



Summary Report: Parent Focus Groups

In February of 2007, Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), commissioned surveys of bereaved parents who had recently lost a child to a terminal illness or condition and parents whose child is undergoing treatment for a terminal illness or condition.

Participants were first asked their general feelings about and actions around end-of-life thinking, talking, and planning. Then participants read and reacted to content about three topics – advance care planning, palliative care, and hospice – drawn from Caring Connections Website, www.caringinfor.org. Rather than quantifying things in numbers, these survey results are reflected in narratives and in summary form.

1. Survey Findings: About the Parents

Parents surveyed represent a wide variety of circumstances and experiences, particularly in regards to the circumstances of the loss. One child died only days after birth, while another lived with an increasingly debilitating disease for over 20 years. A few children were diagnosed with common — meaning better understood — conditions such as Cerebral Palsy and Downs Syndrome, but a few were diagnosed with uncommon atypical disorders such as a very rare stomach cancer. In yet another case, one parent told us that it is likely that she will never know why her daughter passed away suddenly at two months of age; the autopsy was inconclusive. Parents of children who are currently suffering from a terminal illness or condition also represent a variety of illnesses and conditions, time since diagnosis and time in treatment, making their experiences equally difficult to categorize.

My youngest daughter died when she was 20 -- it was Christmas Day 2005. She had a brain disease that was diagnosed at age ten. It's a genetic disease. It started at age five with loss of vision, and then seizures by the time she was eight, and then real regression began at age ten. When she passed away, she could no longer eat, walk, talk, or use any of her skills. She was totally dependent on us.

— Bereaved parent

Timing is a key factor.

- Most of the parents who have lost a child appear to still be grieving their loss, regardless of whether it occurred one or five years ago. They have not been able to move past the death of their child and are numbed by it. This could be due in part to the lack of support they received. In any event, their feelings about end-of-life issues and decision-making are affected by their loss. Thinking retrospectively, they are open to learning more about end-of-life issues and are more likely to recommend that others inform themselves as well.
- In contrast, many parents who are caring for a terminally ill child, whose illness is either in remission or at a more manageable stage, appear to be in denial and do not necessarily feel advance care planning is something they need to engage in just yet. While they approve of planning in theory, they are not yet prepared to confront the possibility of losing a child. They agree that it is best to postpone talking about end-of-life issues until long after any initial diagnosis.

Parents are also unevenly knowledgeable about planning for end-of-life.

- Some parents who have lost a child seem more aware of the end-of-life options available to them and their child than others. A handful say they were approached by hospital staff, be it clergy, social workers, or medical personnel, who suggested they consider advance care planning in some

form, particularly hospice options, while others were left to navigate those final days or weeks on their own.

- Parents whose children are currently undergoing treatment exhibit the same inconsistencies in their awareness and levels of knowledge, as well as their attitudes toward advance care planning for their child.
- Two in particular, whose children are currently healthy, felt that end-of-life discussions are not necessary, as if they did not apply to their situations. One parent said, “It’s reality. I think it’s important. I thought it was informative. If I had a dying child, I like what I read. I hope I never have to face this, but I think it’s important.” The other parent agreed. “It doesn’t refer to me now, but if it did, I would really like information on it.”

Decision-making about end-of-life care is highly individualized.

- This combination of unique circumstances and varying awareness and knowledge levels made for very different decision making processes between both sets of parents. For example, one parent, whose son was diagnosed only weeks before his birth with a fatal brain tumor, said, “Everything happened so quickly.” His only focus postpartum was on pain management. “A social worker came by [to discuss our options] but we weren’t ready,” he added. In contrast, one parent, whose daughter suffered for more than 20 years with Batten Disease, said doctors walked her through what was likely to happen and what to expect of her daughter’s final days. They opted for hospice at home, so that they could continue to serve as her main caregiver. Her daughter lived for an additional 12 months with hospice care being provided on and off.

2. Advance Care Planning

This section explores parents’ feelings about and actions around end-of-life issues, including any planning they have done or had done prior to the death of their child.

Advance care planning is a more familiar term in theory than in practice.

- Although many had heard the term prior to the surveys, only a handful of parents said they had made any plans for the future of their sick child. Even among this handful are parents who are more familiar with the concept but use different words to describe it. When asked whether she was familiar with advance care planning, this grandparent replied, “Not those words, but I had talked to his pediatrician about what I could expect.”
- Notably, many participants have trouble with the term. As was the case in other focus groups, initial thoughts tend to center on financial planning, and one or two parents talked about planning for funerals. “When I think of advanced care planning,” said one, “I think of the future things that are going to happen ... a lot of people base their decision on what is this going to cost me? Can I afford this? A lot of times people don’t get certain treatments because they can’t afford it.” One parent’s top-of-mind association was with “long term care insurance.”
- Parents who had not heard the term before the survey disagree over its connotation, with one saying it sounds “too financial,” another saying it sounds “too vague” or “too broad” and yet another saying it “has nothing to do with end-of-life.” Notably, one grandparent who chose hospice care for her grandson does not equate that with advance care planning. It was simply something she chose to do to keep him comfortable.

A few parents do not see the need for planning.

- Two parents in particular come to mind. Both are caring for a child who is in a “healthy phase” right now, which may factor into their attitude. Neither of these parents believes she is in a place where thinking about end-of-life decisions is necessary. One parent, whose daughter is currently in remission with a rare and potentially fatal stomach cancer, says no one has ever brought this to her attention. Meanwhile, another parent whose son has Spina Bifida does not have to face his potential death on a daily basis, since he could live for another 10 or 20 years. Hence their

comments refer mainly to what others might want or need rather than something from which they could benefit.

- Parents who have already lost a child are more likely to have engaged in advance care planning.
- A handful of parents had done some form of advance care planning prior to their child's death. Each of these parents said that they are glad that they made those decisions ahead of time.
- One parent had planned financially for her son's medical needs, but also decided to sign a DNR order. As she explains it, "My husband and I talked about how we were going to progress with his treatments. It didn't work out. It was a sudden death, but we felt good about how we planned and how we put our money aside to take care of him."
- Another set of parents was approached by their son's doctor and a social worker and ended up deciding on hospice for their newborn. Unfortunately, he died before they could implement any of their plans. Their main focus in the few days that he was alive was on pain management.
- Three other parents also made plans for their child. One cared for her sick child for more than 20 years and says only that she had made "end-of-life decisions" for her daughter very early on. The other two made the decision not to prolong life once organ failure set in. They all say that their doctors were pivotal in guiding them through the process. One parent describes her mindset at the time, "My husband and I and the doctors there in the ICU had talks about if her kidneys started to fail, what would we do? We decided that we would not try and continue if her organs started to fail...When she passed away, we were there with her ... We'd had enough time [with the idea] that 'this was the end,' and she passed away very quietly."

Most parents agree over the timing of end-of-life discussions – not too soon, they say.

- While earlier is better in theory, most parents feel strongly that no one is ready to turn their thoughts to advance care planning or discussing end-of-life issues when their child is first diagnosed. They explain that they are often in shock, followed immediately by denial after the diagnosis. As one parent said, "You are numb. Absolutely numb." They also say that parents need time to grieve and mourn, "What you expected for your future" and "make sense of the diagnosis" first. According to one parent, "If I had a situation where I had a child that had a terminal illness and it was going to be several years, I don't know if I'd want to be talking about what I was going to do at the very end at the very beginning."
- A small minority of parents feel that talking about palliative or end-of-life care immediately after diagnosis would be most beneficial. As this parent explained, "After the crying is done, yeah [it would've helped] ...Then you either fall apart or pull yourself together and do what you have to do. If you had the information, which I didn't get, it would have helped a lot." Another parent said she was "glad we did it" at the beginning, right after diagnosis, because having the information was useful. In the end, parents agree that it is an individual matter, dependent on each individual case.

When he was first born, I didn't want to hear anything. I was just so in denial. The counselors would tell me about these support groups and they gave me pamphlets on Spina Bifida. I trashed them. I threw them away, because I just didn't want to hear that. I wasn't ready for that.

—Parent whose child is mid-treatment

3. Palliative Care

This section explores parents' feelings about palliative care and its many components, namely hospice care.

Palliative care is unfamiliar and confusing to many.

- Most parents' surveys had not heard of the term palliative care prior to the survey discussions. A good indicator of this – many parents placed a question mark by the "Palliative Care" topic because they had no idea what it meant. In addition, one of the first comments was, "But nobody ever

What is palliative care? I know what hospice is, but I don't know what [palliative care] is.

—Bereaved parent

hears about palliative care. I mean, here are three of us that didn't even know what it was. All you hear is hospice."

- Later, when they are given more detail, some bereaved parents say that their child indeed "received much of this," but they did not know to refer to the care as "palliative." One grandparent spoke at length about the morphine her dying grandson had received to keep him comfortable, yet she did not equate this with "pain management" or "relieving symptoms." Even after some discussion of the concept, many parents say that they still don't quite understand it.

A handful of parents are familiar with the concept.

- A few parents define palliative care correctly right from the start. Their definitions reflect the idea that it is given when there is no longer hope for a cure. One parent said, "If there is no cure, then hospice provides palliative care." Another said, "I kind of was thinking if there was no cure. I kind of put them hand and hand, it's sort of what hospice does, provide palliative care. Make them comfortable. That was my understanding." One had heard about it in a Web chat room for parents of children with brain tumors, another at a Batten Disease annual conference. Notably, these are some of the same parents that also came with a good understanding of advance care planning.
- Like with advance care planning, a few parents are familiar with the concept but not the term. Said one parent, "I can see it in the way we were treated, a lot of this stuff. But I never heard the word used."

Some components of palliative care are particularly attractive to parents.

- Even those without a complete understanding of the concept show appreciation for some of the specific components of palliative care. They especially like that palliative care can be provided in the home, as if keeping their child close makes end-of-life care seem slightly less threatening. One parent explained, "I like the fact that it can be provided at a child's home instead of taking the child outside of the home. Support and counseling and providing in the home, that's what stood out." The mention of different kinds of emotional support for families also stood out positively for many. Another parent noted, "I had someone to lean on. Some people don't. So I'm looking at it for someone who did not have that support outside of the home. This is here for them."
- Of all the components of palliative care, parents are most familiar with hospice. Some parents are able to articulate the difference between palliative and hospice care. As one parent reasoned, "I think there can also be palliative care with hospice. There could be palliative care where the outcome is not imminent death. If you're relieving pain symptoms for someone who's in a serious illness, they don't have to be dying."

4. Hospice

This section explores parents' feelings about hospice care specifically.

Most are familiar with hospice, a few with direct experience.

- Of all the concepts tested in the surveys, hospice care is most familiar to parents. More than half spoke of an elderly loved one who had received hospice care. Their definitions include some of the following components: "end-of-life care," "making it easier," and "at home (even though I know you don't have it have it at home)," "nursing care to keep [someone] comfortable," and "relief, like respite care." Most understand that hospice has a "set time," and that "death is imminent" but that with palliative care, "there could be recovery."
- Two parents had first hand experience with hospice, and a handful of others had considered it for their child. One grandparent had considered hospice care for her grandchild. She was given the option by the hospital social worker. However, her goal was to keep him at home, as comfortable as possible, and hospice was the means to that end. Her knowledge of how hospice worked was

We were set up to go home with hospice. I thought it was a good thing because I could take him home to die.

—Bereaved parent

limited and her definition was one-dimensional, that “they would come in and give him morphine.” Her grandson died the morning they were set to bring him home, so her wishes were never implemented.

- Another parent arranged for hospice care for her daughter, who had struggled with Batten Disease for more than 20 years. She felt her expectations were not met. “They didn’t do anything for her,” she said. Apparently they came once a week to check her medication and that was it. Meanwhile, she was hoping for someone to relieve her at night so that she could be well rested to care for her daughter during the day. She said that hospice told her, “We don’t do nights” and she never pursued it. This parent is still positive about hospice, however, and says if she had it to do over again, she would simply use a different hospice.
- Another parent learned of hospice only after her infant daughter had died. She was touched and grateful for this service. “Everything just all the sudden happened,” she said. “So I had somebody from hospice to come by and talk, especially with my five year old. She wasn’t really understanding what was going on. A lot of times they blame themselves. I thought it was really helpful to kind of help us cope with the situation.”

A few know little about the specifics, but understand the overarching concept.

- Although they say they have heard the term, a few are somewhat confused by the specific components of hospice. One parent confused hospice care with the respite care she receives, but later says she is in fact familiar with the concept. Another recalls overhearing discussions between her parents about whether or not to use hospice care for her dying grandparent but that is the extent of her knowledge. One parent admitted that she did not know hospice could be provided outside the home until the focus group. “I never realized there were hospice facilities. I thought hospice was they come to you, into your home and help you through the day,” she explained.
- These parents also have a more difficult time differentiating hospice from palliative care. One parent understands that palliative care includes support, but does not see that component in hospice care. “It should [offer support], but it’s probably does not other than taking care of the medical portion and making sure the person is as comfortable as possible until the time comes,” she said.

Some parents have a difficult time associating hospice with children.

- Most parents view hospice as something for the elderly and some are much less comfortable with the idea of hospice care for children. Explained one parent, “It just depends on the age of the person. When you’re dealing with kids and someone calls in hospice, this does not sound good.” These parents feel that hospice is understandable in the case of an elderly grandparent who has lived a long life. This image of hospice is a positive one for them. In contrast, they have greater trouble associating hospice care with children. “When you’re dealing with a child, as a parent I’m holding on to every little thing, and if there’s a chance that my child or any other child can survive and they call in hospice, man, that’s just a dark cloud over my head,” said another parent.

Hospice is, ‘we’re waiting on you to die.’ Palliative is, ‘we’re going to make you comfortable.’

— Parent whose child is mid-treatment

5. Information, Guidance And Support

Most parents had only family to rely on for support.

- In terms of support, parents relied most heavily on family. One parent recalls, “I was never offered grief counseling. Nobody ever talked to me about grief ... you can imagine how parents and grandparents do when they have a child like that. The months and years that you go through and struggle to take care of them.”
- Another parent wishes she had had the tools to talk to her other children about what was happening to her son. “I felt completely lost and at odds even talking to my kids about how serious or how not serious it was when we were taking our son for his surgery,” she said. “That was a life-threatening

surgery. I really did not know how much information to give them at 14 and 17. You don't want to scare them.”

- In fact, only a handful of parents say that the opportunity for support groups or counseling was made known to them after diagnosis or after their child died. Two parents had the national Batten Disease organization on which to rely. That organization provided a forum for parents via Internet chat groups and frequent meetings, with chapters throughout the United States, as well as a mentoring program for siblings. Another parent also frequented an Internet chat group for parents of children with brain tumors. She also had the National Brain Tumor Association and Pediatric Brain Tumors groups to which she could turn. Luckily for this small group, they had both their informational and emotional support needs met.

Very few received any information about end-of-life care.

- While parents relied on pediatricians and specialists for medical advice, very few say they received any information about end-of-life care from anyone, including information about support for family members. Said one parent, “The only thing they really said to me [after my son was born with Spina Bifida] was just to take it day by day, see how it goes.” Another felt similarly lost. “I thought that was really a bad thing, because when my son was diagnosed — you have this small baby in your arms and they say he’s really sick. You go through your crying jag and they say, ‘Everything is going to be okay.’ Then you either buckle under or buck up and do the job. They don’t really tell you anything.”
- As a result, many parents are eager to receive information, support and guidance about end-of-life care. Clearly, they ‘don’t know what they don’t know.’ All are unfamiliar with NHPCO and Caring Connections but wish they had known about it at the time of diagnosis and/or death.

Parents value support from other parents who know what they are going through.

- Of all the items discussed (in terms of information, guidance, and support,) parents emphasize that what they needed and often still need is support, mainly from other parents who understand what they are going through. Links to and information about support for parents is the one item that almost all parents would want to see in a resource directory. In contrast, most said they had at least one doctor they could or can rely on for medical advice.
- One striking example of this need is the story of a parent whose daughter was diagnosed with a rare form of stomach cancer when she was only five months old. After many months of isolation, this parent was put in touch with one of the other three families in North Carolina whose child shared this disease. However, because this child was newly diagnosed and their children were at different stages of treatment, this parent felt that she was providing most of the support but getting little in return. Her wish is to find another family that could give her the kind of hope she has given this family. “I want someone who has been through it before and their child is fine now. So I can talk to them,” she said.
- Some parents say that they were told about support groups at the time of diagnosis, but because they were either numb, or in shock or denial at that time, they paid little attention to what was being offered. They also say they were disappointed, later, when there was no follow-up. Explains one parent, “I couldn’t make a choice. I think I missed the boat on that and I wished someone had called me a few weeks later and said, ‘Look you’ve had time. How do you feel? Come in.’ They didn’t pursue it.”
- Overall, parents also feel that the kinds of information they seek is related to where they are in the process. “It depends on where you are. What you’re ready to accept and deal with,” said one parent. They also say that interest in certain topic areas is probably reflective of the type of illness or condition in question.

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