



## [Starting Resources for Parents, Families & Friends](#)

There are a variety of resources that can provide additional help and information as you make your way along this path of serious or chronic illness with your child. The few websites listed here are a place to start and have been selected based on recommendations from other families like yours with kids with chronic or serious medical conditions and from healthcare professionals who work with and care for kids like this.

*We are currently working on a lengthy list of many other resources which will be added shortly—more websites, books, videos, and supportive care resources, so please check back!*

### **Communication Counts: A Toolkit for Families Experiencing Childhood Illness**

<http://danya.com/ccounts/>

- A practical, innovative, and comprehensive resource to support families with a school-aged child living with a life-threatening illness.
- The goals of the materials are to give parents the information they need, when they need it, without overwhelming them and to help increase parents' positive coping skills through direct and open communication with their ill child, other family members, and the healthcare team.
- Three distinct Toolkits are offered, depending on the stage of the illness the child is experiencing (i.e., During Diagnosis and Treatment, While Transitioning to Supportive Care, and Through Bereavement).
- Each Toolkit includes a Parent Guidebook, a Parent DVD, and a Family Activity Book.
- Available for free download by families on the website.

### **Together for Short Lives**

<http://www.togetherforshortlives.org.uk/families>

- The leading charity in the United Kingdom (England) for all children with life-threatening and life-limiting conditions and those who support, love, and care for them.
- They support families and professionals and work to ensure that children get the best possible care, wherever and whenever they need it.
- They have many resources available for download to help families through the main stages of a child's diagnosis.
- Publications are available for download free, and include: Making Critical Care Choices for Your Child, After Your Child's Diagnosis, Understanding Siblings' Needs, Spiritual, Religious, and Cultural Wishes, among many more.

## Parenting a Child with Life-Limiting Illness Toolkit

<http://globalgenes.org/toolkits/parenting-a-child-with-life-limiting-illness/introduction/>

- A Parent Toolkit based on an educational video put together by the National Tay-Sachs & Allied Diseases Association.
- Includes education on Preserving the Family, Special Equipment, Finances, Finding Support, etc.
- Also includes A Resource Guide and Inside Look with additional resources to help parents manage their child's illness and care.

## Caring Connections

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

- HelpLine: 800-658-8898
- Multilingual HelpLine: 877-658-8896
- Web-based resources on a variety of topics including Planning Ahead, Caring for Someone, Living with Illness, Live Without Pain, etc.
- Website also contains educational brochures and information in English and Spanish for parents of seriously-ill children (See "Resources").

## Children's Hospice and Palliative Care Coalition

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

- This organization's mission is to partner with, and work together for children with serious illnesses and all those who care for them.
- Website includes extensive listing of Family Resources across many topics related to caring for seriously-ill children including General Support, Financial Assistance, Home Care, Medical Specialty Organizations, Sibling Support, among many others.
- Also has A Family Advisory Council (FAC) which provides essential parental perspectives to improve healthcare systems that serve medically fragile children.

## Partnership for Parents

[www.partnershipforparents.net](http://www.partnershipforparents.net) and [www.padrescompadres.org](http://www.padrescompadres.org)

- A bilingual online source of support and information for parents of children with life-threatening illness and grieving parents. All materials are available in English and Spanish.
- The site offers useful information for all stages of the journey from initial diagnosis to, if necessary, grief support.
- Site covers topics such as *Talking to Your Child's Doctor*, *Making Sense of Medical Information and Terms*, *Your Child's Pain*, *Getting the Help You Really Need*, etc.

## Children's Project on Palliative/Hospice Services (ChiPPS)

[www.nhpc.org/pediatrics](http://www.nhpc.org/pediatrics)

- A sub-section of the National Hospice and Palliative Care Organization (NHPCO), ChiPPS works to make healthcare professionals who care for children with life-limiting/life-threatening illnesses aware of the best-known practices and services available for these children and their families.
- The website includes a link to a quarterly E-Journal published by ChiPPS on articles relative to pediatric palliative and hospice care treatment and support; each issue tries to include an article (or more) from the patient/family voice perspective.

## [Sources for Purchasing Books and Other Materials](#)

We also encourage you to check out these websites for books, videos, and other supportive care materials which are available for purchase from the following sites.

### **The Centering Corporation's Grief Resources Catalog**

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

1-866-218-0101

- Primarily a grief and loss website which has extensive materials and literature for sale, including publications on Children and Grief, Infant Loss Resources, and Death of a Child.
- Also offers resources helping families deal with Serious and Terminal Illness, Illness in Children, Creative Journaling, and Special Care Infants, among others.
- They have resources for children, teens, adults, and professionals.

### **Compassion Books**

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

1-800-970-4220 (Inside the US)

1-828-675-5909 (Outside the US)

- **A web-based source of more than 400 books, videos, and audios to help children and adults through serious illness, death, dying, and grief/loss.**
- Specifically offers resource materials in these and other categories: Children & Grief, Teens & Grief, Helping Children & Teens, Death of a Family Member, Facing Life-Threatening Illness, Death of a Child/Baby, Storytelling, Rituals & Remembrance, and more.

### **The Dougy Center**

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

1-866-775-5683

- A safe place for children, teens, young adults and families to grieve
- Offers materials related to grief and bereavement for adults and children. They are widely-known for their grief support model.

## [Other Helpful Websites](#)

### **American Childhood Cancer Organization (formerly known as Candlelighters)**

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

- An organization that provides support, education, and advocacy to families whose lives have been impacted by childhood cancer.
- They claim to be the largest publisher and distributor of free childhood cancer books in the US, with their books and materials targeted at parents, young patients, siblings, educators, and caregivers.

### **Brave Kids**

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

- A program of United Cerebral Palsy which provides support and resources for children and youth, ages 6-17, with disabilities and chronic/life-threatening illnesses and their families and caregivers.

### **Cancer Hope Network**

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

- A national non-profit organization that provides free and confidential one-on-one emotional support to cancer patients, their caregivers, and their families. They match cancer patients or family members with trained volunteer cancer survivors who themselves, have undergone and recovered from a similar cancer experience.
- Through their internal and external resources, they share cancer success stories, dispel myths and uncertainty, and provide support and hope to help patients look beyond the diagnosis and cope with treatment and living life.

### **Caregiver Action Network**

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

1-202-772-5050

- The nation's leading family caregiver organization working to improve the quality of life for those who care for loved ones with chronic conditions, disabilities, disease, etc.
- It serves a broad range of family caregivers, including parents of children with special needs and provides education, peer support, and free resources to family caregivers across the country.
- Resources include: Family Caregiver Forums, Peer Network, Family Caregiver Toolbox, among others.

## Chai Lifeline

<http://www.chailifeline.org>

- An extensive network of free programs and services designed to help every family member cope during times of pediatric illness.
- They strive to bring joy to the lives of young patients and their families through family-centered programs, activities, and services and to offer these programs free-of-charge when/where possible.
- Check website for multiple regional offices.

## Find-a-Therapist

[www.find-a-therapist.com](http://www.find-a-therapist.com)

1-866-450-3463

- A leading web-based provider of services that helps to “connect people to the right therapist at the right time”; that is, by calling the 866 number, their experts will help to find a confidential referral for a therapist in your area.
- However, their materials cite that this service is not intended to diagnose or treat any medical conditions and that all of the therapists operate independently of Find-a-Therapist.

## Growth House, Inc.

<http://www.growthhouse.org>

- Their primary mission is to improve the quality of compassionate care for people who are dying through public education and global professional collaboration
- Provides resources that educate about life-threatening illness and end-of-life care.
- Their search engine gives access to one of the web’s most comprehensive collection of reviewed resources for end-of-life care.

## National Organization for Rare Disorders (NORD)

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

1-203-744-0100

- A non-profit federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them.
- NORD is committed to helping families through the identification, treatment, and care of rare disorders through programs of education, advocacy, research, and service.
- Websites includes information on Patient Assistance Programs, Patient Meetings, Patient Stories, Online Patient Communities, News about Clinical Trials, and more.

## [Caring for Babies/Infants with Life-threatening Illness](#)

### Perinatal Hospice & Palliative Care

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

- A caring and practical resource for parents who have received a prenatal diagnosis that may indicate that their baby will die before birth or after birth.
- It provides a comprehensive list of perinatal hospice and palliative care programs by state.
- It also includes a list of Resources for Parents, including books, other website links, video links, online forums, information on specific conditions/diagnoses, perinatal bereavement photography, organ donation, and other relevant topics.
- A downloadable sample birth/parenting plan is available to help parents think through and prepare for what they may/may not want to have happen when their baby is born.

### Share Pregnancy & Infant Loss Support, Inc.

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

1-800-821-6819

- Share's mission is to serve those whose lives are touched by the tragic death of a baby through pregnancy loss, stillbirth, or in the first few months of life.
- They strive to provide information, education, and resources on the needs and rights of bereaved parents and siblings at the time of a baby's death, and afterwards.
- The website has information on Care for Parents, Facts for Family & Friends, Encouragement for Kids, Rights of Parents When a Baby Dies, Funeral and Memorial Resources, among others.

## [Just for Teens](#)

### **Starbright World**

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

1-310-479-1212

- Starbright World promotes itself as the first-ever social network for teens with chronic and life-threatening medical conditions and their siblings. Members are able to connect with others experiencing similar medical journeys.
- The managers of this site claim to make a concerted effort to maintain safety and security within their community in order for parents to feel comfortable letting their teens participate in this forum independently.

### **Teens Living with Cancer (TLC Connect)**

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

1-585-563-6221

- A web-based community for teens/young adults facing cancer.
- It has education on cancer as a disease, treatments, coping, school issues, etc. all written for a teen with cancer in mind.
- Also has a community of teens online to share their cancer journeys and educate and support one another.



## [Websites to Help with Communicating Updates to Family/Friends](#)

Setting something like this up, or your own e-mail blast system, is highly encouraged to help limit/stop the number of well-intended phone calls coming into your cel phones or the house.

### Caring Bridge

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

- A web-based means of communicating with family and friends via online posts when a child is seriously or chronically-ill or hospitalized.
- Families can determine the privacy level of their site, can keep a journal of their posts, and allow others to comment on the posts, as a means of offering support to families during a family illness.

### CarePages

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

1-646-728-9500 (Office)

1-888-852-5521 (Telephone Support for Webpages)

- CarePages are free patient blogs on the web which allow patients, or their families/caregivers, to communicate with and connect with friends and family during a health challenge.
- Posting updates on a child's condition allows parents to keep family and friends informed during his/her illness or a hospitalization.

## *Places to Stay While Your Child is in the Hospital*

### Ronald McDonald House

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

1-630-623-7048

- Local chapters provide a “home-away-from-home” for the families of seriously-ill or injured children getting treatment at nearby hospitals.
- Families either stay at no charge or are asked to make a donation of up to \$25.00 per day, depending on the Ronald McDonald House.
- Some hospitals also have Ronald McDonald Family Rooms in hospitals which provide families a place to rest and regroup in the hospital while their sick child is hospitalized.

## [Wish-Granting Organizations](#)

### **Make-A-Wish Foundation**

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

1-602-279-9474 (or check website for local chapters)

- Grants the wishes of children under 18 diagnosed with life-threatening medical conditions in the US, to help strengthen and empower children during their battles with their life-threatening conditions