



## CHILDREN'S HOSPICE AND PALLIATIVE CARE COALITION

### Parent Survey Report

In spring 2006, Children's Hospice & Palliative Care Coalition (CHPCC) — with funding from the California Healthcare Foundation — administered a survey for parents during the launch of its web-based resource program, "Partnership for Parents." The more than 200 responses confirmed that when it comes to hospice and palliative care for children much more can and must be done to help the children in managing their pain, both emotional and physical, and to support their families in coping with the multitude of accompanying issues.

CHPCC holds strongly to the belief that parents are vital and irreplaceable members of their child's medical team. They are on the front line every day and as experts in their child's well-being, they know firsthand about the challenges, what's working and what's not, and what we as a society can do to better support them and their child.

#### On-Line Family Surveys

CHPCC collected information from 225 families of children with life-threatening conditions and/or bereaved parents using its web-based parent resource program, "Partnership for Parents." This website ([www.partnershipforparents.org](http://www.partnershipforparents.org)) offers resources and support for parents whose children have diagnosed with a life-threatening condition, and for families grieving the loss of a child. It is a very supportive and informative resource for parents of seriously ill children that offers an on-line community as well as resources. The website provides CHPCC an opportunity for continuous learning about the challenges these parents experience and the types of help and support they need.

#### The Findings Include:

*(n.b. not all responses add up to 100 percent as they were multipart questions and/or not all parents answered all of the questions)*

##### 1. Home state of the respondent

- Sixty-eight percent (68%) were Californians who had heard about the survey from professionals and community groups working with CHPCC partners in California.

##### 2. The child's primary diagnosis.

- Seventy-nine percent (79%) indicated a form of cancer
- Nineteen percent (19%) indicated a variety of diseases and conditions, among them were cystic fibrosis, renal failure, and birth defects
- Two percent (2%) indicated accidental death or suicide

### **3. Types of treatments received at home, between hospitalizations**

- Forty-nine percent (49%) received no treatment
- Thirty-four percent (34%) received in-home nursing visits
- Twenty-eight percent (28%) received support from a social worker
- Thirteen percent (13%) received 24/7 on-call nursing
- Fourteen percent (14%) received respite care
- Eleven percent (11%) received bereavement/grief support

### **4. What services are needed most**

- Seventy percent (70%) stated support from a social worker
- Sixty-seven percent (67%) stated respite care (and noted that they had NOT received it)
- Sixty-five percent (65%) stated that they needed grief/bereavement support (and noted that they had NOT received it)
- Sixty-five percent (65%) stated 24/7 on-call nursing
- Sixty-five percent (65%) stated volunteer visitors to help with daily chores
- Fifty-one percent (51%) stated spiritual support

### **5. Scope of insurance coverage**

- Twenty-four percent (24%) said their health insurance did NOT cover services at home
- Seventeen percent (17%) said their health insurance did cover services at home
- Fifty-two percent (52%) did not know if their insurance covered services at home

### **Family Interviews:**

Six extensive, private interviews were conducted with parents of children who had died after lengthy treatment and extended hospitalizations. These interviews gave parents an opportunity to elaborate on their answers to the questions posed in the on-line survey.

#### ***Families who received hospice care and/or adequate support at home:***

- Two of the families interviewed received adequate hospice care. Both children were Medi-Cal/CCS recipients. The cost of hospice care in both cases was primarily covered by foundation and donor funding, although it saved the state an enormous amount of money.
- The mother of a 14 year old girl with a terminal heart condition shared the feelings of the entire family, "If we did not have hospice with us during this tragic time we also would feel like dying. I don't know how we could have survived her death without our hospice people helping us."

#### ***Families who did not receive hospice care and/or needed more support:***

- Three of the families were not offered and never received hospice care. All three of these families expressed grave regrets that their children were not able to die at home. The regret and anger expressed by these families was immense.
- The mother of a teen who died after many years of treatment for cystic fibrosis stated, "We did not know what questions to ask to get help at home. They said he would die in the hospital."

- The mother of a 15 year old boy who underwent treatment for cancer for nearly ten years shared the following feelings and frustrations: “I wish I didn't have to give my son shots every day. I wish I didn't have to take him to the germy emergency department when his immune system was low. I wish someone “qualified” could have come and taken care of my son so my husband and I could have some time alone together. Even once would have been nice. I wish I didn't have to fight and beg the insurance people for every little thing. And the big things. I wish I didn't have to pay for PET scans with my credit card. I wish there had been someone I could call in the night when I had questions and was worried about my son's condition instead of having to take him once again to the emergency department. I wish my son could have died at home instead of in the hospital with tubes, IV lines, beeping machines, and strangers. I wish there was grief support in this community.”
- The father of a child with Ewing Sarcoma who lives nearly 100 miles from their local children's hospital stated, “We had very little support at home and we made many visits back and forth to the hospital. We would have been able to help our son if we knew there was someone to call. We were afraid and he died in the hospital. We are grateful for all the care but wished there were a way to have him home.”
- CHPCC also interviewed the family of a young girl who died from a brain tumor who lost her hospice care when her parents decided to try additional life-prolonging and life-saving treatments. They shared, “It was confusing and disruptive to have to go back and forth. Every time we went back into the hospital, we had to drop our hospice service and then when she seemed to be ‘dying again’, get back on. It caused more stress to an already unbearable situation.”

### **Conclusions:**

- Families of children with life-threatening conditions have unique needs that are not being met under the current hospice eligibility regulations.
- The hospice scope of services would be beneficial to families if provided from the time of diagnosis or early on in the treatment continuum of a life-threatening condition.
- It would be difficult, if not impossible, for families to choose to give up treatment intended to cure their child's disease or prolong their life in order to qualify for palliative/hospice services.
- Families are not aware of what palliative care offers them and therefore do not consider it as an option.
- Integrating palliative care (including hospice services) with curative treatment would improve the quality of life for the entire family of a child with a life-threatening condition.