



Engaging Parents As Messengers

Bereaved parents and parents currently caring for a child with a life-threatening condition can bring a compelling and powerfully realistic voice to the value of palliative care and hospice support for children. By sharing their stories and experiences, with others, parents have the capacity to expose the intimate, complex and volatile journey that often accompanies a child's life-threatening diagnosis. As messengers, parents can:

- ✓ Compassionately bridge the chasm that exists between families and healthcare providers;
- ✓ Provide peer support to families;
- ✓ Serve as media spokespeople; and
- ✓ Rally community support for pediatric palliative care and hospice services.

Here are some tips to help identify, engage and support parents as messengers:

- 1. Develop guidelines.** Before engaging parents, develop a set of criteria that clearly define the boundaries and values you will use in selecting parent messengers for your community.

Asking the following questions may assist you in drafting a selection strategy:

- Does the parent have the emotional capacity, time, and energy to participate?
- Is the parent willing to give you permission to confirm with a clinical team member their readiness to participate in the campaign?
- Has enough time passed for a bereaved parent to participate? Many programs suggest a one-year minimum, some three years. Some programs have no requirement.
- If their child still undergoing treatment is there someone on the care team who can assess the parent's capacity and appropriate timing to serve as a messenger?
- Does the family have adequate emotional, spiritual, and psychosocial support to sustain them in their role as messengers?

Once you have determined the criteria for participation, create a system whereby parents can self-determine their level of engagement. For example, some parents will be comfortable talking to the media, and some will be more at ease supporting other parents.

Make certain that parents have the opportunity and freedom to say "no" and/or opt out at any time.

2. Identify qualities of effective parent messengers. Below are some suggested skills, talents, and abilities you may want to consider when choosing parent messengers:

- Able to maintain appropriate boundaries in relationship to personal grief and therefore able to share their experiences in a way that benefits others;
- Effective written and/or verbal communication skills;
- Flexible and willing to partner with clinicians; and
- Open to receiving constructive feedback.

3. Recruiting parent messengers. Locating parent messengers that fit your criteria can be challenging. Establish relationships with hospital social workers and/or clinicians who have trusted relationships with families. You can also seek assistance from local chapters of national parent organizations.

Social workers are an excellent resource because of their established relationship with families. They can help identify parents who may find participation as messengers both healing and empowering.

National organizations with local chapters are often willing to refer parents who would benefit from the opportunity to serve as pediatric palliative care messengers. You can find a comprehensive list of resources at (www.childrenshospice.org/resources.)

The following are just a few examples of national organizations serving families of children with life-threatening conditions.

- The Partnership for Parents (www.PartnershipforParents.org) is a national network of parent advocates and parent experts in the field of pediatric palliative care. The website also offers a great deal of information and resources for parents.
- Candle-lighters (www.candlelighters.org) offers support to parents of children with cancer. They have local chapters and offer support groups, events and information.
- The Compassionate Friends (www.compassionatefriends.org) is a national organization with local chapters offering support groups for bereaved parents.
- Family Voices (www.familyvoices.org) is a national parent advocacy organization with local and state chapters. They specialize in supporting parents of children with special healthcare needs, not necessarily palliative care.

4. Look for a variety of experiences and perspectives. Make sure the parents identified within your group have a variety of perspectives and experiences. This will be helpful in identifying parents who can be appropriately matched with each messaging opportunity. Consider parents of:

- Children with life-threatening conditions currently in treatment;
- Surviving children who are no longer receiving treatment;
- Children with different illnesses and conditions;
- Children who have died receiving palliative care;
- Children who have died without palliative care services; and
- Various socioeconomic/ethnic/religious backgrounds

- 5. Meet with parents.** The intention of interviewing potential parent messengers is to cultivate a relationship based on trust and shared respect while determining whether participation would be mutually beneficial to the individual and the program.

Asking parents to share their stories and experiences about caring for their child is highly personal and requires a willingness to listen compassionately. Personal contact is essential and face-to-face interviews are always best. Telephone contact is a good alternative if it is not possible to meet in person.

General principles that will help guide your discussion with parent candidates are:

- Be clear about what you are asking them to do. Make sure the parents know that in their role as a messenger they will be asked to share their personal story in a public forum.
 - Take the time to listen ... listen ... and then listen some more. You are asking parents to share very personal and often painful information. Maintain a professional, yet compassionate space for them to share safely.
 - Seek their guidance in determining the capacity in which they would like serve: i.e., as a media spokesperson, talking to potential donors, presenting to other parents or to the community at large.
- 6. Don't forget to say thank you.** After you meet with a parent or family, send a card or give them a call to say thank you. Highlight/reference components of their story which were meaningful to you.
- 7. Find other ways parents can be of service.** You may find that not all of the parents you speak with are appropriate campaign messengers. Make a list of other tasks they can do to be of service beyond this role. Remember, it is often a part of a parent's own healing journey to be able to give back. Parents can:
- Assist your organization with mailings, fundraising events, make- a-difference day, cooking meals, etc;
 - Provide your program development staff with insight regarding a parent's experience;
 - Join the Partnership for Parents, the national alliance of parents of children with life-threatening conditions; and/or
 - Attend an Initiative for Pediatric Palliative Care Retreat (www.ippcweb.org) and assist healthcare professionals by sharing a parent's perspective.
- 8. Seek on-going support and training for parents.** Make certain you provide parent messengers with on-going support and pediatric palliative care training and education. Provide parents with books, articles, studies, and legislation that is related to palliative care. This will empower them and enhance their expertise.

Also, the Initiative for Pediatric Palliative Care hosts three-day retreats nationwide and utilizes parents as experts, educators and partners in teaching clinicians about pediatric palliative care. In a relaxed, retreat-like setting, parents develop an awareness of their value as educators and experts and a profound appreciation for the importance of sharing their experience to further the cause of pediatric palliative care and hospice.

9. Engage Parents as Your Campaign Partners. As you plan your outreach for the Partnering For Children campaign:

- **Include the parents** you have selected as messengers in the planning process;
- **Partner with parents** in seeking opportunities to present the value of pediatric palliative care and hospice to other parents, the media, funders, and your local community. Sometimes it's a good idea to "buddy" each parent with a staff member; and
- **Coordinate with parents** in determining meaningful and safe messaging opportunities that reflect their communication skills, emotional capacity, and availability.

Here are some ideas about how to engage parents with various campaign audiences:

Parents as Messengers to Other Parent Groups

- Seek out and schedule opportunities for parents to make presentations about the value of pediatric palliative care and hospice to local parent organizations and parent support groups. Hospitals, hospices and/or other community support agencies usually have parent groups who may be receptive to learning about and discussing the value of palliative care and hospice.
- Consult with local chapters of national parent organizations like those listed above about scheduling a parent presentation for their local group/chapter.
- Ask local chapters about regional, state and national opportunities to present at national parent conferences. The Partnership for Parents can also help identify national parent conferences and meetings.
- Make sure, when appropriate (since some parent groups are for parents only), that someone from the campaign team accompanies the parent or co-presents with the parent.

Parents as Messengers to Clinicians

- Assure clinicians that the parents you refer are well trained and supported. Share the criteria you used in determining the parents' ability to communicate in a way that is helpful to others and confirm a high level of knowledge and expertise beyond their own.

Parents and the Media

- Please give parents "Media Tips for Parents" (See document located in the Outreach Guide.)

Parents Engaging the Community

- There are groups/audiences in most communities that will be receptive to parent presentations about the palliative care and hospice services that are being provided in your community. Community groups like Rotary, Kiwanis, and the local Chamber of Commerce are interested in what is going on in the community and seek to support services – especially to children.

10. Be patient and flexible. As you know, the struggles many of these parents have faced have been heartbreaking, so please keep that in mind when working with them.