

Clarion  
Crawford  
Erie  
Forest  
Jefferson  
Lawrence  
McKean  
Mercer  
Venango  
Warren



## Northwest Pennsylvania Supportive and Bereavement Resource Guide

For families, volunteers and medical professionals caring for children with life-limiting illnesses.



*Working together for medically fragile children.*

# Welcome

## **Our Mission:**

To provide resources to families, volunteers and medical professionals caring for children with life-limiting illnesses.

We hope this resource directory can help you with whatever situation you are facing. You may have learned your child or newborn has a serious or life-threatening illness or condition and want more information. You may have been caring for a very ill child for a long while and need some relief or respite. You may be grieving the loss of a child. Or you may be a professional in search of additional resources.

Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.\*

It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centers and even in children's homes.

\* World Health Organization (WHO) Definition of Palliative Care for Children (WHO; 1998a)

## Hospices

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### Clarion Forest VNA Hospice

814-297-8400  
[www.cfvna.org](http://www.cfvna.org)

### Great Lakes Hospice

814-877-6120  
[www.upmc.com/locations/hospitals/hamot/services/hospice/pages/default.aspx](http://www.upmc.com/locations/hospitals/hamot/services/hospice/pages/default.aspx)

### Hospice of Crawford County

814-333-5403  
[www.hospice.mmchs.org](http://www.hospice.mmchs.org)

### Hospice of Warren County

814-723-2455  
[www.hospiceofwarrencounty.com](http://www.hospiceofwarrencounty.com)

### Jameson Hospice of Lawrence County

724-652-8847  
[www.upmcjameson.com/hospice](http://www.upmcjameson.com/hospice)

### Penn Highlands Clearfield Hospice

814-768-2012  
[www.phhealthcare.org/penn-highlands-clearfield/hospice-services/hospice/page.aspx?id=1481](http://www.phhealthcare.org/penn-highlands-clearfield/hospice-services/hospice/page.aspx?id=1481)

### VNA of Northwestern PA

814-362-7466  
[www.vnanwpa.com](http://www.vnanwpa.com)

## Home Health/Shift Nursing

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### Bayada Pediatrics *(Erie Office)*

814-835-2400  
[www.bayada.com/pediatrics](http://www.bayada.com/pediatrics)

### Care Unlimited, Inc. *(Erie Office)*

1-800-828-1813  
[www.careunlimitedinc.com](http://www.careunlimitedinc.com)

### eKidzCare *(Meadville Office)*

814-807-116  
[www.ekidzcare.com](http://www.ekidzcare.com)

### Interim Healthcare

814-836-8836  
[www.interimhealthcare.com](http://www.interimhealthcare.com)

### Pediatrics *(Erie Office)*

814-833-0221  
[www.pediatricakids.com](http://www.pediatricakids.com)

### Peritech *(Clarion Branch Office)*

814-226-4058  
[www.peritech.com](http://www.peritech.com)

## Durable Medical Equipment

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### Apria Home

**Medical Equipment** *(Erie Office)*  
814-454-5995  
[www.apria.com](http://www.apria.com)

### Blackburn's *(Erie Office)*

814-454-2863  
[www.blackburnsmed.com](http://www.blackburnsmed.com)

### MedCare

Erie Office: 1-800-503-5554  
Meadville Office: 814-337-6900  
[www.medcareequipment.com](http://www.medcareequipment.com)

### Vantage Home Medical Equipment

Erie Office: 814-835-6662  
Meadville Office: 814-724-7191  
[www.vhcn.com/vantage-medical-equipment-and-oxygen](http://www.vhcn.com/vantage-medical-equipment-and-oxygen)

### The Durable Medical Equipment (DME) List

Clearinghouse for used DME, connecting people who need DME with those who have it to give.

[www.thedmelist.com](http://www.thedmelist.com)

## Medical Support

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Every insurance has someone known as a "special needs case manager." If you are caring for a child with life-limiting illness, you can access this professional by calling the insurance number and asking to speak with them.

### PA Elks Home Service

Toll-free hotline to reach an Elks Nurse to answer questions regarding resources, etc. Referrals for free in-home service coordination.

1-800-986-4550  
[www.paelkshomeservice.org/](http://www.paelkshomeservice.org/)

### Pennsylvania Health Law Project

Provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage or services.

1-800-274-3258  
[www.phlp.org](http://www.phlp.org)

### Supportive Care at The Children's Hospital of Pittsburgh of UPMC

412-692-3234  
[www.chp.edu/our-services/supportive-care](http://www.chp.edu/our-services/supportive-care)

## Funding

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### Caleb's Foundation

#### Pennies from Heaven Fund

Referral from social worker/healthcare professional, provides extra financial support to families with a critically ill child. Cover a rent/mortgage payment, electric or medical bill, other utilities.

[www.calebspennies.org](http://www.calebspennies.org)

### Pennsylvania Assistive Technology Fund

Provides financing opportunities to individuals with disabilities to help acquire assistive technology devices and services to improve quality of life. This includes wheelchair vans, home modifications, etc.

[www.patf.us](http://www.patf.us)

### Social Security

Find your local office:

[socialsecurityhop.com/social-security-office-finder](http://socialsecurityhop.com/social-security-office-finder)

Instructions:

[www.socialsecurity.gov/online/ssa-4.html](http://www.socialsecurity.gov/online/ssa-4.html)

### Tracy Alison Fleisher Memorial Fund

Provides funds for equipment for critically ill children. Checks are provided directly to the vendor. Requires social worker letter.

[www.thetracyfund.org/funding.php](http://www.thetracyfund.org/funding.php)

### United Healthcare Children's Foundation

Provides up to \$5,000 for families in need to help pay for medical services and equipment (e.g. physical therapy, occupational therapy, speech and language therapy, counseling, surgeries, prescriptions, wheelchairs, etc.) No home/vehicle mods. Must have commercial insurance.

[www.uhccf.org](http://www.uhccf.org)

### Variety The Children's Charity

Variety enables children with disabilities to live life to the fullest and to have opportunities to discover the possibilities for their own lives. The will funds specially adapted bikes, strollers, and communication devices in all NW counties. Forest, Mckean, and Jefferson only has funding for bikes.

[www.varietypittsburgh.org/](http://www.varietypittsburgh.org/)

## Respite

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### **PA Ventilator Assisted Children's Home Program**

Funding for supplemental nursing hours for respite for children who use technology for respiration assistance (this includes children who use biPAP/cPAP overnight only).

412-692-6494  
[www.kidshome-vent.org](http://www.kidshome-vent.org)

### **Pediatric Specialty Care**

Inpatient respite.

877-291-6535  
[pediatricspecialty.com](http://pediatricspecialty.com)

### **The Children's Institute**

Inpatient respite.

412-420-2400  
[www.amazingkids.org](http://www.amazingkids.org)

## Recreation

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### **Icing Smiles**

Bakes beautiful, one-of-a-kind, custom cakes and other treats for children impacted by critical illness and their families, free of charge.  
[www.icingsmiles.org](http://www.icingsmiles.org)

**Make a Wish of Greater PA and West Virginia**  
[www.greaterpawv.wish.org](http://www.greaterpawv.wish.org)

**The Woodlands Foundation Camp**  
724-935-6533  
[www.woodlandsfoundation.org](http://www.woodlandsfoundation.org)

## Parent Support

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**Courageous Parent's Network**  
[www.courageousparentsnetwork.org](http://www.courageousparentsnetwork.org)

**Parent-to-Parent of Pennsylvania**  
Matches parents of children with similar diagnoses within Pennsylvania to create a supportive partnership.

1-888-727-2706  
[www.parenttoparent.org/](http://www.parenttoparent.org/)

**The Mighty**  
[www.themighty.com](http://www.themighty.com)

## Grief and Bereavement

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Grief support is often offered by hospice services or funeral homes for their clients. Check with the family's providers to see if they have an in-house program.

**Children's Hospital of Pittsburgh of UPMC**  
Bereavement support available to families of all CHP patients.  
**Bereavement Coordinator:**  
**Lori Malazich**  
412-692-3585  
[lori.malazich@chp.edu](mailto:lori.malazich@chp.edu)

**Empty Arms Support Group**  
For parents who have experienced neonatal death or miscarriage. Second Tuesday of every month at 7:30pm.  
814-838-6346  
[www.emptyarmseriepa.wordpress.com/about](http://www.emptyarmseriepa.wordpress.com/about)

**Great Lakes Hospice Bereavement Support Groups**  
Open to the public, support for those who have lost a loved one.  
814-877-6527  
[www.upmc.com/locations/hospitals/hamot/services/hospice/pages/default.aspx](http://www.upmc.com/locations/hospitals/hamot/services/hospice/pages/default.aspx)

**Highmark Caring Place** *(Erie Location)*  
Support for children who have lost a loved one, and their families.  
866-212-4673  
[www.highmarkcaringplace.com/cp2/index.shtml](http://www.highmarkcaringplace.com/cp2/index.shtml)

## Prism

Support for single parents and step-parents experiencing grief. Meets at St. Mark Catholic Center in Erie.

814-824-1253

## Diagnosis Specific

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### **American Cancer Society Road to Recovery Program**

Free rides to cancer diagnosis-related appointments. Patients under 18 must be accompanied by a legally responsible adult. Call at least 2 days in advance of the appointment to schedule. Operator can offer other resources for the family.

1-800-227-2345  
[www.cancer.org/treatment/supportprogramsservices/road-to-recovery](http://www.cancer.org/treatment/supportprogramsservices/road-to-recovery)

### **Reflections of Grace**

Financial assistance to families of children with brain cancer.

[www.reflectionsofgrace.org](http://www.reflectionsofgrace.org)

### **Travis Roy Foundation**

Quarterly (March/June/September/December) grants to individuals with spinal cord injuries for adaptive equipment and vehicle/home modifications.

[www.travisroyfoundation.org](http://www.travisroyfoundation.org)



**Palliative Care** no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently.

— Mattie Stepanek (1990-2007)



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