

FOLLOW-UP CARE AFTER PERINATAL LOSS

A Guide for Healthcare Professionals



PROJECT POPPYSEED

PROJECT
POPPYSEED

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INTRODUCTION

ABOUT THIS BOOKLET

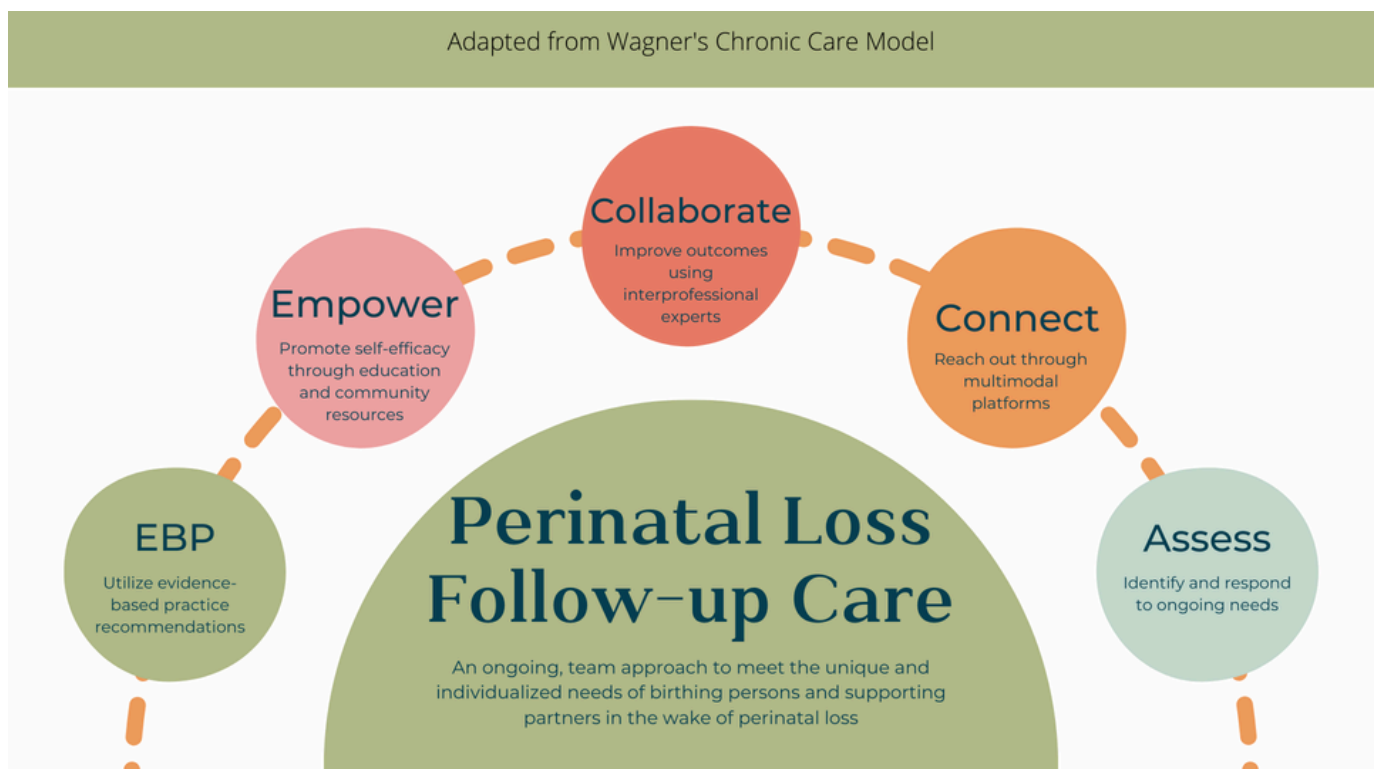
The purpose of this booklet is to serve as a guide for healthcare professionals providing follow-up care to parents in the year after a perinatal loss experience. Components of the follow-up care program include a timeline for intentional contact to assess parents' holistic needs. A robust follow-up care program entails utilization of evidence-based recommendations within a multidisciplinary team to empower parents to heal in their grief experience.

TOOLKIT COMPONENTS

- Timeline - Recommended timeframe for intentional contact with parents
- Scripts - Guidance in facilitating conversations with parents
- Assessments - Utilization of valid and reliable questionnaires
- Resources - Tools and information for parents



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Timeline

The following increments are a measurement in days or weeks after the patient is discharged from the healthcare facility.

Day 3

Phone call from lactation specialist.

Lactation consultant makes contact to assess the following:

- Milk production
- Pain & pain management
- Milk suppression
- Milk expression
- Milk donation

Suggested Script:

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. Is now a good time for a conversation?”

“The body begins to produce breast milk about three days after giving birth. The production of breast milk can be emotionally painful. If you’re comfortable, I would like to talk about what happens when the body produces breast milk and some things you can do. Would that be okay with you?”

Day 7

Automated text.

Automated Text

“We want to check in and see how you are doing one week after your loss. Please do not hesitate to reach out if you need anything, you and your family are in our thoughts. If you need support, please select from the following options:

- 1 – Lactation support
- 2 – Questions about bleeding, pain, or vaginal discharge
- 3 – Questions or support about grief and coping
- 4 – Please do not contact me at this time

Please respond with a number above to let us know how we can support you.”

Day 14

Automated text with subsequent phone call.

Automated Text:

“We want to check in and see how you’re doing two weeks after your loss. If you would like to speak with a member of your healthcare team, please respond with one of the following options:

- 1 – Yes, I would like to talk with someone
- 2 – No, please do not call me at this time
- 3 – I would like to talk with someone, but next week would be better

Please remember that you are not alone and that there are many people who care about you.”

Phone Call

Suggested Script:

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. If now is a good time, would you be comfortable answering some questions about how you’re doing?”

“There’s no right or wrong way to be feeling right now. I’d like to ask you some questions about:

Suggested topics:

- Physical changes (bleeding, lactation, pain)
- Postpartum depression
- Coping
- Grief
- Partner relationship
- Living children (if applicable)
- Support system

Week 4

Automated text with subsequent phone call.

“We want to check in and see how you’re doing one month after your loss. As life continues, many parents struggle to understand their grief. If you would like to speak with a member of your healthcare team, please respond with one of the following options:

- 1 – Yes, I would like to talk with someone
- 2 – No, please do not call me at this time
- 3 – I would like to talk with someone, but next week would be better

Please remember that you are not alone and that there are many people who care about you.”

Phone Call

Suggested Script:

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. If now is a good time, would you be comfortable answering some questions about how you’re doing?”

“There’s no right or wrong way to be feeling right now. I’d like to ask you some questions about:

Suggested topics:

- Postpartum depression
- Coping
- Grief
- Partner relationship
- Living children (if applicable)
- Support system

Week 8

Automated text with subsequent phone call.

“We want to check in and see how you’re doing two months after your loss. As life continues, everyone around you may seem like they forgot what you went through. If you would like to speak with a member of your healthcare team, please respond with one of the following options:

- 1 – Yes, I would like to talk with someone
- 2 – No, please do not call me at this time
- 3 – I would like to talk with someone, but next week would be better

Please remember that you are not alone and that there are many people who care about you.”

Phone Call

Suggested Script:

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. Is now a good time for a conversation?”

“It’s been two months now since your loss. Everyone around you may seem like they are back to ‘normal life,’ and you may or may not feel this way. How are you doing?”

“Thank you for talking with me today. I’m going to text you the link to a few questionnaires. We use questionnaires like these as screening tools to see how we can better support parents who have lost a baby. I’d appreciate you taking the time to fill them out. If you need anything, please do not hesitate to reach out. You can get ahold of us by calling or texting [contact information]”

Assessment Questionnaires

- Depression (PHQ-9)
- Anxiety (GAD-7)
- Grief intensity (PGS)
- Coping (CABLE)
- PTSD (PCL-C)

Suggested topics

- Partner relationship & intimacy
- Isolation & social interactions
- Social support
- Talking with living children (if applicable)

Week 12

Automated Text & Office Visit

Automated Text

“It’s time for your three month follow-up appointment. So we can best support you, please select the priority concern you would like to address during our visit from the following options:

- 1 - Grief
- 2 - Coping
- 3 - Partner Relationship
- 4 - Partner Intimacy
- 5 - Social Support
- 6 - Other

Assessments

- Depression (PHQ-9)
- Anxiety (GAD-7)
- Grief intensity (PGS)
- PTSD (PCL-C)
- Coping (CABLE)
- Drinking (CAGE)

Suggested Topics

- Partner intimacy
- Partner relationship (Coping, Communication)
- Supporting living children (if applicable)
- Interacting with social circle

Month 6

Automated Text & Office Visit

Automated Text

“It’s time for your six month follow-up appointment. So we can best support you, please select the priority concern you would like to address during our visit from the following options:

- 1 - Grief
- 2 - Coping
- 3 - Partner Relationship
- 4 - Partner Intimacy
- 5 - Pregnancy
- 6 - Other

Assessments

- Depression (PHQ-9)
- Anxiety (GAD-7)
- Grief intensity (PGS)
- PTSD (PCL-C)
- Coping (CABLE)
- Drinking (CAGE)

Suggested Topics

- Subsequent pregnancy
- Partner intimacy
- Partner relationship (coping, communication)
- Supporting living children (if applicable)
- Interacting with social circle

Month 9

Automated Text & Office Visit

Automated Text

“It’s time for your nine month follow-up appointment. So we can best support you, please select the priority concern you would like to address during our visit from the following options:

- 1 - Grief
- 2 - Coping
- 3 - Partner Relationship
- 4 - Partner Intimacy
- 5 - Pregnancy
- 6 - Other

Assessments

- Depression (PHQ-9)
- Anxiety (GAD-7)
- Grief intensity (PGS)
- PTSD (PCL-C)
- Coping (CABLE)
- Drinking (CAGE)

Suggested Topics

- Subsequent pregnancy
- Partner intimacy
- Partner relationship (coping, communication)
- Supporting living children (if applicable)
- Interacting with social circle

Year 1

Automated Text & Office Visit

Automated Text

“It’s time for your one year follow-up appointment. So we can best support you, please select the priority concern you would like to address during our visit from the following options:

- 1 - Grief
- 2 - Coping
- 3 - Partner Relationship
- 4 - Partner Intimacy
- 5 - Pregnancy
- 6 - Other

Assessments

- Depression (PHQ-9)
- Anxiety (GAD-7)
- Grief intensity (PGS)
- PTSD (PCL-C)
- Coping (CABLE)
- Drinking (CAGE)

Suggested Topics

- Subsequent pregnancy
- Partner intimacy
- Partner relationship (coping, communication)
- Supporting living children
- Interacting with social circle

Scripts

Bleeding Script

Begin Conversation

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. After being pregnant, the body will continue to pass blood for some time. Bleeding after loss may be emotionally difficult. It’s important to understand what to expect and when to contact your provider. Is now a good time to talk about bleeding and any concerns or questions you may have?”

Questions

- Have you been bleeding, if so, how heavily?
- Do you have enough pads to last you through the week?
- Buying pads can be very emotional for some people, is there someone I can ask to bring you some pads?
- Bleeding is often a reminder for women that they are no longer pregnant. Some people feel frustrated or sad, would you like to talk about how your bleeding has made you feel?
- What questions do you have about bleeding?

Closing Conversation

“Before ending our conversation I just want to go over some warning signs, please see a doctor if you saturate a pad within an hour, pass a blood clot bigger than a golf ball, begin to see stars or have spotty vision, develop pain in your lower right ribs, feel like you cant breath, or have a headache that is not resolved with medication.

Thank you for taking the time to talk with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

Coping

With the permission of the parents, use the baby's name whenever possible.

Phone Call

"Hi, this is [name], I'm calling from [facility] to check in and see how you're doing after your loss. If now is a good time, would you be comfortable answering some questions about how you're doing?"

Coping

Begin Conversation

"There's no right or wrong way to feel after your loss. There are some ways to cope that are healthier than others? May I ask you some questions about how you're coping with your loss?"

Questions

- How are you doing right now?
- What has been helping you get through the days?
- Have you been able to take care of your basic needs, like sleep, eating, or getting outside?
- When things feel overwhelming, what do you tend to do?
- Are there ways of coping that don't feel helpful or that concern you?
- Do you find yourself spending more time alone than you normally would?
- What's been hardest to keep up with lately?
- What do you do to cope when you are alone?
- Have you noticed that you're sleeping more or less than you normally do?
- Have you noticed that you're eating more or less than you normally do?
- Have you noticed that you're using substances like medications or alcohol to numb how you're feeling?
- May I share some warning signs about coping that may not be healthy?

Coping (Cont.)

Suggestions for Healthy Coping

- Journaling
 - Meditation
 - Exercise (running, walking, yoga, YouTube exercise videos)
 - Spending time with friends
 - Poetry
 - Setting time aside for an enjoyed hobby
-
- If you find yourself wanting to learn about coping on your own time you can visit the information provided in the follow up text.
 - Would you be interested in resources, such as counseling or a support group?
 - Do you have any questions for me about coping?

Closing Conversation

“Thank you for talking with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

Red Flags

- The grief has prevented them from being able to take care of themselves or those around them*
- They feel that they have been consumed by grief and that there is not way out**
- They refuse to talk about their grief with anyone
- Absent or unhelpful support system
- The partner is pushing them to ‘get back to normal’
- Utilization of unhealthy coping mechanisms
- They pretend that the loss did not happen

*Conduct a postpartum depression or depression assessment (help patient schedule a follow-up appointment if positive for depression)

**Conduct a suicide assessment (if suicide screen is positive, do not hang up until they are safely in the care of a family member or healthcare professional. It may be necessary to call 911)

Grief Script

Begin Conversation

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. If now is a good time, would you be comfortable answering some questions about how you’re doing?”

Grief after loss is a deeply human response. The grief and emotions people feel after loss can be confusing and complex. This is a safe space to discuss what you’re feeling. Would you like to talk about the grief and emotions you’re going through right now?”

Questions

- What feelings have been coming up most often since your loss?
- What feels hardest to manage right now?
- Are there moments when the grief feels especially intense or different?
- How do you usually cope when those feelings arise?
- How has your day-to-day life been affected?
- Who have you been able to talk to about this?
- Are you noticing changes in sleep, appetite, or energy?
- What questions do you have about grief?
- Do you ever feel stuck or unable to move forward?
- Have you had thoughts that life isn’t worth living, or wishing you could join them?
- There are resources available for grieving parents. Are you interested in learning about different resources?

Grief Script (Cont.)

Grief Assessment

If the Perinatal Grief Scale was not completed prior to the phone call:

“Learning how to heal and live with grief after perinatal loss can be difficult. Sometimes people experience what is called complicated grief and need additional resources to learn how to heal. There’s a questionnaire called the Perinatal Grief Scale that is able to identify if someone needs additional resources. Would you be interested in filling out this questionnaire so we can know how to best support you?”

Closing Conversation

“Thank you for talking with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

Red Flags

- The grief has prevented them from being able to take care of themselves or those around them*
- They feel that they have been consumed by grief and that there is not way out**
- They refuse to talk about their grief with anyone
- Absent or unhelpful support system
- The partner is pushing them to ‘get back to normal’
- Utilization of unhealthy coping mechanisms
- They pretend that the loss did not happen

*Conduct a postpartum depression or depression assessment

**Conduct a suicide assessment

Lactation Script

This script will be prompted if the patient requests a conversation regarding lactation from the automated text center. With the permission of the parents, use the baby's name whenever possible.

Begin Conversation

“Hi, this is [name], I'm calling from [facility] to check in and see how you're doing after your loss. I'm calling today because you responded that your milk has come in. Many women who experience perinatal loss after 14-weeks gestation are surprised when their milk comes in. It can be an emotionally painful reminder when this happens. It can also be physically painful. Would you like to talk about your milk coming in and some tools that can help ease this transition?”

Questions

- How have you been doing since your milk came in?
- Are you experiencing breast pain, discomfort or tenderness?
- Would you like to talk about how you are feeling?
- Some people say they are sad or frustrated, have you experienced those feelings? Would you like to talk about them?
- What are some questions you have about your milk coming in?
- Would you like some information on ways to reduce pain or discomfort?

When your milk comes in, you have a few choices. You can cause milk production to stop or you can donate breast milk. What are your goals regarding milk production?

Milk Suppression

- Would you like to know about milk suppression?

Milk Donation

- Some people have found that donating milk was helpful for them to give back
- Would you like information on donating milk?

Closing Conversation

Thank you for discussing lactation with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you're doing, would (insert day) or (insert day) work for you?

Partner Relationship Script

Begin Conversation

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. If now is a good time, would you be comfortable answering some questions about how you’re doing?”

Going through a loss like this can be very hard on relationships. People respond to grief in many different ways, sometimes there can be misunderstandings or hurt feelings. Are you comfortable talking with me about how you and your partner are doing?”

Questions

- How is your relationship with your partner right now?
- What stands out to you right now about your relationship with your partner?
- Are you able to talk with your partner about how you’re feeling?
- Is your partner able to talk with you about how they are feeling?
- Would you like your partner to be part of this conversation?
- Would your partner like to be part of this conversation?
- Have you noticed that you’re arguing more often than normal?
- Have you noticed you’re not talking to each other as much as you normally would?
- Would you be interested in talking about some ways to talk with your partner?
- Intimacy after loss can be very difficult for many people. Would you like to talk with me or someone else about intimacy with your partner?
- Would you be interested in talking about couple’s counseling or other resources?
- Do you have any questions for me about your relationship with your partner?

Closing Conversation

“Thank you for talking with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

Social Support Script

Open Conversation

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. I know that this is a very difficult time for you (and your family, if applicable), and having support during this time can be very helpful in processing grief. If now is a good time, I would like to talk with you about your support system.

Support systems are an important part of healing in grief. Everyone’s support system looks different. Sometimes those around you are very supportive and helpful, other times they may not be. This is a safe space for you to share what’s going well or what may not be going well.

Questions

- Who do you have as a support person(s) in your life that you can go to?
- How close does your support person live?
- How would you describe your support system?
- In what ways has your support been helpful?
- In what ways has your support been unhelpful?
- What do you wish you could have from your support system right now?
- Would it be okay if I sent your support person a message about your needs at this time?
- Have you considered, or are you open to becoming a part of a support group?
- Do you feel you’ve been able to communicate your needs to your support person(s)?
- Is there anything you would like to talk about regarding your support system?
- I have a list of support groups and resources, may I share some of those with you?

Close Conversation

“Thank you for talking with me today. You are not alone and the people around you want to help. It is okay to share your grief with those you love. Is there anything else you would like to talk about before we end the conversation? (If no) We will talk again on (date). If you need anything before then, please do not hesitate to call (number).

If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

Subsequent Pregnancy Script

Wait a minimum of six months after the loss to discuss and understand that this may be a very sensitive and emotionally volatile topic for the family.

Begin Conversation

“Hi, this is [name], I’m calling from [facility]. It’s been six months since (your miscarriage) OR you had (baby’s name) and I wanted to check in and see how you’re doing after your loss. We recognize you’re grieving the loss of (baby’s name) and understand that everyone grieves differently.

Everyone is on a unique timeline for processing their loss. Some parents begin thinking about pregnancy about six months after loss, which may be scary and emotional. There’s no perfect timeline and now may or may not be the right time for you. Is now a good time for me to ask you some questions about your pregnancy intentions?

Questions

- Are you considering becoming pregnant?
 - **If yes:** continue with questions
 - **If no:** Without intentional prevention measures, you may become pregnant if you are intimate with your partner.
 - How do you plan to prevent pregnancy?
 - Would you like more information on pregnancy prevention strategies?
- What are your thoughts about becoming pregnant?
- What kind of emotions come up when you think about becoming pregnant again?
- How do thoughts of pregnancy impact your intimate relationship?
- Have you discussed pregnancy with your partner?
 - How does your partner feel about pregnancy?
 - If you’re unsure of how to bring up pregnancy with your partner, may I share some suggestions on how to begin the conversation?
 - Writing a letter or small note sharing your pregnancy intentions
 - Scheduling a coffee date specifically to talk about pregnancy
 - Going on a walk with the intention to talk about pregnancy
- Is there anything else that you would like to talk about regarding pregnancy?

Close Conversation

Thank you for discussing your pregnancy intentions with me today. If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?

Talking with Children Script

Open Conversation

“Hi, this is [name], I’m calling from [facility] to check in and see how you’re doing after your loss. I know that this may be a very difficult time for you and your family. Talking about perinatal loss is difficult, especially when trying to talk to children.

Many parents who have experienced perinatal loss worry that they will say something wrong or not know how to support their children. If it is okay with you, I would like to talk with you about how to discuss perinatal loss with your children.”

Questions

- Have you talked with your children about (baby’s name if appropriate)?
- How has talking with your children about (baby’s name) been going?
- There are resources on how to support children after the death of a sibling, such as a child life specialist, books, support groups, would you like to learn more about any of these?
 - If yes: Would you like to be connected with a child therapist, support groups and bereavement camps for children who’ve lost a sibling?
- What has been helpful or not helpful for your child? Books, videos, talking, special outings?*
- What questions do you have about talking with your children about (baby’s name)?

Close Conversation

I appreciate you for taking the time to talk with me today. Do you have any other concerns you would like to talk about? Are there any social support resources that I could assist in connecting you to?

If you have any further questions or want to learn more about this topic, you can use the link in the follow-up text. We will be calling again to check in on you to see how you’re doing, would (insert day) or (insert day) work for you?”

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