“Developing Community Support for Bereaved Parents” is written for professionals who want to develop or enhance community services available to parents who lose a baby during pregnancy or shortly after birth. The purpose of this document is to

- provide guidelines for education/support (short term, closed) and open-ended support groups,
- provide information and recommended resources for starting and maintaining a parent support group, and
- suggest ideas and resources for other types of community support.

General Information about Support Groups

Two types of support groups--education/support (closed) and open-ended--are described below. To introduce you to these two types of groups, we will write about ideas and structure that pertain to both. The topics in this section include reasons for starting a support group, some basics about support groups, group facilitator, the role of co-facilitators, the importance of ground rules, and ideas for group activities that encourage the expression of feelings.

Reasons for starting a support group

Parents who attend either type of support group need a place that feels safe and within which they receive compassion and sensitivity. It is a place for meeting other “members of the club” who have also experienced a pregnancy, newborn, or infant loss. It is a place where defenses are down and grief can flow. But support groups are not for everyone.

Some basics about support groups

We recommend that you affiliate with an agency or institution if you start a support group. Affiliation guarantees some important things: a consistent place to meet, help with publicizing the group, and a referral base. The group should meet in the same place each time. Provide tissues, some scratch paper for doodling, and light refreshments. Support groups are not therapy groups. Those with complicated grief should not be referred to this type of group. There should be no fee.

Group facilitator

We believe a facilitator for a bereaved parent grief support group needs to be a person knowledgeable about grief, communication skills, group process, and referral. Facilitators need to know their own grief issues and "triggers" before they can be emotionally free to facilitate a bereaved parents group.

The role of co-facilitators

Support groups are complex and complicated, not at all what you might think if you have not facilitated one. In fact, experts in bereavement say that facilitating a parent support group is one of the hardest things they have done professionally. For that reason, we recommend that support groups have co-facilitators (e.g., spiritual advisor and nurse, social worker and parent, physician and nurse). One focuses on the work of the group: welcoming everyone, introducing a speaker, setting the stage for the meeting, and helping things move along. The other may welcome
latecomers, leave with a group member who becomes upset, and monitor the process of the group. Co-facilitators should be comfortable with and respectful of each other. They both must make a commitment to the group and to each other to attend consistently. You might wonder if there are minimal requirements to be a support group facilitator. Here’s what we think is important.

The goal of the bereaved parents support group is parents helping parents by sharing their experiences and ideas on how to deal with grief. The parents are to share and problem solve with each other by directing their conversation and questions to the other participants and not one of the facilitators. The facilitator needs to be vigilant on what is going on in the group process and feel comfortable in redirecting a participant or the group. For example, the facilitator manages group process by redirecting a participant who is monopolizing the group’s time. A facilitator knows when to intervene if there is clearly an unhealthy response and use it as a teaching moment without affecting the participant's self-esteem or self-worth.

Parents need to be able to function and make decisions outside the group without worrying if the facilitator would approve. The facilitator should make sure the meeting starts and ends on time. This will allow for some structure and boundaries so parents can feel secure in being part of the group.

**Ground rules**
The resources in the “Open-Ended Support Groups” section give more extensive examples of ground rules than we provide you in this document. You can use one of the resources to write your own set of ground rules. The purpose of having ground rules is to create a safe environment for parents. A number of ground rules pertain to protecting a parent’s privacy and providing emotional safety. Ground rules might include

1. What is said here, stays here.
2. We protect the privacy and confidentiality of providers and institutions by not using names.
3. Everyone’s loss is unique to that person. No one’s loss is greater than another’s. We are not here to compare.
4. Tears are welcome here. There are tissues on the table. If you cry, we won’t hand you a tissue. Doing so might distract you or make you feel that you should stop crying. Instead, we will wait until you indicate you need a tissue. Then we’ll help you get one.
5. We will not ask questions. You are free to share or not share.
6. If you need to leave before the end of the meeting, feel free to do so. One of us will go with you to be certain that you are ready to drive home.

**Activities that help people express feelings**
Here are two ideas for helping people recognize and talk about feelings.

- A parent or facilitator can randomly choose one card in a stack of “Support Cards,” each containing a question about how one is feeling (e.g., “What is the hardest part of my grief?”). The question can be the basis for group discussion or individual reflection.
- “Feeling Hearts,” a bag of ceramic hearts in many textures and colors, is designed to help someone express emotion. Each person takes a heart and responds to this or a similar phrase: “Tell us about what the heart means to you.”

Both of these resources are available from Grief Watch at [www.tearsoup.com](http://www.tearsoup.com)
**Education/Support Group (short-term, closed)**

An education/support group is short-term and closed, meaning it has a starting and ending date and those attending sign up in advance, rather than drop in. The length of the session varies, but usually is from 4 to 6 weeks. Education is presented in the context of an interactive, supportive structure. Try to keep didactic information to 30 – 45 minutes. Here are some guidelines for designing an education/support group.

- Meet weekly, twice a month, or monthly.
- Schedule 1.5 hours for 6-7 parents; 2 hours for 8-10 parents.
- Start and end on time.
- Use ground rules (see above).
- Have everyone check in at the beginning (check-ins are brief: a few words or a couple of sentences). Ideas for check ins:
  - Share a high and low of the past two weeks (or whatever the interval between group sessions).
  - Share a moment you were caught off guard.
- Use the last 5-10 minutes for the parents’ responses to, “How was this for you?” Alternatively, you can ask that they fill out and then share an evaluation of the activity.
- Celebrate the end of the group by combining a social time (e.g., food, casual conversation) with the meeting so parents can say good-bye to each other and to the facilitator.
- Continuing to connect with each other when the group ends is a natural outcome of the group process. Often parents will exchange phone numbers or other contact information.

A sample curriculum for a 4-session education/support group follows.

| Session 1: What is grief, how long does it last |
| Session 2: Relationships and different ways of expressing grief: partners with each other, children, other family members, and friends |
| Session 3: Handling the holidays, rituals, birthdays, anniversaries of the loss, coping through the years |
| Session 4: Moving on: forgiveness of self, others, the situation; signs of depression; recognizing the new self |

Education/support groups may work better than open-ended support groups (described next) in rural areas or other places where the number of bereaved parents who could participate is small.

**Open-ended Support Groups**

Support groups for bereaved parents provide an opportunity to join with others who have experienced a similar loss to talk, listen, and heal. An open-ended group means that parents attend, as they need, for whatever length of time is best for them. Open-ended groups usually meet monthly for 1½ hours. Parents may “drop in” and do not necessarily attend on a regular basis. Some may come during holiday time or when feeling stressed about an anniversary date.
If you want to start a parent support group, it is important to remember that only about 10% of an eligible population will attend a support group one time. When attendance is low, parents may feel “on the spot” to talk or not receive the support they deserve from a group of people with a similar experience. Low attendance is also hard on facilitators. Here is one strategy for guaranteeing adequate attendance. Ask parents to call and leave a message at a number with voice mail no later than the Friday prior to the meeting. Then depending on whether the group size is adequate, leave another message in the same voice mailbox letting parents know whether the meeting is on or off. Most facilitators recommend canceling the group unless at least 4 and perhaps 6 people indicate they plan to attend.

To foster adequate attendance (8 – 10 people is ideal; 4 – 6 is minimum), you may need to partner with other institutions or agencies in your area. Linkages are very important. Referrals have to come from a large community. We recommend that if you plan to start a support group that you do so by being part of an agency or institution that can publicize the group to parents who may need it. To learn more about starting and maintaining a support group, here are three good resources:


Information on starting a SHARE group
http://www.nationalshareoffice.com/startingasharegroup.asp

**Internet Resources**

Parents may find help and support from a variety of Internet resources. We recommend that interactive resources be monitored. The two listed below (chat groups and message boards) are provided by SHARE and have professional facilitators.

- SHARE has the following monitored resources at www.nationalSHAREoffice.com:
  
  Monday: Bereaved Parent Chat, 8 to 10 pm (Central Time)
  Tuesday: Pregnancy after Loss Chat, 8-9 pm (Central Time)

  **Four SHARE message boards:**
  Bereaved Parent, Pregnancy after Loss, Fathers’ Issues, Parenting after Loss

- Wisconsin Association for Perinatal Care:
  “Childbearing Loss and Grief” position statement
  http://www.perinatalweb.org/association/pdf_docs/childbearing%20general%20ref.PDF

  “Childbearing Loss and Grief General References”
  http://www.perinatalweb.org/association/pdf_docs/childbearing%20general%20ref.PDF

- Wisconsin Stillbirth Service Program Perinatal Bereavement Program Registry at http://www.wisc.edu/wissp/map/index.html
Other Types of Community Support

1. Offer annual or semi-annual events. Remember, services and other commemorative events do not need to be elaborate.

Perinatal Memorial Service
A hospital-sponsored memorial service can be a source of support and healing for families as well as the staff who worked with them at the time of their loss. Designing the service in memory of babies who died during pregnancy or the neonatal period (rather than in memory of patients of any age who died at the hospital) allows the service to be more personal and tailored to the needs of the families who attend. The frequency at which the service is held will depend upon the number of losses at your hospital. Memorial services can be personalized in many different ways. Examples include reading the names of the babies being recognized and providing each family with a memento of the service such as a candle or ornament. The service can have a seasonal or holiday theme and be designed to include music and readings that will be meaningful and appropriate to the culture, religion and spiritual background of the families you are inviting (e.g., pertaining to Christmas or Yom Kippur). Refreshments and an opportunity for families to visit with the staff who attend can follow the service.

2. Other opportunities for support:
   - **Walk to Remember** in October (in honor of Pregnancy and Infant Loss Awareness Month and SIDS Awareness Month) or Infant Loss Remembrance Day, October 15.
   - Can include babies with adult memorial services (particularly in more rural areas where perinatal losses are few)
   - Holiday Candlelight Service
   - Annual graveside burials for early pregnancy loss
   - Weekend event with a speaker and small group sessions
     - For parents and professionals
     - Need babysitting services
     - Works well when sponsored by a place of worship

Invitations
Personal invitations are optional. It is best to ask before sending an invitation “out of the blue.” Families may have moved on, may feel that an invitation is an intrusion, or be surprised to hear from you. In addition, your hospital’s interpretation of HIPAA guidelines may preclude sending invitations. If you send a written invitation, get permission first. You might ask before discharge, “We have a memorial service. Would you like an invitation?” Or you could invite someone during a follow-up phone call. Because families' needs change over time, it is a good idea to include on any written invitation the option to be removed from your mailing list. Consider other options for publicizing an event.
   - Advertise in a local paper
   - Advertise in the parent newsletter
   - Send announcements to local churches and synagogues.
   - Post at YWCA/YMCA's or fitness centers.

A multicultural perspective
All communities are multicultural. Planning non-denominational events for parents of different ethnic backgrounds, religious beliefs, and cultural practices requires sensitivity.
For example, those who plan an event may shape the event in keeping with their own religion or culture. Here are some examples of how an event may have an unintentional Christian focus:

- quotations from New Testament scripture
- angels as comforting imagery or as mementos
- concepts of heaven and afterlife
- prominent Christian icons where the service is held
- Christmas tree ornaments as mementos

To avoid a theme related to one religion or culture, it is important to meet with the leaders of the various ethnic and religious groups in your community to learn what would be helpful to parents when a baby dies. Have people from other faiths and traditions review any programs you propose.

You may also choose to plan an ecumenical service or event, one that is comprised of pieces of a number of traditions. We use Judaism as an example for this handout. The Jewish calendar has many aspects that are connected to the seasons. Besides Yom Kippur, which is part of the New Year Holy Days, three others are known as pilgrimage holidays when people traveled to the temple in Jerusalem with harvest offerings. Today these holidays are still marked by ritual that is related to seasonal harvest. So, attention to the seasons is appropriate—and universal to many traditions.

Another Jewish tradition that could be used in an ecumenical service is making a commitment to live in a way that honors the memory of the deceased. This commitment to living well, a recommitment to life after a period of intense grieving, includes this phrase: “May his/her memory be only for a blessing.” In other words, parents remember the blessings of having had their baby and appreciate the blessings they still have and will continue to have in the future.

Unlike Christian holidays, the dates of Jewish holidays change from year to year. To avoid scheduling an event during the Jewish holidays, check holiday dates through 2007 on the website http://www.ujc.org. From the home page click Jewish Life, then click Jewish Holidays Calendar.

Amish, Hmong, American Indian, Muslim, and Hindu and many other cultures define their celebrations within their ethnic community or family system. Community bereavement support is effective when it is done within that context.

**Peer Support Training**

In some communities, willing parents would like to reach out to others. For more information on Peer Support Training, contact Phillip Nielsen, MSW, 608.791.9410 or Bonnie Gensch, RN, 608.775.4270.

**Hospital burial of losses under 20 weeks**

If your hospital contracts with another hospital for laboratory testing and disposition, check to see if that hospital has a final disposition policy for products of conception. Many hospitals provide cremation or burial. For cremation, ask if the cremains are scattered by the facility or returned to the parents. For burial, ask when the burial takes place and find out if the bereaved family can be invited or be told where the gravesite is located. Parents may want the baby or products of conception back for their own private burial. See if your facility has a courier service that could deliver the baby/products of conception to the original hospital and clinic so the parents or a funeral director of their choice can do the removal. If parents choose not to use a cemetery plot, they will need to follow local ordinances regarding burial on their own land. A local Register of Deeds can assist families with the law and what paper work is needed.
We recommend the book *Bittersweet…hellogoodbye: A Resource in Planning Farewell Rituals When a Baby Dies*, available from SHARE at [www.nationalshareoffice.com](http://www.nationalshareoffice.com)

**Conclusion**

We hope that this guide is helpful to you as you plan ways of supporting families in your area who experience perinatal loss. It was prepared by professionals and parents who, like you, have a passion for helping when a baby dies during pregnancy or after birth. If you have feedback or would like more information on WAPC, please contact us at [wapc@perinatalweb.org](mailto:wapc@perinatalweb.org). Or you can call us at 608.267.6060.

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