes, **develop a way to make all staff aware of a patient's loss before any calls or patient visits**. This helps prevent harmful questions about how the baby is doing. If a chart alert is not available, think about how to make the front desk aware, prior to a visit in order to practice trauma-informed care when greeting the patient.

*All patients who have experienced perinatal loss are at increased risk for depression; referral is recommended. See JAMA US Preventative Services Task Force: Recommendation Statement on Interventions to Prevent Perinatal Depression. JAMA. 2019;321(6):580-587. doi:10.1001/jama.2019.0007

Reflect Language	**Reflect the language the patient uses when referring to their loss.** For example, if they talk about 'losing their baby' rather than clinical terms like 'stillbirth' or 'miscarriage,' use that language. If they refer to their child by name, use the name when discussing their loss.
Discussing Reproductive Goals	**Discuss birth control and future pregnancies with sensitivity.** If there were complications, offer testing or specialist referrals, but avoid assuming the patient wants to try again. Use phrases like, "*If you're considering a future pregnancy, I'd recommend...*" For patients who can become pregnant again, remind them that pregnancy can occur during lactation or pumping without contraception.
Assessing Family Wellbeing	**Ask how the patient's partner, children, and close family members are coping with the loss.** You can recommend support and resources by providing the *Coping with the Loss of a Pregnancy or Baby* for patients. It may also be helpful to suggest speaking with their child's pediatrician for guidance on sibling grief.

Considerations for Patients with a History of Loss

In addition to providing accommodations immediately following a loss, providers can also keep in mind some **key considerations when seeing a new patient who may have a history of perinatal loss:**

Pregnancy History Screening	**When asking about pregnancy history, frame questions with sensitivity.** For example, you might say, *"I know this can be a sensitive topic, but have you ever been pregnant before?"* This approach acknowledges the potential for perinatal loss history and respects the patient's experience.
Mental Health Referral	Due to the increased risk of perinatal depression, **it's best practice for patients with a history of perinatal loss to be offered a referral for mental health support,*** even if the loss occurred years ago. A new pregnancy may bring up difficult emotions related to the prior loss, and the patient may not have received support at that time. Please see page 7 for **some referral options.**

*See JAMA US Preventative Services Task Force: Recommendation Statement on Interventions to Prevent Perinatal Depression. JAMA. 2019;321(6):580-587. doi:10.1001/jama.2019.0007

Grief or Depression?

Considerations when evaluating a patient after perinatal loss

Some signs of depression are similar to the effects of grief (difficulty sleeping, lack of appetite, and a feeling of hopelessness, inability to feel pleasure, depressed mood, or feeling emotionally numb).

- **The hallmark of grief** after the loss of a pregnancy or baby is the intense focus on thoughts and memories of the baby accompanied by sadness, yearning, and longing.
- **The hallmark of depression** is depressed mood that is persistent and not focused on the baby. In depression, thoughts are self-critical and pessimistic, **with feelings of worthlessness, hopelessness, or of being undeserving of life.**

Evaluating a Patient After Perinatal Loss

Approaches to consider for first follow-up visit:

- **Acknowledge the loss,** recognizing that loss can be difficult, uncomfortable, and complex, and that grieving is a process.
- **Ask about mood, activities of daily living and social functioning**.
- **Ask about grief responses:** (deep longing, crying, fatigue, difficulty concentrating, anger, guilt, sleep interruption, change in appetite, feelings of hopelessness, aching arms, or headache).
- **Help your patient understand that these responses can be part of the grieving process.** Acknowledge that it's entirely natural—and even beneficial—for patients to experience and express a range of grief responses.
- **Share with your patient that some days may be especially emotional.** These can include the anniversary of their loss, their baby's birthday, their due date or holidays like Mother's Day and Father's Day. If your patient has a history of infant or pregnancy loss, try to be mindful of these dates and offer extra sensitivity during these times.
- **Offer a referral** to a mental health professional and/or encourage patient to seek additional support.*

*See JAMA US Preventative Services Task Force: Recommendation Statement on Interventions to Prevent Perinatal Depression. JAMA. 2019;321(6):580-587. doi:10.1001/jama.2019.0007

Evaluating Symptomology

In the first few weeks after a loss, intense sorrow and feelings of being overwhelmed may disrupt the ability to accomplish normal tasks.

The time it takes for someone to resume daily tasks of living can vary widely. **However, if the patient is experiencing an extended disruption in their functioning**, **offer a referral** to a mental health professional who can evaluate them for depression. This may look like an inability to do normal tasks (i.e. maintain hygiene, dress daily, simple chores, usual childcare).

Depression symptoms tend to be fairly constant. There may be persistent anhedonia, a withdrawal from normal contacts, persistent feelings of worthlessness, or persistent feelings of hopelessness. Normal conversation, engagement, and planning for the future is diminished. **If your evaluation reveals a patient is experiencing these depression symptoms, offer a referral for additional support by a mental health professional.**

If a patient's symptoms put them at risk – such as not caring for self, not getting out of bed, unable to care for other children, talking excessively about guilt or feeling worthless, hints of self-harm or suicide – send them to one of the following locations for immediate evaluation for a higher level of care than outpatient services can provide:

- Call Oaklawn Crisis Center 24/7 at 574-283-1234 for assistance
- Oaklawn Walk In Crisis Center at 420 N. Niles Avenue, Suite 100. Open 8a to 8p daily
- Hospital ER
- Psychiatric hospital

Discussing Support and Treatment Options

For grief:

It is recommended to offer additional support for every grieving parent. This may include a support group, pastoral counseling, or seeing a mental health professional.

Help with symptom management may be appropriate. (i.e. for sleep disruption.)

Offering guidance on the typical course of grief and its common symptoms, along with a plan if symptoms escalate, can ease patients' anxiety.

For depression:

If you determine that your patient has depression, **it is best practice to consider the use of both medication management and a referral to a mental health professional**. Explain that the two therapies work together to get the patient through a healing time and to a better state. Please see pages 6 through 10 for some counseling options and pages for diagnosis codes.

What About You?
Vicarious Trauma: Considerations for Providers and Staff

Providers and staff grieve too.
The American Counseling Association defines **vicarious trauma** as:

> *"the emotional residue of exposure to traumatic stories and experiences of others through work; witnessing fear, pain, and terror that others have experienced; [and] a preoccupation with horrific stories told to the professional."*

Caring for patients who experience perinatal loss can lead to vicarious trauma. Providers may notice appetite changes, trouble concentrating, feelings of anger or sadness, preoccupation with thoughts of the event, emotional numbness, low mood or anxiety, difficulty maintaining professional boundaries, and loss of hope or pessimism. Others may experience intrusive memories, nightmares, dissociation, or strong emotional distress related to a patient's loss.

Melancholia by Albert Gyorgy

Coping with Vicarious Trauma

- Taking time to grieve the losses you've witnessed can be vital for your emotional well-being, helping to prevent burnout and ensuring that you can continue offering the best care to your patients.
- **Some healthcare providers have found the following interventions helpful for reducing the impact of vicarious trauma:** journaling, practicing physical movement, increasing opportunities for physical and mental rest, building boundaries, creating pauses in your day, connecting with peers, building a self-care routine, and seeking professional support.
- Self-compassion is an effective method for minimizing the effects of vicarious trauma. For more information or practical exercises, **self-compassion.org** is a helpful resource.

Local Grief Support Organizations

Updated May 2025

Angel of Hope Memorial Garden

http://www.angelofhopemichiana.org

Located in South Bend's Pinhook Park, overlooking the St. Joseph River, this garden was created to be a place of reflection and remembrance for all who have lost a child. You can visit their website for information about ordering a personalized memorial brick to be part of the garden. This organization holds several events throughout the year in honor of families and their lost children.

Ava's Grace

https://diocesefwsb.org/avas-grace/

Offers faith-based emotional spiritual, and practical support to families who suffer miscarriage, stillbirth, or infant loss, including memorial masses, an annual retreat for couples, and a monthly support group via Zoom.

Virtual Support Groups

The Compassionate Friends of South Bend Indiana

Local chapter of The Compassionate Friends, a non-profit organization whose mission is to support families after the loss of a child.
Local Facebook page: https://www.facebook.com/groups/132176043533689/
National website: https://www.compassionatefriends.org/

Dustin's Place

https://www.dustinsplace.org/

11802 Lincoln Hwy, Plymouth, IN 46563

Offers free grief support groups for children, teens, and families. Also offers a free summer children's grief camp.

In-Person Support Groups

Northern Indiana Chapter – Hope Mommies

Local chapter of Hope Mommies, a non-profit Christian organization whose mission is to support those who have experienced miscarriage, stillbirth, or infant loss.
Local Facebook page: https://www.facebook.com/groups/1189893537721311/
National website: https;//hopemommies.org

Ryan's Place

https://ryansplace.org

Goshen-based organization that provides grief support to children, teens, and families. This includes free support groups for adults and children, as well as a day camp for children who have experienced the death of a loved one.

In-Person Support Groups

Local Grief Therapy and Counseling

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A Beautiful Mind
https://www.abeautifulmindinfo.com/
2410 Grape Rd Suite 1, Mishawaka, IN 46545
574-243-9370
Offers therapy for individuals, couples and families.

Bontrager Therapy Services
https://www.dawnbontrager.com/
203 E Mishawaka Ave, Mishawaka, IN 46545
574-256-3699
Offers therapy for individuals, couples, and families.

Center for Hospice Care
https://cfhcare.org/
501 Comfort Place Mishawaka, IN 46545
574-243-3100
Offers individual, family, and group counseling for children, teens and adults.
Also offers Camp Evergreen: a day grief camp for teens and a day camp for youth and families.

Emily Lehmen Counseling Associates
https://www.emilylehmanlmhc.com/
510 Lincolnway E Suite E,
Mishawaka, IN 46544
574-400-7250
Individual counseling in person and online.

Family Psychology of South Bend
https://family-psychology.com/
922 E Wayne St., Suite 205-206, South Bend,
574-280-8199
Offers counseling for individuals, couples, and families.

Lisa Haines, LLC
www.lisahainesllc.com
574-635-1117
lisa@lisahainesllc.com
Grief counselor that offers services only via telehealth.

Mental Health Awareness of Michiana
https://mhamichiana.org/pro-bono-counseling-project/
405 W Dubail Ave, South Bend, IN 46613
574-393-8809, option 3
Offers the Pro Bono Counseling Project, which provides **free**, short-term counseling with a volunteer mental health professional.

OAKLAWN
https://oaklawn.org/our-services
OPEN ACCESS walk in clinic
415 E. Madison St, South Bend.
Hours available Monday through Friday.
Check website for details.
WALK IN CRISIS CENTER
420 N. Niles Ave., Suite 100, South Bend
Open 8a to 8p daily, ring bell for entrance.
574-533-1234
Call 24/7 at 574-283-1234

Story of Hope Counseling
www.facebook.com/storyofhopecounseling
574-904-9959
Mishawaka, IN
storyofhopecounseling@gmail.com
Offers counseling services for individuals, couples and families.

Tree of Life Healing Arts
https://traceymalesawheaton.com
429 W. LaSalle Ave #2, South Bend
574-520-8444
ajourneyinward@gmail.com
Offers counseling for individuals

National Organizations/Websites

Updated May 2025

Bereaved Parents of the USA
https://www.bereavedparentsusa.org/
A nationwide organization designed to aid and support bereaved parents and their families who are struggling to survive their grief after the death of a child.

Facts about Miscarriage
http://pregnancyloss.info
A website dedicated to providing information, help and healing.

First Candle
http://firstcandle.org/bereavement/online-support-groups/
Offers peer-to-peer online support groups for individuals and families coping with pregnancy and infant loss.

Virtual Support Groups

Mommies Enduring Neonatal Death (MEND)
https://www.mend.org/
A grief support site for parents after a miscarriage, stillbirth or early infant death.

Mother in Sympathy and Support (MISS)
https://missfoundation.org/
MISS helps grieving parents after the death of an infant, stillbirth or SIDS.

National Maternal Mental Health Hotline
Call or text: 833-852-6262
Free, confidential, 24/7 mental health support for parents and families before, during, and after pregnancy. English and Spanish speaking counselors are available.

Virtual Support Groups | Phone-Based Support

Postpartum Support International
https://www.postpartum.net/
Support for families experiencing mental health issues related to childbearing, including online support groups, phone or text helpline, educational resources, and more.

Virtual Support Groups | Phone-Based Support

Preeclampsia Foundation
https://www.preeclampsia.org/
Provides patient support, education, and resources related to preeclampsia and other hypertensive disorders of pregnancy, as well as a platform to share personal stories.

Return to Zero Hope
https://www.rtzhope.org
Provides compassionate and holistic support for people who have experienced unimaginable loss during their journey to parenthood.

Virtual Support Groups

Share Pregnancy & Infant Loss Support
http://nationalshare.org/
A grief support site offering: stories, poetry, chat, support, and memorial information.

Sisters in Loss
www.sistersinloss.com
Creates a space for Black women to share pregnancy and infant loss and infertility stories, offering culturally relevant support and healing resources.

Star Legacy Foundation
https://starlegacyfoundation.org/
This website offers a variety of support groups for parents and grandparents experiencing perinatal loss, information about pregnancy after loss, and a phone support line.

Phone-Based Support

Unspoken Stories (March of Dimes)
https://www.marchofdimes.org/find-support/community-stories/unspoken-stories
Builds a supportive community by sharing honest stories of pregnancy, parenthood, and loss, encouraging connection and understanding.

Guidance on DSM-5-TR Diagnosis Codes

A challenge when providing care for a patient who has experienced a perinatal loss is that they may require additional visits following their loss, or they may require a visit sooner than the typical 6-week postpartum visit. Providers may be able to bill for postpartum visits based on a patient's mental health concerns, using the below guidance on relevant diagnosis codes from the DSM-5-TR.

Uncomplicated Grief (Z63.4)

A "normal reaction to the death of a loved one." May present with symptoms of Major Depressive Disorder (MDD): sadness, insomnia, poor appetite, weight loss. Will see grief experience and possible depressed mood as "normal." Duration varies considerably among different cultural groups. Could transition to MDD if 2+ weeks and meet criteria for MDD with peripartum onset.

Prolonged Grief Disorder (F43.81)

- Death of someone close to bereaved individual occurred at least 12 months ago.
- Symptoms of persistent grief response (i.e. Intense yearning/longing for the deceased person and/or preoccupation with memories of the deceased person).
- 3+ functional issues: identity disruption, disbelief, avoidance of reminders, emotional pain, difficulty reintegrating, emotional numbness, viewing life as meaningless, intense loneliness.

Adjustment Disorders (F32.21 to F43.25)

Development of emotional or behavioral symptoms in response to identifiable stressors occurring within 3 months of onset of stressors.

- Marked distress out of proportion to severity or intensity of the stressor.
- Significant impairment in social, occupational, or other areas of functioning.

Acute Stress Disorder (F43.0)

Experiencing or witnessing a traumatic event, with 9+ symptoms of the following:

- **Intrusion Symptoms**: recurrent, involuntary, intrusive distressing memories; Recurrent distressing dreams (related to the event); Dissociative reactions (e.g. flashbacks); Prolonged psychological distress.
- **Negative Mood**: Persistent inability to experience positive emotions.
- **Dissociative Symptoms**: Altered sense of reality of one's surroundings or oneself; Inability to remember an important part of the traumatic event.
- **Avoidance Symptoms**: Efforts to avoid distressing memories, thoughts, or feelings associated with traumatic event; Efforts to avoid external reminders (people, places, activities, situations).
- **Arousal Symptoms**: Sleep disturbance; Irritable behavior and angry outbursts; Hypervigilance; Problems with concentration; Exaggerated startle response.

Relates to symptoms within 3 days to 1 month of traumatic event. If symptoms last more than one month, diagnosis of PTSD should be considered.

Major Depressive Disorder (MDD) (F33.0 to F33.2), add specifier

5 or more of the following symptoms over a 2-week period:

- Depressed mood
- Anhedonia
- Appetite changes
- Problems sleeping
- Psychomotor agitation or retardation
- Fatigue
- Feelings of worthlessness
- Problems with concentration
- Suicidal ideation (with/without plan or intent)

Screening tools such as the PHQ-9 can be helpful to differentiate diagnosis.

Responses to a significant loss (e.g., bereavement) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss, which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgement based on the individual's history and the cultural norms for the expression of distress in the context of loss.

Post-Traumatic Stress Disorder (PTSD) (F43.10)

A diagnosis of PTSD requires meeting the following criteria:

- **Criterion A**: Exposure to actual or threatened death, serious injury, or violence
- **Criterion B**: At least 1 intrusive symptom (unwanted upsetting memories, nightmares, flashbacks, emotional and physical reactivity to cues)
- **Criterion C**: At least 1 symptom of avoidance of stimuli (avoiding distressing memories/thoughts/ feelings, avoiding external reminders)
- **Criterion D**: At least 2 symptoms of negative changes in thoughts and mood (dissociative amnesia, negative beliefs about self and the world, self-blame, persistent negative emotional state, anhedonia, detachment from others, problems with experiencing positive emotions)
- **Criterion E**: At least 2 symptoms of trauma-related arousal and reactivity (irritability, hypervigilance, exaggerated startle response, problems with concentration, and sleep problems)
- **Criterion F**: Duration lasting more than 1 month
- **Criterion G**: Disturbance causing clinical distress or impairment in social, occupational or other functioning.

Screening tools such as the PC-PTSD-5 can be helpful to differentiate diagnosis.