Early Pregnancy Loss in the Emergency Department

Recommendations for the Provision of Compassionate Care

FINAL REPORT | March 31, 2017

Provincial Council for Maternal and Child Health
building a brighter future

Champlain Maternal Newborn Regional Program
Programme régional des soins à la mère et au nouveau-né de Champlain

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INTRODUCTION

Experiencing a pregnancy or infant loss can be a very emotional and traumatic time for expectant parents. The gestational age at the time of the pregnancy loss often determines not only the setting for care, but also the standard of care associated with addressing bereavement.

When patients first experience the symptoms of an early pregnancy loss, they frequently seek medical care in an Emergency Department (ED) due to the urgency and uncertainty associated with vaginal bleeding, abdominal pain and their implications for the wellbeing of the pregnancy. In 2015, 25,000 patients in Ontario attended an ED experiencing a pregnancy loss[i]. However, because these cases still represent a small proportion of total ED visits (less than 1%), healthcare providers and other staff in the ED may not have as much experience treating them, in particular, addressing their emotional and bereavement needs. As such, pregnancy loss may be treated as a physical complaint and not acknowledged as a loss of life with emotional dimensions.

The physical and emotional care that healthcare providers can offer to individuals experiencing an early pregnancy loss has an important impact on their long-term emotional well-being. While the medical management of pregnancy loss may be familiar practice, the way in which psychological and emotional support is provided is not. Significant barriers to providing compassionate care are the inexperience with and the lack of knowledge of perinatal bereavement care strategies and communication skills. Furthermore, ED staff may often prioritize functional physical tasks over supportive emotional care in order to deal with the pressures associated with long wait times, overcrowding and the urgent physical needs of other acutely ill patients in the ED. Despite this, it is critical that healthcare providers working in EDs attend to the patients' psychological and emotional needs in an empathetic, caring environment. Compassionate care acknowledges pregnancy loss as a loss of life and considers the spiritual, emotional and cultural expressions of the pain that accompanies the loss of a baby.

OBJECTIVES

The objective of this report is to provide guidance, in the form of recommendations, to ED healthcare providers and staff in the provision of compassionate care to patients presenting with a ***confirmed early pregnancy loss (less than 20 weeks gestation)***. The components of the recommendations include environmental considerations, communication strategies, cultural, religious and spiritual considerations, addressing patients' informational and psychological needs, ensuring proper supports, the importance of mementoes and memory-making, dealing sensitively with disposition of the fetal remains, discharge considerations, as well as recommendations pertaining to the training and well-being of healthcare providers and staff.

[i]Intellihealth, March 2017

METHODS

The report's recommendations for the provision of compassionate care in EDs were based on a literature review of quantitative and qualitative studies, position statements from professional organizations, evidence-based practice guidelines, current practices and resources from hospitals across the country, and expert panel consensus. The recommendations were further validated by a patient engagement survey.

Literature Review

A literature review included a search of the following databases: PubMed, CINHAL, and EMBASE. Keywords used included synonyms of words that encompassed bereavement, pregnancy loss, and empathy. Included in the literature findings were qualitative and quantitative studies as well as synthesized evidence such as systematic reviews and clinical guidelines.

Current Practice Review

Current practices regarding compassionate care and early pregnancy loss in EDs across the country were sought out. A call for documentation/current processes was made via various organizations: Ontario LHIN leads, PCMCH Maternal-Newborn Advisory Committee, Canadian Perinatal Programs Coalition (CPPC) listserv, Maternity Care Discussion Group (MCDG) listserv, Canadian Association of Perinatal and Women's Health Nurses (CAPWHN) discussion forum, Best Start listserv; and through networks of ED and obstetrical social workers, and ED and obstetrical educators across Ontario.

The project team reviewed documentation, literature and protocols from 16 hospital EDs spanning LHINs 1 through 11 in Ontario, and a number of others across Canada.

Expert Advisory Panel Consensus

The development of these recommendations was led by a Project Team that was supported by an Expert Advisory Panel. The role of the Panel was to guide the development of the recommendations, provide content expertise and feedback on the materials created, and act as a liaison between the project team and experts in the field when required.

The Expert Advisory Panel was composed of ED healthcare providers (physicians, nurses, social workers), Early Pregnancy Loss Clinic healthcare providers (physicians and nurses), perinatal healthcare providers (obstetricians, family physicians, midwives, nurses, social workers), and included representation from high- and low-volume EDs in both urban and rural settings. The panel also included representation from the Pregnancy and Infant Loss (PAIL) Network and Health Quality Ontario (HQO), and three of the panel members also acted as patient advisors. See ***Appendix A*** for the Project Team and Expert Advisory Panel membership list.

The panel reviewed the recommendations at multiple stages throughout the development process, provided input and feedback in each iteration of the revisions, and finalized the recommendations and materials via consensus.

Patient Engagement Survey

An important component of the development of the recommendations was engagement with families who experienced an early pregnancy loss in an ED. A diverse set of perspectives from all regions of Ontario was sought. In order to help ensure equitable accessibility to all those interested in participating, an anonymous online survey was conducted by PCMCH through its various communication channels. Individuals were eligible to participate in the survey if they or their partner had experienced an ectopic pregnancy or a pregnancy loss at less than 20 weeks gestation in the last 12 months, and had received care and/or services for the pregnancy loss in an Ontario hospital's EDs.

The survey utilized a mixed quantitative and qualitative approach. Participants were asked to identify the types of information and supports that were made available to them in the ED at the time of their pregnancy loss. Additionally, participants were asked to comment on aspects of the care they received, and to suggest ways in which the overall experience of families experiencing a pregnancy loss in the ED could be improved.

Over a two week period, 52 participants completed the survey across all regions of Ontario. The results were used to validate the draft recommendations and to identify any gaps that necessitated the creation of additional recommendations.

RECOMMENDATIONS

An early pregnancy loss can be a very emotional and traumatic time for individuals experiencing the loss and their families. For those patients presenting to an ED, it is essential that both their physical and emotional needs are addressed. While the former may be familiar practice for healthcare providers, the latter may not be due to a lack of comfort with or knowledge of perinatal loss and bereavement care. Assessment of emotional needs is crucial to ensure that patients receive compassionate bereavement care specific to their feelings of loss.

These recommendations have been created to guide the provision of compassionate care to patients with a *confirmed early pregnancy loss* (less than 20 weeks gestation) in an ED. They are intended to provide guidance to ED staff, both clinical and non-clinical, who provide care to this patient population. Patients experiencing a pregnancy loss at greater than 20 weeks gestation would typically not be seen in an ED, and would seek care in a hospital's birthing unit.

It is important to note that patients may present to the ED multiple times before their pregnancy loss is confirmed. While these recommendations and general principles of care are developed specifically for patients with a confirmed pregnancy loss, they can be adapted for patients with a threatened pregnancy loss, a late pregnancy loss, or to other settings, such as primary care and early pregnancy loss clinics.

The recommendations were derived from evidence-based practice guidelines, peer-reviewed literature, review of current practices, consensus from care providers, and patient engagement. The recommendations are intended as a tool for providing compassionate care and do not supersede clinical recommendations of the medical management of early pregnancy loss. Hospitals' policies and protocols should be respected and these compassionate care recommendations should be integrated to ensure patients receive sensitive, family-centered bereavement care.

Principles of Care

There are several principles of care to be considered with any patient-care interaction.[1–3] Providing personal, compassionate, and individualized support to patients and their families while respecting their unique needs, including their social, spiritual, and cultural diversity is important.[4,5] In addition, when talking with patients and their families, healthcare providers should be honest, open, and realistic, providing reassurance when appropriate.[6,7]

It is recommended that the following principles of care be followed when providing information and care for an individual experiencing an early pregnancy loss:

Principles of Care	
1. Validate the loss and legitimize grief	6. Be open and listen with intent
2. Encourage patients to share their feelings	7. Be empathetic
3. Acknowledge patients' feelings	8. Be honest and realistic
4. Assess level of patients' knowledge	9. Provide reassurance where appropriate
5. Provide additional information	10. Maintain confidentiality

Recommendation Themes

The recommendations for the provision of compassionate care for early pregnancy loss in the ED are organized into the following themes: *environmental considerations, communication strategies and considerations, cultural, religious and spiritual considerations, informational needs, psychological needs and supports, memories and mementoes, disposition of fetal remains, discharge considerations and follow-up, and training and support of healthcare providers and staff*. For a summary of the recommendations, please see ***Page 4***.

For each recommendation, rationales and/or implementation considerations are included to provide supplementary information and guidance to healthcare providers and staff implementing the recommendations. Supporting materials are available in ***Appendices B to H.***

ENVIRONMENTAL CONSIDERATIONS	
Recommendations	**Rationale/ Implementation Considerations**
1. Ensure that patients and their families are in a private and comfortable area/ examination room when receiving care and discussing pregnancy loss management.[4,5,8–11]	• It is important that individuals/ families do not feel isolated or unsupported on a busy unit.[12]

COMMUNICATION STRATEGIES & CONSIDERATIONS	
Recommendations	**Rationale/ Implementation Considerations**
2. With patient consent, offer that a support person be present when the patient is being informed of the pregnancy loss diagnosis and management plan.[5,10,11]	• It is important for a support person to accompany the patient as the patient may not hear all of the advice and education due to the distress they may be experiencing.[10] • Contact with support services can also be offered (e.g., social work, pregnancy loss coordinator, spiritual care).[10]
3. Acknowledge the loss with the patient and family, and ensure that they are afforded dignity, respect, and time to grieve.[13,14]	• Healthcare providers should be physically available to support the patient in whatever expressions of feelings or emotions are appropriate for them, and be comfortable conveying empathy in words or gestures.[13–16] • Acknowledgement of the loss is an important aspect in post-pregnancy loss support. When the loss is ignored or passed over to discuss medical concerns, the patient may feel that their loss is inconsequential to others.[15,17,18] • Provide families with time to grieve, to understand the events that have happened, and/or to make decisions regarding plan of care that will happen.[19]

4. Provide information about pregnancy loss as soon as possible, using simple, patient-centered language, and avoid medical jargon.[10]	• Tools such as a Bereavement Checklist and a Perinatal Loss Flowsheet can be used to help with the documentation of discussions and interventions provided to patients and their families, however, they should be used cautiously as checklists/ flowsheets themselves are not indicative of providing quality patient care.[20,21] • Refer to ***Appendix B – Bereavement Checklist Example*** for an example of a bereavement checklist. • It is important that healthcare providers pay attention to details in their language. They should follow the patient's lead with regard to the terminology used when referring to the loss and recognize that the meaning of a loss will be different for each parent.[5,14] • Patients appreciate when healthcare providers verbally communicate with them in a sensitive but clear and honest way.[5] • Patient-centred and plain language should be used.[15,22] • Healthcare providers should be aware of the non-verbal messages and cues they may be sending (e.g., posture, gestures, facial expressions, and tone of voice) and also respond to patients' non-verbal cues.[5,23] • Avoid describing the fetal remains as "specimen", "biomedical waste" or "products of conception", which can dehumanize the baby and depersonalize the experience.[20]
5. Communicate information verbally and in a written format, and seek translation services when required.[13,24]	• Written and verbal information must be accurate and complete, in a format each person can understand, and readily available when a person wants to make decisions.[5,19]
For further guidance, please refer to: ***Appendix B– Bereavement Checklist Example*** ***Appendix C – Communication Strategies for Breaking Bad News*** ***Appendix D – Communicating with Families Experiencing a Pregnancy Loss***	

CULTURAL, RELIGIOUS & SPIRITUAL CONSIDERATIONS	
Recommendations	**Rationale/ Implementation Considerations**
6. Ensure that patients' cultural and religious needs are considered when	• Healthcare providers should be aware of how personal, cultural, religious and spiritual

providing pregnancy loss care and support, and offer referral to spiritual services or to contact the patient's own spiritual leader.[4,5,7,11,25–27]	beliefs may affect patients' wishes and decisions. Assumptions should never be made based on these factors.[5] • Religious or spiritual rituals can have an important spiritual, social and/or emotional significance and may be comforting to some families. Most religious rituals (e.g., baptism, prayer, naming ceremony, songs, and readings) that patients and families might want to perform can be easily accommodated.[5]

INFORMATIONAL NEEDS	
Recommendations	**Rationale/ Implementation Considerations**
7. Inform the patient of all pregnancy loss management options (i.e., possible referral, surgical, medical, or expectant management), including the risks and benefits of each.[5,17]	• Full information about all test results, diagnoses and any available procedures or care options should be offered (Sands, 2016). • Information may need to be repeated multiple times as stress and grief may interfere with comprehension and recall of information.[10,14] • Allow time for patients and families to absorb information provided, discuss their thoughts, concerns and/or feelings and ask questions.[5,10] • Staff should answer any questions directly and honestly.[5]

8. Inform patients about what to expect during the course of their care while in the ED.[4,28,29]	• Information should be provided on what to anticipate when undergoing expectant management:[29]
	  ○ Expected rate and amount of bleeding.
	  ○ Description of expected size and appearance of the baby or fetal remains.
	  ○ Anticipated level of pain and pain management options.
	  ○ Directions for collection, storage, and transportation of fetal remains for analysis.
	• It is important to recognize that all patients are different and that the type and amount of information that they want will vary.[5]
	• Patients and families may also have different levels of medical knowledge and some may need more explanation to help them understand the information they are given.

	All communication should be tailored to the needs and wishes of individual patients and families.[5] • It is important that all staff interacting with patients and families are aware of what has already been discussed. It can be distressing for patients and families to have to repeat the same information multiple times and to receive inconsistent or contradictory information.[5]
9. Encourage patient involvement in shared decision making.[6,13,19,28,30]	• Provide patients and their families with time to process the information and engage in informed decision making with regards to the plan of care.[19] • Patients and their families should be supported to feel in control of their care.[10]
10. Consider providing a bereavement package to patients and families experiencing a pregnancy loss. (Expert Advisory Panel Consensus)	• Refer to ***Appendix E - Bereavement Package and Mementoes*** for suggested contents of an ED early pregnancy loss bereavement package. • EDs may consider partnering with community or patient groups to develop bereavement packages.
For further guidance, please refer to: ***Appendix E - Bereavement Package and Mementoes***	

PSYCHOLOGICAL NEEDS & SUPPORTS	
Recommendations	**Rationale/ Implementation Considerations**
11. Determine how the pregnancy loss is perceived by the patient and their family, and aim to better understand their unique experiences and needs.[4,9]	• It is important for healthcare providers to recognize that the experience of pregnancy loss is not the same for all patients. Some may view the end of the pregnancy as a minor event, while others may view it as a significant loss of a baby.[12,14,29–33] • Healthcare providers should acknowledge the patient's feeling of loss and emptiness, and not just treat the patient's medical conditions.[34]
12. Reassure the patient that in the vast majority of cases the loss is not due to anything that the patient did or did not do.[6,10,22,35]	• It is common for individuals to experience guilt in thinking their actions may have triggered the event.[22] • Healthcare providers should take into account hospital policies/ procedures and offer to investigate the potential cause of the pregnancy loss.[19,22,36]

13. Reassure and educate bereaved patients and families about the grief process, including the physical, social and emotional responses of individuals and families.[5,14]	• Grief is a one-of-a kind experience, unique to each person.[14]
	• Patients will express grief in different ways. Assumptions should not be made about whether or not a patient needs emotional support based on their outward expressions of grief.[5]
	• Patients may find it helpful to know:[5]
	  ○ That there a wide range of physical and emotional reactions when grieving and healthcare providers should reassure patients that there is no "right" or "healthy" way to express or deal with grief.
	  ○ Grief can persist for much longer than most people expect.
	  ○ Grief usually eases over time but it may be triggered by certain dates, events or experiences.
	• Refer to ***Appendix F – Normal Grief Response*** for a list of physical, emotional, intellectual, spiritual, social and occupational grief responses.

14. Assess the patient's support systems and coping strategies, and reinforce coping mechanisms that were found to be effective in the past.[14,37]	• Healthcare providers can offer to make calls or adapt visiting policies so family and friends can provide the kind of support needed while in hospital and after discharge.[14] • Grieving families need encouragement to believe in their ability to survive their difficult journey.[14]
15. Inform the patient of the potential benefits of communicating their feelings of loss to family and friends, and the importance of connecting with social networks (e.g., church groups, support organizations, and grief support groups).[22]	• Without this knowledge, family and friends may not understand the magnitude of the loss, ignore the subject, or make comments that, although well-intentioned, may minimize the event.[22] • Refer to ***Appendix G – List of Resources for Families and Healthcare Providers*** for a list of support organizations and grief support groups.
For further guidance, please refer to: ***Appendix F – Normal Grief Response*** ***Appendix G – List of Resources for Families and Healthcare Providers***	

MAKING MEMORIES & MEMENTOES

Recommendations	Rationale/ Implementation Considerations
16. If the baby's body or remains are obtained, offer the patients and their families the chance to see and hold them, and provide support throughout this process.[4,5,9–11,27,28]	• Healthcare providers should counsel families about the appearance of the baby's body or remains and allow patients and families to make their own choice about whether or not they wish to see them.[29]
17. When applicable, encourage patients and families to honour their baby in some way.[7,26]	• Examples include: naming the baby, making a keepsake album, planting a bush or tree, purchasing special jewelry, participating in a community event (e.g. remembrance walk/run, memorial service, holiday candle lighting.[7]
18. Offer patients and families mementoes in a sensitive and respectful manner, and inform them of the potential importance of these mementoes.[4,7,9,11]	• Mementoes increase the sense of identity of the baby.[27] • Although many families find it helpful to have keepsakes of their baby, some may decline on personal, cultural or religious grounds. Some families may find certain specific keepsakes unacceptable.[5] • Protocols and checklists have been created to ensure that mementoes are offered. However, these checklists and procedures should not be adhered to as directives, rules or tasks that must be completed but should be used to offer suggestions and choices to patients and families.[5] • Refer to ***Appendix B – Bereavement Checklist Example*** for an example of a bereavement checklist. • Refer to ***Appendix E - Bereavement Package and Mementoes*** for a list of items that can be included in an early pregnancy loss package.
For further guidance, please refer to: ***Appendix E - Bereavement Package and Mementoes***	

DISPOSITION OF FETAL REMAINS

Recommendations	Rationale/ Implementation Considerations
19. Familiarize yourself with your institution's process as well as provincial regulations in regards to the disposition of fetal remains.[7,26]	• All hospitals should have a process in place in regards to the disposition of fetal remains.

20. Treat the baby's body or remains with dignity and respect, in the same manner as an adult body would be treated.[4]	• Wherever possible, healthcare providers should accommodate patient's preferences about the handling, transportation or storage of their baby's body or remains as this may have an effect on their bereavement experience.[4,38] • The baby's body or remains should not be treated as biomedical waste.
21. Offer patients information about pathological examinations that may be clinically indicated.[5]	• Healthcare providers should refer to their hospital processes for fetal pathological examinations. • All hospitals should have a process in place for fetal pathological examinations.
22. Regardless of the baby's gestation and weight, inform patients and their families of the options for disposition that are available to them.[5,7,10,14]	• It is important for healthcare providers to keep in mind that funeral services and burials are an individual choice, based on preference, tradition, culture and religion.[7] • Patients should be given the details of all available options for burial or cremation that can be arranged by the hospital or privately before they make a decision. [5] • Staff should be aware of, and have access to, information about local burial and cremation options in their community, such as special disposition programs where fetal remains are communally cremated or buried.[5,10,14]
23. Ensure that patients and their families are afforded the time to decide and process their decision regarding the disposition of fetal remains, and provide them with an opportunity to revise the care plan before it is carried out.[19,25]	• Staff should acknowledge that these decisions may be difficult and offer patients as much time as they need to make them.[5] • If patients have not made a decision before they leave the hospital, they should be given the details of whom to contact when they have reached a decision.[5] • Patients should be told for how long the fetal remains will be stored and the arrangements that will be made if they do not make a decision within this timeframe.[39]

DISCHARGE CONSIDERATIONS & FOLLOW-UP	
Recommendations	**Rationale/ Implementation Considerations**
24. Upon discharge, provide patients and their families with bereavement information, including common responses to grief and loss, community and online resources, and a list of	• Refer to ***Appendix F – Normal Grief Response*** for a list of physical, emotional, intellectual, spiritual, social and occupational grief responses. • Refer to ***Appendix G – List of Resources for***

symptoms and concerns that warrant contacting a healthcare provider.[4,9,10,14,17,18,40]	***Families and Healthcare Providers*** for a list of support organizations and grief support groups. • Refer to ***Appendix H – Discharge Teaching for Patients Experiencing an Early Pregnancy Loss*** for a list of topics that should be discussed with the patient upon discharge.
25. Identify the patient's obstetric and/or primary care provider and notify them of the patient's pregnancy loss, and provide patients with the summary of their care.[4,5]	• This is important for both follow-up obstetric care and to avoid having the patient continue to receive communications from the provider regarding routine prenatal care, such as screening tests and pregnancy classes, when she is no longer pregnant.[4] • The primary care provider may also wish to order specific testing on the mother or baby.[4]
26. Discuss a follow-up plan with patients and families experiencing a pregnancy loss, prior to their discharge.[4]	• Referral to relevant healthcare providers and services should be offered prior to discharge, particularly for counselling/ psychological support services (e.g., genetic counsellor, social worker, spiritual care).[10] • Patients should be encouraged to follow-up with a healthcare provider based in the hospital or community in the event that they need ongoing support, have any questions, and to discuss potential results from tests or post mortem investigations.[5,10,28] • All staff who contact patients after a pregnancy loss should have training in bereavement care and should feel confident and competent in supporting distressed patients and families.[5]
For further guidance, please refer to: ***Appendix F – Normal Grief Response*** ***Appendix G – List of Resources for Families and Healthcare Providers*** ***Appendix H – Discharge Teaching for Patients Experiencing an Early Pregnancy Loss***	

TRAINING & SUPPORT OF HEALTHCARE PROVIDERS AND STAFF	
Recommendations	**Rationale/ Implementation Considerations**
27. Ensure that education is available for all healthcare providers and staff who provide care for patients experiencing a pregnancy loss in the ED.[4,8,9]	• Education is important to address misconceptions about pregnancy loss, increase confidence in providing support, and promote effective care.[4,5,8,9,41] • Good communication skills are a critical part of providing bereavement care and should be included in training programs.[28,42,43]

28. Ensure that emotional support is available for all healthcare providers and staff who care for patients experiencing a pregnancy loss in the ED, and encourage debriefing after a difficult loss situation.[4]	• Healthcare providers should be allowed to recover after providing care to a grieving patient to avoid burnout and allow other healthcare providers to practice compassionate skills related to bereavement.[44]

CONCLUSION

Women may not remember all of the information they are given in hospital, but they do remember the kind of care they receive. It's clear that kindness, compassion, sensitive language and clear explanations can make all the difference in helping people through this difficult time.[5] The recommendations provided in this report aim to guide ED healthcare providers and staff in providing compassionate bereavement care specific to a patient's feelings of loss at this potentially very emotional time in their lives.

It is also important not to forget the needs of the ED healthcare providers and staff. Bereavement care education, as well as care for their own emotional wellbeing are important and should be included as part of a holistic approach to providing compassionate care to patients presenting to the ED with an early pregnancy loss.

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APPENDICES

Appendix A – Project Team and Expert Advisory Panel Membership

Name	Title/ Position	Organization
Project Team		
Doreen Day	Senior Program Manager	Provincial Council for Maternal and Child Health
Olha Lutsiv	Program Analyst	Provincial Council for Maternal and Child Health
France Morin	Perinatal Consultant	Champlain Maternal Newborn Regional Program
Laura Zahreddine	Masters of Nursing Candidate	Health Quality Ontario
Expert Advisory Panel		
Sonia Baruzzo	Social Worker (Obstetrics); Patient Advisor	The Ottawa Hospital
Nadine Duhil-Enns	Midwife	Family Midwifery Care
Josh Gohl	Registered Nurse (Emergency Department); Patient Advisor	Guelph General Hospital
Batya Grundland	Family Physician; Maternity Care Lead for Family Practice Obstetrics	Women's College Hospital
Terri Irwin	Director, Quality Standards	Health Quality Ontario
Kate MacWilliams	Registered Nurse (Emergency Department); Clinical Educator	St. Joseph's Health Centre Toronto
Barbara Matteucci	Founder of Butterfly Run Quinte; Doula; Patient Advisor	Butterfly Run Quinte
Howard Ovens	Emergency Physician, Chief of Department of Emergency Medicine	Sinai Health System
Gareth Seaward	Obstetrician (Maternal-Fetal Medicine Specialist); Vice-Chair of Quality Improvement and Patient Safety in Department of Obstetrics and Gynaecology	Sinai Health System
Elaine Senis	Social Worker (Emergency Department)	St. Michael's Hospital
Lindsey Sutherland	Family Physician (Primary Care, Obstetrics, Emergency Medicine, Hospital Medicine)	Chatham-Kent Health Alliance

Heather Tempest	Registered Nurse (Labour and Delivery, Early Pregnancy Clinic)	North York General Hospital
Melissa Theriault	Nurse Practitioner (Emergency Department)	Hôpital Montfort
Jackie Thomas	Obstetrician/ Gynecologist; Founder of Early Pregnancy Clinic	Sinai Health System
Catherine Varner	Emergency Physician	Sinai Health System
Ashley Waddington	Obstetrician/ Gynecologist (Early Pregnancy Clinic)	Kingston General Hospital
Jo Watson	Nurse Practitioner; Operations Director of Women & Babies Program; Director of Pregnancy and Infant Loss Network (PAIL)	Sunnybrook Health Sciences Centre
Arthur Zaltz	Obstetrician/ Gynecologist; Chief of Department of Obstetrics & Gynecology and Women & Babies Program	Sunnybrook Health Sciences Centre

Appendix B – Bereavement Checklist Example

Please Note: This is an example of a beareavement checklist that can be adapted to the ED of any institution.

Internal Referral

☐ **Referral to Social Work**	Date/Time _____	HCP signature: _____
☐ **Referral to Spiritual Care**	Date/Time _____	HCP signature: _____
☐ **Referral to Early Pregnancy Clinic**	Date/Time _____	HCP signature: _____
☐ **Consult to Social Work Complete**	Date/Time _____	HCP signature: _____
☐ **Consult to Spiritual Care Complete**	Date/Time _____	HCP signature: _____

Community Referral

☐ **Referral to HBHC**	Date/Time _____	HCP signature: _____
☐ **Referral to Support Group**	Date/Time _____	HCP signature: _____

Psychosocial Needs

☐ **Patient Viewed Baby**	Date/Time _____	HCP signature: _____
☐ **Family Viewed Baby**	Date/Time _____	HCP signature: _____

Bereavement Package & Mementoes

☐ Discharge & Follow-Up Information	☐ Tea Packets	☐ Ultrasound Images
☐ Hospital Supports Information	☐ Sympathy Card	☐ Photographs
☐ Community Supports Information	☐ Poems/ Letters	☐ Baby Clothing/ Blanket
☐ Sanitary Pads & Tissues	☐ Memory Journal	☐ Stuffed Animal
		☐ Children's Book
	Date/Time _____	HCP signature: _____

Disposition of Fetal Remains

☐ **Pathology Requisition**	☐ **Private Arrangements**	☐ **Hospital Arrangements**
_____	_____	_____
_____	_____	_____
	Date/Time _____	HCP signature: _____

Memorial Service

☐ **Invited to Annual Memorial Service Held at:** _____

☐ **Invitation Card Given**	Date/Time _____	HCP signature: _____

Follow-Up

☐ **ED Arranged**	Date/Time _____	HCP signature: _____
☐ **Patient Arranged**	Date/Time _____	HCP signature: _____

When: _____ **Where:** _____

Legend: ED = Emergency Department; HBHC = Healthy Babies Healthy Children Program; HCP = healthcare provider

Appendix C – Communication Strategies for Breaking Bad News

Communicating bad news to patients is one of the most difficult tasks for healthcare providers. In addition to the verbal component, it requires the ability to recognize and respond to the patient's emotions, deal with the stress that the bad news creates, and still be able to involve the patient in decisions.

Below are a sampling of frameworks that have been developed to provide structure to the process of communicating bad news.

SPIKES Protocol For Breaking Bad News
S – SETTING and LISTENING SKILLS
P – Patient's PERCEPTION of the condition and its seriousness
I – INVITATION from patient to give information
K – KNOWLEDGE – giving medical facts
E – Explore EMOTIONS and EMPATHIZE as patient responds
S – STRATEGY and SUMMARY
Adapted from Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. The Oncologist. 2000;5(4):302–11.[45]

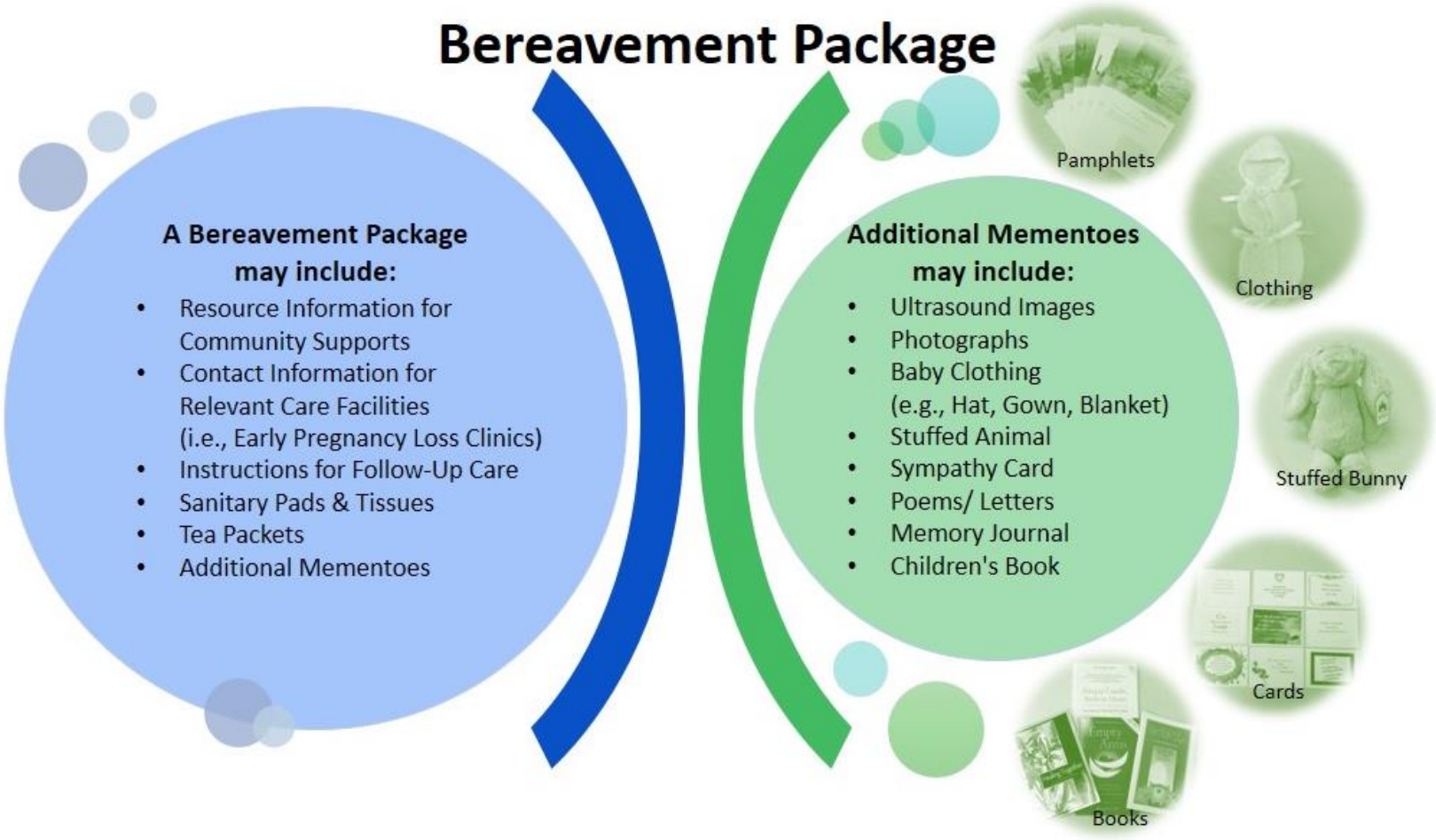
ABCDE Mnemonic for Breaking Bad News
Advance preparation
Build a therapeutic environment/relationship
Communicate well
Deal with patient and family reactions
Encourage and validate emotions
Adapted from VandeKieft GK. Breaking bad news. Am Fam Physician. 2001 Dec 15;64(12):1975–8.[46]

Kaye's 10 Step Model to Breaking Bad News	
Step 1	Preparation
Step 2	What does the patient know?
Step 3	Is more information wanted?
Step 4	Give a warning shot
Step 5	Allow denial
Step 6	Explain if requested
Step 7	Listen to concerns
Step 8	Encourage ventilation of feelings
Step 9	Summarize
Step 10	Offer further help
Adapted from Kaye P. Breaking Bad News: A 10 Step Approach. Northhampton, Australia: EPL Publications; 1996.[47]	

Appendix D – Communicating with Families Experiencing a Pregnancy Loss

DOs and DON'Ts of Communicating with Families Experiencing a Pregnancy Loss	
What to Say "I'm sorry" "I wish things would have ended differently" "I don't know what to say" "I feel sad" or "I am sad for you" "How are you doing will all of this?" "Tell me how you feel" "Tell me more, I'd like to know" "Can you tell me what happened today?" "What is going on right now?" "What is the hardest part for you right now?" "What can I do for you?" "This isn't what you expected…" "I'm here and I want to listen" "Do you have any questions?" "We can talk again later"	**What Not to Say** "This happened for the best" "It could be worse" "You can have more children" "Time will heal" "You have an angel in heaven" "It's good your baby died before you got to know him/ her well" "It was not meant to be" "Over time you will forget your baby"
What to Do • Acknowledge the patients' loss • Listen to the patients and families • Answer questions honestly • Allow time for discussion and support • Be comfortable showing emotions • Be comfortable touching the baby • Use simple and straightforward language	**What Not to Do** • Do not avoid questions • Do not argue with patients and their families • Do not forget to support partners/ relatives • Do not use medical jargon • Do not call the baby a "fetus" or "it"
Adapted from van Aerde J, Canadian Paediatric Society (CPS). Guidelines for health care professionals supporting families experiencing a perinatal loss. Paediatr Child Health. 2001 Sep;6(7):469–90.[11]	

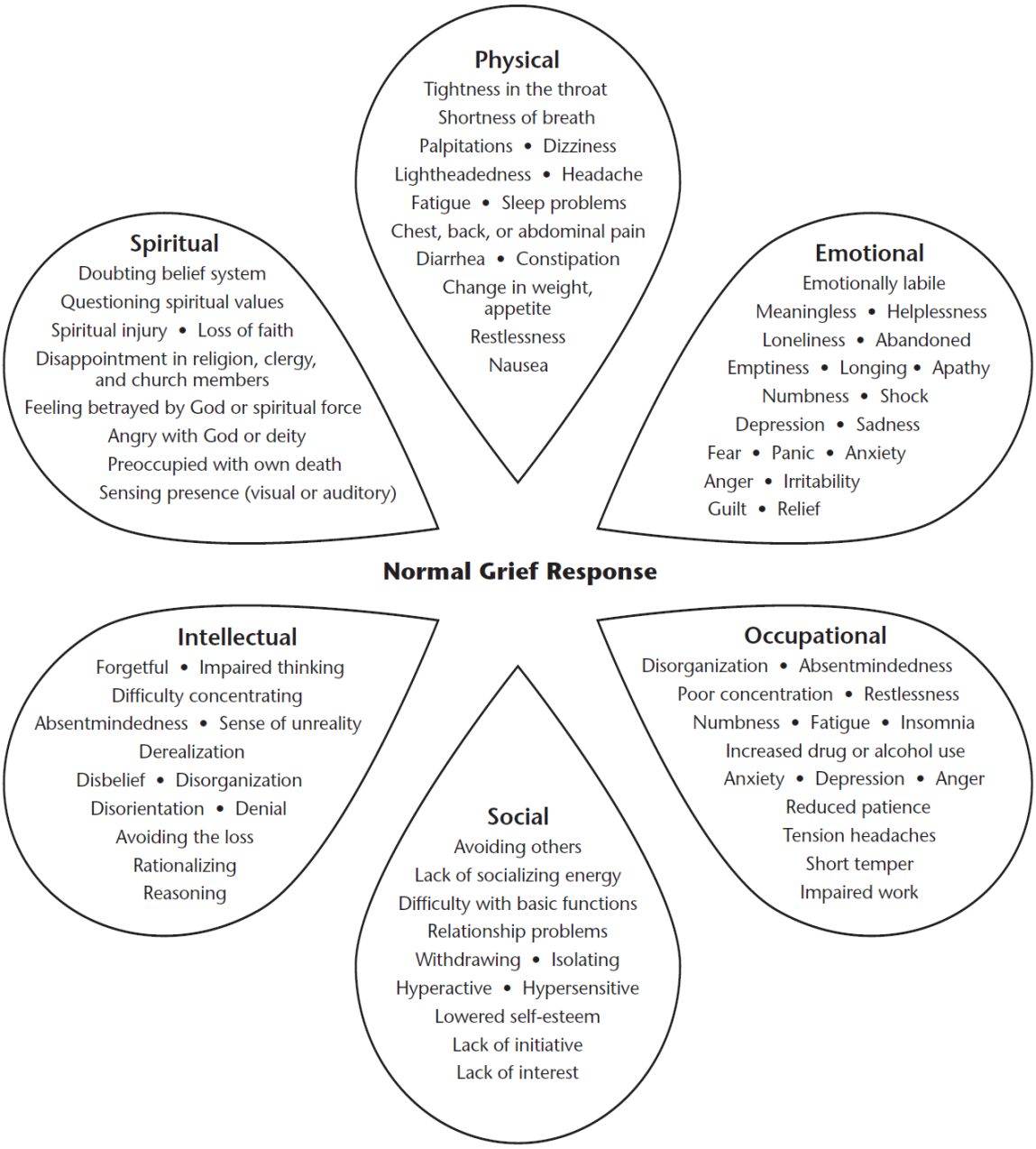
Appendix E – Bereavement Package and Mementoes



Please Note: A Bereavement Package can be organized in a cloth envelope or box that incorporates informational needs and mementoes.

Appendix F – Normal Grief Response

According to the Dyer Model of Grief, grief is a multifaceted response to loss that affects the entire person. It includes physical, emotional, intellectual, spiritual, social and occupational elements.



Adapted from Dyer KA. Identifying, understanding, and working with grieving parents in the NICU, Part I: Identifying and understanding loss and the grief response. Neonatal Netw NN. 2005 Jun;24(3):35–46.[48]

Please note: Complicated grief is defined as a prolonged, abnormal response to loss that impairs participation with usual daily activities.[49,50] Consultation and treatment should be sought when the grief if very intense, all-consuming, and disrupts the person's ability to engage in normal daily activities.[35]

Appendix G – List of Pregnancy Loss Resources for Families and Healthcare Providers

Organizations with Resources and Information on Pregnancy Loss		
Organization	**Description**	**Website**
Ontario-Based Organizations		
Bereaved Families of Ontario	Organization across Ontario that provides compassionate non-denominational mutual aid support for families and individuals who have lost a significant person to death.	www.bereavedfamilies.net
Bereavement Ontario Network	Diverse group of organizations and individuals throughout the province of Ontario that work in the field of grief, bereavement, and mourning as professionals and volunteers. *(Does not provide grief counselling or direct services)*	www.bereavementontarionetwork.ca
Pregnancy and Infant Loss (PAIL) Network	Organization of volunteers who support families who have suffered pregnancy and infant loss. They achieve this through education, peer and telephone support.	www.pailnetwork.ca
The Butterfly Run	Fundraising event to increase awareness of pregnancy and infant loss in the community. Proceeds of the run are used to provide staff eduation, bereavement packages (Emergency Departments and maternity floor) and additional resources at Quinte Health Care.	www.butterflyrunquinte.ca
Unspoken Grief	A safe place to share, talk, support and learn about the impact of miscarriage, stillbirth and neonatal loss. This organization aims to support everyone who has been touched by perinatal grief.	www.unspokengrief.com
Canada-Based Organizations		
Compassionate Friends of Canada	International, non-profit, non-denominational, self-help organization, offering friendship, understanding, grief education and hope for the future of all families who have experienced the death of a child at any age, from any cause.	www.tcfcanada.net
Pregnancy and Infant Loss Awareness Day	The October 15th campaign raises awareness for a variety of issues that are the direct result of the death of a child, either before birth (during pregnancy) or after birth.	www.october15.ca
Share Grief	Organization of volunteer grief specialists that provides on-line grief support, education and resources for the bereaved.	www.sharegrief.com

International Organizations		
A Place to Remember	Support materials & resources for those who have been touched by a crisis in pregnancy or death of a baby. Jewelry, gifts, ornaments, baby announcement cards, literature, music, etc.	www.aplacetoremember.com
Babyloss	Organization that provides information and support for anyone affected by the death of a baby during pregnancy, at birth, or shortly afterwards.	www.babyloss.com
Faces of Loss, Faces of Hope	Non-profit organization that provides emotional support and resources to those who have experienced the loss of a child through miscarriage, stillbirth or infant loss and raises awareness of prengnacy/infant loss throughout the great community.	www.facesofloss.com
Go Pink and Blue	International pregnancy and infant loss awareness campaign created to invite the world to support what used to be a silent topic.	www.gopinkandblue.org
Grief Watch	Publisher and manufacturer of bereavement books, videotapes, audiotapes and other helpful resources aimed at persons who have suffered loss.	www.griefwatch.com
Grieve Out Loud	Comprehensive holistic bereavement care program serving families and professionals touched by pregnancy loss and/or infant death. The program offers different services to families: pen pal program, private online support group and customizable individual support. It also offers consulting services to birth professionals.	www.grieveoutloud.org
Grieving Dads	A personal blog designed to reach out to all bereaved dads and to provide a conduit to share their stories.	www.grievingdads.com
Healing Hearts Baby Loss Comfort	Organization that offers resource and memorial pages, and comfort support products for grieving families and friends.	www.babylosscomfort.com
Miscarriage Association	National charity in the UK that offers support and information to anyone affected by the loss of a baby in pregnancy. Raises awareness and promotes good practice in medical care.	www.miscarriageassociation.org.uk
Miscarriage Matters	Organization that offers a free online live chat support services.	www.mymiscarriagematters.com
MISS Foundation	International, volunteer based organization providing counselling, advocacy, research, and education services to families experiencing the death of a child.	www.missfoundation.org

Now I Lay Me Down to Sleep (NILMDTS)	Bereavement photography foundation that trains, educates, and mobilizes professional quality photographers to provide beautiful heirloom portraits to families facing the untimely death of an infant.	www.nowilaymedowntosleep.org
Pregnancy Loss and Infant Death Alliance (PLIDA)	Alliance of professional groups, institutions, and individuals who provide care and support to families who experience a perinatal loss. Organization that provides professional continuing education, positions statements and practice guidelines.	www.plida.org
Resolve Through Sharing (RTS)	Organization that provides bereavement training to healthcare professionals working at hospitals in the form of evidence based courses, consultation services and support material.	www.gundersenhealth.org/resolve-through-sharing/
Silent Grief	Support for all who have suffered miscarriage and later child loss.	www.silentgrief.com
The Centering Corporation	Non-profit organization in the US that provides education and resources for the bereaved and healthcare providers.	www.centering.org

Please note: This list of organizations and websites is not exhaustive, but meant to provide a good starting place for tapping into available resources that can offer support, information, insights and guidance.

Appendix H – Discharge Teaching for Patients Experiencing an Early Pregnancy Loss

Topic	Explanation
Physical Well-Being	
Vaginal Bleeding	• You will probably still have vaginal bleeding, similar to a heavy menstrual period. This will slow down over the next 7 days. Most women will experience some bleeding or spotting for up to 3 weeks. • While bleeding, you should only use sanitary pads (**not** tampons), and you should also avoid having a bath (showers are acceptable), douching, swimming, or having sexual intercourse.
Menstruation/ Family Planning	• You can expect a normal menstrual period 4 to 8 weeks after a pregnancy loss. Talk to your healthcare provider if this does not occur. • It is possible to become pregnant immediately after a pregnancy loss, even before your menstrual period has returned. You should use some form of birth control (e.g., pill, condoms, intrauterine device) during this time. • It may be advisable to wait a few months before another pregnancy. Discuss this with your healthcare provider.
Breast Care	• After a pregnancy loss, your breasts may still produce milk. • If you experience breast discomfort: ○ Wear a well-fitting bra with good support. ○ Apply cold compresses for comfort. ○ Take warm showers to help the milk drip out. ○ If your breasts feel very full, you may hand express a small amount of milk from your breasts. Expressing a spoonful or two will not increase your milk production, and may help you be more comfortable. ○ Fullness should decrease over the next 3 to 4 days.
When to Seek Immediate Medical Care	• Consult your healthcare provider or go to the nearest Emergency Department **immediately** if you: ○ Suddenly have severe pain in your abdomen that is not controlled by pain medication. ○ Suddenly feel faint or feel like passing out. ○ Have very heavy bleeding (soaking more than 3 sanitary pads in 3 hours). ○ Have chills or a fever greater than 38°C. ○ Have foul smelling vaginal discharge.
Psychological Well-Being	
Getting Support	• Family and friends want to do the right thing but often are unsure of how to help or what to say. Let them know how you feel and what you need at this time. • If you feel you need someone to talk to, there are skilled people in your community. Discuss a referral with your healthcare provider. • A hospital social worker or spiritual care provider may also be available to help.
Grieving and Remembering Your Baby	• It is important to allow yourself to grieve the loss of this pregnancy. • There is no right way to feel after a pregnancy loss. • The experience of grief is powerful and you may feel physically and emotionally drained. • Remember that by grieving you are helping yourself heal. • You may find that planning for the future is difficult during this time. • Some parents have found the following things helpful to provide comfort and begin healing: ○ Take care of yourself ○ Take time to be with your partner ○ Take time to cry and to grieve ○ Take a break from your regular schedule ○ Make a memento box or scrap box to commemorate your baby and the pregnancy experience ○ Write a poem or letter to your baby or about your baby ○ Keep a diary about your experience ○ Name your baby ○ Have a ceremony to recognize your baby ○ Light a candle ○ Plant a tree or make a memorial garden ○ Talk to family, friends, religious leaders, or healthcare providers ○ Talk to families that have had a similar experience ○ Attend a bereavement support group, such as through PAIL Network
Adapted from BC Women's Early Pregnancy Clinic, 2014;[51] Nova Scotia Health Authority;[52] Pregnancy and Infant Loss (PAIL) Network, 2015;[53] Trillium Health Partners.[54]	

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