

# SURVEY FOR FAMILIES WHO HAVE EXPERIENCED THE DEATH OF A CHILD

Thank you in advance for taking the time to fill out this survey on such a difficult subject. A group of service providers and families have created a coalition in Pittsburgh that is working to improve the care of medically fragile children and their families. In order to achieve this mission, we have created a needs assessment survey to document the needs and experiences of medically fragile children and their caregivers. If you have any questions, comments or suggestions, please feel free to contact Yvonne Van Haitsma at the Bayer Center for Nonprofit Management at Robert Morris University at 412-227-6874 or [vanhaitsma@rmu.edu](mailto:vanhaitsma@rmu.edu).

You can also complete the survey and learn more about the Pittsburgh Pediatric Palliative Care Coalition online at [www.pitt.edu/~tbauerlpppc/questionnaire.html](http://www.pitt.edu/~tbauerlpppc/questionnaire.html). By completing this survey, you will be a part of improving the system!

## DEMOGRAPHICS

This section will allow the coalition to discover and address any differences in services to families of various backgrounds (e.g., race, finances, family structures, etc.)

What county do you live in?

- Allegheny
- Beaver
- Butler
- Fayette
- Washington
- Westmoreland
- Other

Would you consider yourself: *(Check all that apply)*

- African American
- Caucasian
- Asian
- Latino
- Multi-Racial
- Other

What is your marital status?

- Married
- Single/Divorced/Widowed

What is your relationship to the child who has passed away?

- Mother
- Father
- Grandparent
- Guardian
- Other

How many siblings does your child have?

- None
- One
- Two
- Three
- More than three

Household income

- Less than \$25,000
- \$25,001 – \$50,000
- \$50,001 – 75,000
- \$75,001 – 100,000
- More than \$100,000

What kind(s) of health insurance did you have to help pay for your child's health care costs? *(Check all that apply)*

- Medicare
- Medicaid/DPA
- Other government health insurance plan (e.g. military, state plan)
- Private health insurance plan
- Other program that pays for medical care
- None – What one reason best explains why?

What was your child's diagnosis? *(Check all that apply)*

- Cancer/Oncology
- Heart/Cardiology
- Lungs/Pulmonology (cystic fibrosis, etc.)
- Gastroenterology (ex. liver failure, stomach/bowel diseases, metabolic diseases, etc.)
- Blood/Hematology (sickle cell, Fanconi's, etc.)
- Neurology (M.S., cerebral palsy, seizures, etc.)
- Rheumatology (systemic lupus, dermatomyositis, etc.)
- Transplants (bone marrow, stem cell, organ, etc.)
- Immunology (immune deficiencies, HIV, etc.)
- Urology/Nephrology (renal diseases, etc.)
- Other – Please specify: \_\_\_\_\_

Was your child born with this condition?

- Yes
- No

How old was your child when she or he passed away?

- Less than 1 month
- 1 month to 1 year
- 1+ to 3 years
- 3+ to 5 years
- 5+ to 8 years
- 8+ to 11 years
- 11+ to 14 years
- 14 + to 18 years
- 18+ to 21 years

How recent was the death of your child?

- Less than a year
- 1 to 2 years ago
- 2 to 3 years ago
- 3 to 5 years ago
- More than 5 years ago

How long between your child's diagnosis and time of his or her death?

- Less than a month
- One month to a year
- 1 to 2 years
- 2+ to 4 years
- 4+ to 6 years
- More than 6 years

Where did your child pass away?

- Home
- Hospital/Medical facility
- In-patient hospice facility
- Other

What services did your family receive other than medical care?

- Case management/Social worker
- Pain management
- Home health care
- Support groups
- Hospice care
- Respite (short-term, temporary care)
- Long-term care placement
- None
- Other – Please specify: \_\_\_\_\_

Who provided you with information about the services available to your family? (Check all that apply)

- Received little information about other services available
- Hospital
- Doctor
- Another parent
- School
- Support group
- Case manager
- Social worker
- My own research
- Advertising
- Resource guide
- Other – Please specify: \_\_\_\_\_

**SERVICES** – We have focused on five service areas for medically fragile children and their families: respite care, long-term care, case management, hospice and end-of-life care and grief support. The following sections ask about your experiences with these services.

## RESPITE CARE

Have you heard the term respite care?

- Yes
- No

*Respite care* is short-term, temporary care that the family receives apart from the care provided by the child's primary caregiver or insurance-allotted nursing hours. Respite care allows time for the primary caregivers to take a break from the daily routine of caregiving. This time allows the caregiver the opportunity to do such things as attend appointments for themselves or for other children, complete chores, attend social functions, or be used in a crisis situation. Respite care can last for a few hours, overnight or for a few days. It can be provided by family, friends or professionals. It can be also be provided in the family's home or in a facility.

Based on the definition above, who provided respite care for your child when you needed to be away or needed a break? (Check all that apply)

- Extended family member
- Organization/nonprofit
- Day care facility
- Home health care agency
- Other – Please specify: \_\_\_\_\_
- None available
- We did not use respite care

How much respite care did you receive in the year before your child passed away?

**Day/Evening:**

- None
- Less than 1 hour/month
- 1-2 hours/week
- 3-6 hours/week
- 12-24 hours/week
- 48-72 hours/week
- Full-time assisted care

**Overnights:**

- None
- 1-2 nights/year
- 3-7 nights/year
- 2-4 weeks/year
- Child primarily lived outside of the home

How much did you need?

**Day/Evening time**

- None
- Less than 1 hour/month
- 1-2 hours/week
- 3-6 hours/week
- 12-24 hours/week
- 48-72 hours/week
- Full-time assisted care

**Overnights:**

- None
- 1-2 nights/year
- 3-7 nights/year
- 2-4 weeks/year
- Child primarily lived outside of the home

If you used overnight respite care, in what way?

- In a facility
- In my home
- Family member's home
- Other
- No
- Not applicable

How much did you spend for respite care in the last year?

- 0-\$250
- \$251-500
- \$501-750
- \$751-1000
- \$1001-1500
- More than \$1500
- Not applicable

How was it paid for?

- Self-pay
- Insurance
- Grant or fund specifically for respite care
- Free service
- Not applicable
- Other – Please specify: \_\_\_\_\_

What kinds of restrictions made it difficult for your family to benefit from respite services offered? (Check all that apply)

- Didn't know services were available
- No services are available for my child
- Did not accept technology-dependent children (trach, feeding tubes, ventilator)
- Did not accept children with my child's diagnosis of: \_\_\_\_\_
- Too old – Age \_\_\_\_\_
- Too young – Age \_\_\_\_\_
- Lack of money
- Times available weren't convenient
- Too few allowable days per year
- Agency couldn't meet demand – not enough personnel
- Didn't like the set-up of program
- Other – Please specify: \_\_\_\_\_
- Not applicable

If you had access to overnight respite care at a facility that was dedicated to quality care for medically fragile children and their families, would you have used it?

- Yes
- No – Why? \_\_\_\_\_
- Not applicable

How many nights a year do you think you would have used an overnight respite facility?

- 1-5
- 5-10
- 10-20
- 20-30
- More than 30
- Not applicable

## LONG TERM CARE

Total care for a medically fragile child at home can be overwhelming and unmanageable. In some locations in the United States, there are residential nursing facilities dedicated to the long term care of medically fragile children. The following section is about your experiences and views on a long term care placements.

Had anyone ever spoken to you about placing your child in a long-term nursing care facility?

- No
- Yes – Who?
  - Pediatrician
  - Specialty care doctor (oncology, pulmonology, neurology, etc.)
  - Nurse
  - Social worker
  - Case manager
  - Other – Please specify: \_\_\_\_\_

Did you ever consider placing your child in a long term nursing care facility?

- Yes
- No

Did your child ever stay in a long-term care nursing facility?

- Yes
- No

If you had access to a long-term care facility designed expressly for children and devoted to the well being of each child, would you have considered placement for your child?

- Yes – Why? \_\_\_\_\_
- No – Why? \_\_\_\_\_

Were the needs of your child significant enough that a long-term skilled nursing facility would have been helpful?

- No
- Yes – For how long?
  - A few weeks
  - One month
  - 1 to 6 months
  - More than 6 months
  - Episodic

## CASE MANAGEMENT SERVICES

Case managers provide referrals and coordinate services available. These services come in many forms from many different agencies. This section is about your experiences and views of case management.

Did your child have a case manager?

- Yes       No

If yes, what agency was your case manager with?

- Insurance company  
 MH/MR agency  
 Children, Youth and Family Services  
 Other – Please specify: \_\_\_\_\_

What were some of the limitations of your case manager?

- Only able to assist with issues related to their agency  
 Was not familiar with other community services  
 Only gave information about things we specifically asked about  
 Other – Please specify: \_\_\_\_\_

Do you believe more comprehensive case management services would have been helpful in caring for your child?

- Yes       No

Which services would have been helpful from a case manager?

*(Check all that apply)*

- Being assigned at time of diagnosis  
 Provide emotional support to myself, family and my child  
 Assist with navigating the medical system  
 Assist with navigating the insurance system  
 Assist with coordinating all of the services involved with my child's care  
 Assist with finding other services (such as respite, support groups, educational resources)  
 Provide continuing service through age 21  
 Other – Please specify: \_\_\_\_\_

## HOSPICE

Hospice programs provide family-centered care to enhance the quality of life of children and their family to the fullest extent possible. Hospice assists the child and family in the decision-making process about services and treatment choices.

Was a hospice involved in your child's care?

- Yes – Why? \_\_\_\_\_  
 No – Why? \_\_\_\_\_

Who referred you to hospice?

- Not applicable  
 Pediatrician  
 Specialty care doctor (oncology, pulmonology, neurology, etc.)  
 Nurse at hospital  
 Social worker  
 Spiritual care provider  
 Case manager  
 Self  
 Other – Please specify: \_\_\_\_\_

How long did you receive hospice services?

- Less than a month  
 1 to 2 months  
 2 to 4 months  
 4 to 6 months  
 More than 6 months  
 Not applicable

Would you recommend hospice services to other families with terminally ill children?

- Yes – Why? \_\_\_\_\_  
 No – Why? \_\_\_\_\_

How were the hospice services provided?

- In our home  
 In a hospice facility  
 In the hospital  
 Not applicable  
 Other – Please specify: \_\_\_\_\_

## END-OF-LIFE CARE AND GRIEF SUPPORT

Who was the first person to talk with you about the possibility of your child dying?

- Not applicable
- Pediatrician
- Specialty care doctor (Oncology, pulmonology, neurology, etc.)
- Nurse at hospital
- Nurse from home health agency
- Hospice nurse
- Social worker
- Case manager
- Other – Please specify: \_\_\_\_\_

What sources of professional support were the most helpful to your family regarding end of life issues and decisions?

- Not applicable
- Social worker
- Counselor/Psychologist
- Doctor
- Nurse
- Other medical personnel
- Hospice provider
- Pastor
- None
- Other – Please specify: \_\_\_\_\_

What sources of personal support most helped you through the end-of-life and grieving process?

- Spouse
- Grandparents
- Congregation
- Other relatives
- Support group
- Other parents who had gone through similar circumstances
- None
- Other – Please specify: \_\_\_\_\_

Did you participate in any grief support services prior to your child's death?

- Yes – Why? \_\_\_\_\_
- No – Why? \_\_\_\_\_

Have you participated in any grief support services since your child's death?

- Yes
- No

Are you participating in grief support services currently?

- Yes
- No

Would you recommend that families seek out grief support prior to their child's death?

- Yes – Why? \_\_\_\_\_
- No – Why? \_\_\_\_\_

Would you recommend that families seek out grief support following their child's death?

- Yes – Why? \_\_\_\_\_
- No – Why? \_\_\_\_\_

What barriers to grief support did you encounter?

- Child care
- Transportation
- Lack of time
- Not available
- Too far away
- Not applicable
- Other – Please specify: \_\_\_\_\_

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What other services would benefit you, your child, or your family?

Please feel free to add any comments.

*Thank you for completing this survey. This is very emotional issue that we appreciate you revisiting these difficult experiences. We believe that your input will help improve the way the community supports those in similar situations.*