



## CLINICAL PRACTICE GUIDELINE

TITLE			CODE
<b>Bereavement: Public Health Nursing Services with Families who have experienced maternal death, perinatal death, pregnancy loss, stillbirth or neonatal death</b>			
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### PURPOSE

The purpose of these guidelines is to provide direction for public health nurses in their work with families who have experienced maternal death, perinatal deaths, pregnancy loss, stillbirths or neonatal deaths.

### GOAL

- To offer support to the bereaved family
- To assess client's postpartum recovery and/or or neonatal health and provide appropriate public health nursing services
- To assess emotional health of the family
- To assess family's support system/ resources and provide other Public Health Nursing services as indicated
- To encourage families to access and utilize their support systems and resources including the hospital Social Worker, and their primary care providers
- To offer referrals to community support resources

### SCOPE

- The intended clients for this guideline are families who have been referred to WRHA Public Health Nursing services following the death of a pregnant or postpartum woman, a neonatal stillbirth, a neonatal death, or a pregnancy loss resulting from any cause (including medical inductions).

### DEFINITIONS

PHN = Public Health Nurse

HB = Healthy Beginnings

HPECD = Healthy Parenting Early Childhood Development

**BACKGROUND:** The WRHA Public Health Nursing Practice Council identified that the previous November 2009 working draft for the Bereavement guideline was in need of updating, especially to provide a comprehensive response to the issues highlighted in the Best Practice Issue Paper 11.13 which described how the Winnipeg hospitals without birthing services were not as prepared to provide the services as offered in the two birthing hospitals for women and their families experiencing pregnancy loss or perinatal deaths.



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### PROCEDURE

#### 1.0 Response to Referral

- 1.1 The PHN may contact the respective hospital Social Work department for further information and to coordinate followup support.
- 1.2 The PHN initiates contact with the referred family the day after hospital discharge in accordance with the Healthy Beginnings standards for Contact #1 i.e.: provide initial assessment using the relevant sections of the 'red flags' assessment tool.
  - 1.2.1 If unable to reach by phone to speak with the client, PHNs are to leave a telephone message stating that the PHN will call back later that day or the next day. The timing of the second telephone call is dependent on the PHN's assessment of the information on the postpartum referral – for a total of 2 telephone messages. It is not anticipated that bereaved families will return telephone calls. If unable to connect directly with the client and the messages have not been returned, the PHN will send a letter (see Appendix A)
  - 1.2.2 As with other postpartum families, if it is not possible to leave a telephone message, the PHN will provide a drop-by doorstep visit to attempt to connect with the family. The PHN will offer an initial assessment as per Healthy Beginnings standard Contact#1, utilizing the relevant sections of the 'red flags' assessment.
  - 1.2.3 If there is no contact with the client at a door –step visit, the PHN leaves an 'unable to reach you' letter. (See Appendix A )
  - 1.2.4 The following are possible words that can be used in initial telephone calls or drop-by visits. In addition, other wording can be drawn from the text of the 'unable to reach you letter' to assist in facilitating conversation with bereaved clients.

Hello my name is \_\_\_\_\_. I'm a public health nurse with the Winnipeg Regional Health Authority. You may recall that the hospital nurse mentioned that public health nursing services are available to all families who have experienced (*include statement about pregnancy/birth and about the loss ie death of your baby, pregnancy loss, etc. Refer to the child's first name, express respectful care for the family such as by saying*) I'm so sorry for your loss, or I'm so sorry that your baby died.



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I'm calling to talk about how I may be of assistance to you during this difficult time, and to *(the phn can state what public health nursing interventions are offered to families such as:*

- answer some of your questions,
- provide a health assessment to ensure that your physical recovery is alright,
- listen with you about health concerns and provide information about your health during the time after your pregnancy
- support in connecting with services and community resources
- *and if there are other live babies or baby from this pregnancy*, provide newborn assessment and breastfeeding support

Is this a good time for us to begin to talk, or should I call back later?

- 1.2.5 Refer to the deceased by name with the family contact person. If this information is not on the referral form, inquire about the name or naming of the infant, or the name of the infant's deceased mother.
- 1.2.6 Offer and arrange for a home visit as per the Healthy Beginnings Home Visiting standards if this is an initial referral with the family after the pregnancy.
- 1.2.7 When the PHN is notified of a death subsequent to responding to an initial postpartum referral /infant referral, the PHN offers a home visit to occur within the next week after receipt of the news/referral regarding a perinatal, neonatal death or maternal death.
- 1.2.8 Some infants are discharged home with a plan for pediatric palliative care. PHNs connect with the family and the palliative care nursing team to coordinate PHN services.

### 2.0 Home visit or telephone visit

- 21.1 Follow the Healthy Beginnings and related HPECD standards and clinical practice guidelines as appropriate depending upon who is deceased.
- 2.1.2 Assess the health status of the family, postpartum woman and / or infant (s), provide teaching and anticipatory guidance, and offer links to relevant services such as Families First Home Visitor services.



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2.2 Refer to the deceased by name. If this information is not on the referral form, inquire about the name or naming of the infant, or the name of the infant's deceased mother.

2.3 Invite both the father and the mother who has experienced pregnancy loss, or the death of an infant to speak about the birthing experience. Be prepared to allow for periods of compassionate silence during the conversations and to utilize empathic communication skills.

2.4 Assess support systems of family members, and respect cultural practices regarding death and grieving.

2.5 When there is an infant death, discuss normal physical changes that a postpartum woman will experience; include information about lactation issues.

2.6 Provide bereavement information and anticipatory guidance. Request to see the package of information that the hospital has provided the family and select the relevant handouts to review to match parent(s) comments. Bereaved family members may have found it difficult to open the envelope or the books; and the PHN can assist in accessing information by taking the information out of the envelope or opening a booklet for the client. (see Appendix B)

2.7 Acknowledge with the family that it may be difficult for them to open the package of information or read the material. Pace the discussed topics with the family's indicated readiness.

2.8 Offer and/or accept opportunity to look at the deceased's keepsakes with the parent(s), to acknowledge and convey respect of the individual who has died and of the grief being experienced by the family members. This provides another optional opportunity for the bereaved family members to talk and/or reflect.

2.9 Information to share with bereaved mothers and fathers may include:

- assurance that the hospital social worker and the public health nurse are available as supports and as a resource. Provide the family with the respective contact numbers.
- the information package which the family received from the hospital. Review and refer to selected handouts eg Empty Arms , the listing of community resources and recommended websites. Ask the family to retrieve the information package they received from the hospital, so that you can select the relevant handouts from the envelope for the family to review with during the home visit or at a later time.
- comments that they may notice they are grieving differently than others involved and reinforce that this is normal.



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- encouragement for communication lines be kept open between partners in a couple
- reminder to the family that it is acceptable and helpful to ask for specific kinds of assistance from friends and family, as well as for general support

### 3.0 Referrals

3.1 Facilitate referrals as necessary.

### 4.0 Followup

4.1 Contract with the family for follow up.

4.2 Possible words to use: “if you need anything else or you just need to talk...”

4.3 Personalize the follow up by giving yourself as the contact in addition to the general office telephone number.

4.4 Reinforce identified community services as a resource for each of the parents and the family.

4.5 Contract for future contact as with other referred families, in accordance with implemented Healthy Beginnings Standards and clinical practice guidelines, as well as families’ needs and resources.

### 5.0 PHNs Self-Care

5.1 Respect one’s own awareness of readiness to work with families who have experienced a death; review the practice guidelines; consult with PHN colleagues and/or CNS.

5.2 As a PHN team, acknowledge that a colleague may not be the PHN match for a new referral with a bereaved family such as when a PHN is pregnant or when a PHN is currently experiencing own challenges that may limit their ability to be fully present with bereaved family. Speak with respective PHN and, as feasible with staffing resources, offer the option to provide followup with another referral.

5.3 Offer debrief with colleagues, TM and/or CNS when PHN is working with bereaved families.

5.4 Consider participation in additional opportunities such as EAP, followup consultations with TM and/or CNS, attend more to work and away-from-work life balance, take rest and meal breaks during the workday.



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### VALIDATION

In reviewing the literature, it was determined that the evidence contributes to strong recommendations for the clinical interventions noted in this set of clinical practice guidelines. (see Appendix C)

“Bereaved parents never forget the understanding, respect and genuine warmth they received from caregivers, which can become as lasting and important as any other memories of their lost pregnancy or their baby’s brief life.”<sup>1</sup> “The most beneficial commodities that a healthcare professional can offer to a grieving family are a nonjudgmental, deep sense of caring and personal involvement.”<sup>2</sup>

“ The death of a child around the time of birth is one of the most profound, stressful events an adult may experience....Normal prenatal grief reactions immediately following perinatal death have been well documented and resemble those in other bereavement situations (e.g. after the death of a spouse.) Symptoms of acute grief typically subside with time and for most people the intensity has significantly reduced by six to 12 months post-loss. Yet, grief recovery or rather ‘the normalization of the psychosocial effects of perinatal death’ has been reported to take as long as five to 18 years....Perinatal death has been identified as a risk factor for relationship breakdown...Perceived partner support after the death of a loved one is well known to be a significant protective factor against lasting grief and distress....congruent grieving within couples leads to better relationship outcomes and, conversely, that incongruent grief could result in relationship problems.”<sup>3</sup>

“Research indicates both similar and distinctly different grief responses in mothers and fathers after perinatal death. A review of the effects of perinatal death on fathers identified common themes in paternal and maternal grief such as shock, anger, emptiness, helplessness and loneliness. Feelings of guilt were frequently reported by mothers but were rarely reported by men. [however] well-designed studies which take a more systematic approach to identifying affective and behavioural responses that are specific to mothers and fathers are needed.”<sup>4</sup>

“Although stillbirth can be as devastating as a child’s death, often the baby is known and mourned solely by the parents. Even in high-resource settings in which psychological support might be available, one in five mothers has appreciable long-term depression, anxiety ,or post-traumatic stress disorder after a stillbirth. Fathers are also affected by negative psychosocial consequences. When compared with the leading global causes of death in all age categories, all-cause stillbirths would rank fifth among the global health burdens- before diarrhoea, HIV/AIDS, tuberculosis, traffic accidents, and any form of cancer.”<sup>5</sup>



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“...stigma seems to be a much more prevalent barrier to grief than poverty. ...one of every two mothers’ grief is not accepted in public, and she does not received undivided support for her loss. In many settings, reproduction is central to women’s perceived purpose in society and...one in five women who had a stillbirths is marginalized as a failure, both as a mother and as a spouse. One in seven is considered impure or taboo. Four of five women live in a community with people who expect her to forget and have another child. To avoid stigmatization and shame, women can hide the event completely...it should be noted that general recognition by caregivers of the emotional and psychological pain of stillbirth is a fairly recent, and far from universal development...Parents consistently report more often than do health professionals that their baby was perceived by their community as a taboo object and unequal to a deceased child....The present status of stillbirth is not dissimilar to that of neonatal mortality only a decade ago...”<sup>6</sup>

“The social environment of the griever has been identified as a significant factor in grief outcomes, and the role of social support in parental grief has been well documented. Qualitative studies demonstrate a correlation between support (from doctors, nurses, and families) and lower levels of anxiety and depression in mothers following a stillbirth, with family support reported as most significant...The importance of recognizing the cultural perspective of loss and grief is well supported in the adult loss and grief literature, however only limited attempts have been made to explore the cultural context of perinatal loss.”<sup>7</sup> Care providers must explore their own attitudes about death and grief, and be attentive to respecting the bereaved family’s values, beliefs, traditions and attitudes about health, illness and death. Regardless of cultural or religious background, there are certain ‘dos and don’ts’ to say:<sup>8</sup>

Do’s and Don’ts	
What to say and do	What NOT to say or do
Use simple and straightforward language	Do not say:
Be comfortable showing emotions	“It’s best this way.”
Listen to the parents and touch the baby	“It could be worse.”
“I’m sorry”	“You can have more children”
“I wish things would have ended differently”	“Time will heal”
“I don’t know what to say”	“It’s good your baby died before you got to know him or her well”
“ I feel sad” or “ I am sad for you”	Do not use medical jargon
“Do you have any questions?”	Do not argue with parents
“We can talk again later”	Do not avoid questions
Answer questions honestly	



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“The task for primary clinicians in the area of parental bereavement will be to identify parents who are at increased risk of pathological grief, and who would benefit from referral to mental health services.”<sup>9</sup>

It is important for health care professionals who work with families experiencing pregnancy loss, maternal death and perinatal deaths to utilize self-care measures to strengthen their own coping with stressful circumstances which in turns allows them to be more capable of providing supporting care to grieving families.<sup>10</sup> “Bereavement debriefing sessions focus on the emotional response of health of health care professionals, often in the wider context of a relationship with the patient and not simply the death event itself...bereavement debriefing sessions are usually held within a week of the patient’s death...as opposed to CISD (critical incident stress debriefing) which are offered within hours of the incident.”<sup>11</sup>





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### RECOMMENDED READING

#### Online:

A. Insite link: PPH >Orientation/Learning Modules>Staff Development Sessions>January 2007 Presentations: [http://home.wrha.mb.ca/prog/pph/learning/presentation\\_jan07.php](http://home.wrha.mb.ca/prog/pph/learning/presentation_jan07.php)  
Powerpoint presentation “Providing Care to Women and Families Impacted by Perinatal Loss” and “Grief and Loss assessment and intervention handouts” by Lisa Lloyd-Scott, Manager of Social Work Child and Women’s Health, Health Sciences Centre; and Jacqueline Shortridge, Social Worker Maternal Child Health, St. Boniface General Hospital

B. Presentations from September 2008 Perinatal Loss Conference:

[http://ltc.umanitoba.ca/wikis/healthequity/index.php/Perinatal\\_Loss\\_Conference](http://ltc.umanitoba.ca/wikis/healthequity/index.php/Perinatal_Loss_Conference)

#### Books and Journal Articles:

Ilse, S. 2002. Empty Arms Coping with miscarriage, stillbirth and infant death. Wintergreen Press, Maple Plain, MN.

Kohler, K., Limbo, R., & Oakdale, C. 2012. Childbirth Education for parents receiving perinatal palliative care. International Journal of Childbirth Education, 27(2) 26- 32. note: Information is also relevant for postpartum nursing services.

Limbo, R & Kobler, K. 2009. Will our baby be alive again? Supporting parents of young children when a baby dies. Nursing for Women’s Health , 12 (4)302-311.

Minnick, M, Delp, K, Ciotti, M. 2002. A Time to Decide, A Time to Heal. Pineapple Press, St.Johns, Michigan

Riordan, Jan. 2005 Breastfeeding and Human Lactation 3<sup>rd</sup> Edition. Jones and Bartlett, Toronto. Pages 582-582: The Empty Cradle... When a Child Dies.



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- Smart, C.J. & Smith, B.L. 2013. A transdisciplinary team approach to perinatal loss. The American Journal of Maternal Child Nursing, 38 (2), 110-114.
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- Van Aerde, J., Canadian Paediatric Society fetus and Newborn Committee. 2001; reaffirmed Jan.30, 2012. Position Statement: Guidelines for health care professionals for supporting families experiencing a perinatal loss.
- Wool, C. 2013. Clinician confidence and comfort in providing perinatal palliative care. JOGNN, 42 , 48-58.
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### Appendix A

The 'Unable to reach you letter Monday to Friday & Weekends: French and English' was developed from input by the WRHA Public Health Nurses in all the community areas and the AHCP team, and from consultation with WRHA Communications. An indication of the importance and challenge of this task was that there were almost a dozen drafts of the letter in response to the feedback from the Public Health Nurses and the guidance from Communications to achieve a balance of clarity about the description of Public Health Nursing services and the expression of respectful compassion in the text of the letter.

The letter is to be sent to clients on WRHA Letter Head

Sample letters can be stored on shared drives so that the letter can be typed and printed off as a individualized letter rather than appearing as a 'form letter' and can be personalized to match the families' circumstances.

The italicized font is to be deleted from the text in the letter being sent to a family. Spaces have been left within the text to insert the Public Health Nurse's name, the name of the deceased infant or mother, and the Public Health Nurse's telephone number.



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Office régional de la santé de Winnipeg  
Caring for Health À l'écoute de notre santé

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Name  
Address  
Winnipeg, Manitoba  
Postal Code  
Date

Dear ,

My name is \_\_\_\_\_ and I'm a Public Health Nurse in Winnipeg. I was saddened to learn about the loss of your baby *(add in baby's name)* and wanted to let you know that I'm available to offer support to you and your family during this difficult time. If you wish, I can meet with you in your home or we can just talk on the phone, whichever is most convenient and helpful for you.

I would also like to talk with you to share important information about your health during the weeks following pregnancy. I would like to meet in person with you and do a brief health assessment. This will give you the opportunity to ask questions and discuss any health concerns you might have.

I welcome your calls at \_\_\_\_\_. If I am away from my phone, please leave a message and let me know the best time to reach you.

*(for weekends & stats)* If you and I are unable to connect by telephone this weekend *(or today)*, I will ask your community area public health nurse to call you next week *(or tomorrow)*.

I look forward to your call.

Sincerely,

\_\_\_\_\_  
Name

\_\_\_\_\_  
Community area office



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Nom  
Adresse  
Winnipeg (Manitoba)  
Code postal  
Date

Madame,

Je m'appelle \_\_\_\_\_ et je suis infirmière de la santé publique à Winnipeg. J' étais triste d'apprendre le décès de votre bébé \_\_\_\_\_ (*ajouter le nom du bébé*) et je tiens à vous faire savoir que je suis prête à vous offrir un soutien, à vous-même et à votre famille, pendant cette période difficile. Si vous le souhaitez, je peux vous rendre visite chez vous ou nous pouvons simplement parler au téléphone, selon ce qui est plus pratique et utile pour vous.

J'aimerais aussi vous communiquer des renseignements importants au sujet de votre santé pendant les semaines qui suivent la grossesse. J'aimerais vous rencontrer en personne et faire une brève évaluation de votre état de santé. Cela vous donnera l'occasion de poser des questions et de parler de toute préoccupation que vous pouvez avoir en matière de santé.

Vous pouvez me téléphoner au \_\_\_\_\_. Si je ne répons pas, veuillez me laisser un message et m'indiquer à quel moment je peux vous rappeler.

(*pour fins de semaine et jours fériés*) Si nous ne pouvons pas nous joindre par téléphone cette fin de semaine (*ou aujourd'hui*), je demanderai à l'infirmière de la santé publique chez votre zone communautaire de vous appeler la semaine prochaine (*ou demain*).

J'attends votre coup de téléphone.

Sincèrement,

Nom,

Bureau de la zone communautaire de



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Appendix B

Discharge information packages of handouts from HSC and St. Boniface Hospitals -awaiting decision about access to discharge packages July 2013.

Appendix C

“Quality of Evidence

Recommendations in the guidelines prepared by the Canadian Task Force on Preventive Health Care (CTFPHC) [www.canadiantaskforce.ca](http://www.canadiantaskforce.ca) are graded as either strong or weak according to the Grading of Recommendations Assessment, Development and Evaluation system (GRADE).

The CTFPHC’s judgments about the quality of evidence are summarized by the degree of confidence that available evidence correctly reflects the theoretical true effect of the intervention or service.

We judge evidence as high quality when we are highly confident that the true effect lies close to that of the estimate of the effect. For example, evidence is judged as high quality if all of the following apply: there is a wide range of studies included in the analyses with no major limitations, there is little variation between studies, and the summary estimate has a narrow confidence interval.

We judge evidence as moderate quality when we consider that the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different. For example, evidence might be judged as moderate quality if any of the following applies: there are only a few studies and some have limitations but not major flaws, there is some variation between studies, or the confidence interval of the summary estimate is wide.



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We judge evidence to be low or very low quality when the true effect may be substantially different from the estimate of the effect. For example, evidence might be judged as low quality if any of the following applies: the studies have major flaws, there is important variation between studies, or the confidence interval of the summary estimate is very wide.

### Strength of Recommendations

In addition to the quality of supporting evidence, the strength of our recommendations is influenced by: the balance between desirable and undesirable effects; the variability or uncertainty in values and preferences of citizens; and whether or not the intervention represents a wise use of resources.

Strong recommendations are those for which we are confident that the desirable effects of an intervention outweigh its undesirable effects (strong recommendation for an intervention) or that the undesirable effects of an intervention outweigh its desirable effects (strong recommendation against an intervention). A strong recommendation implies that most individuals will be best served by the recommended course of action.

Weak recommendations are those for which the desirable effects probably outweigh the undesirable effects (weak recommendation for an intervention) or undesirable effects probably outweigh the desirable effects (weak recommendation against an intervention) but uncertainty exists. Weak recommendations result when the balance between desirable and undesirable effects is small, the quality of evidence is lower, and there is more variability in the values and preferences of individuals. A weak recommendation implies that we believe most people would want the recommended course of action but that many would not. Clinicians must recognize that different choices will be appropriate for different individuals, and they must support each person in reaching a management decision consistent with his/her values and preferences. Policy-making will require substantial debate and involvement of various stakeholders.

This companion document to Task Force recommendations is also available on the Canadian Task Force on Preventive Health Care's website at

[www.canadiantaskforce.ca](http://www.canadiantaskforce.ca)



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<sup>3</sup> Koomans, L. Wilson, T, Cacciatore, JI, Flenady, V. Support for mothers, fathers and families after perinatal death. Cochrance Database of Systematic Reviews 2013, Issue 6. Art. No.: CD000452.DOI:10.1002/14651858.CD000452.pub3.

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