This treasure trove of resources was put together by an attendee of a past Legacy Retreat, a mother living with a life-threatening illness. Her background was in social work, and she graciously used her skills to put together everything she could find that might be of benefit to you and your family. There may be many here that do not apply to you, yet there may be a few, or even just one, that blesses you greatly. This is her gift to you!

Resources for Parents with a Life-Threatening Illness

Especially Helpful Websites for ill parents and their children:

Inheritance of Hope  
http://inheritanceofhope.org  
Provides all expense paid retreats, scholarships, resources, and other support to young families with a parent who has a life-threatening illness.

Growth House, Inc.  
http://www.growthhouse.org  
Provides information and referral services for agencies working with death and dying issues. Located in San Francisco but maintains extensive links to nationwide resources and other information, has online bookstore and chat rooms and special section on helping children with illness and grief.

Mommy’s Light Lives On Fund  
http://www.mommyslight.org  
Mommy’s Light “brings joy and comfort to children and teens by helping them keep alive traditions and simple pleasures they shared with their mothers.” Serves children between 3 and 18 years old whose mothers are in life threatening situations or are deceased. Must live in southeastern PA, southern NJ, or northern DE. The family must directly request Mommy’s Light’s support. Also grief education
**www.kidscope.org** helping kids understand when a parent has cancer; download a coloring book/info journal, DVD avail. For nominal charge or lending libraries in every state (contact info given.) “links” section is outdated, with over 50% “dead” links

**www.kidskonnceted.org** “The mission of Kids Konnected is to provide friendship, understanding, education and support for kids and teens who have a parent with cancer or have lost a parent with cancer.” Care packages, camp opportunities, and more. Be sure to visit the Resources section for an excellent list of books to share with children in different stages of a parent’s illness

**www.childrenstreehousefdn.org** “the mission is to ensure that every child whose parent is diagnosed with cancer is given the early tools and emotional support to cope.” Contact info for CLIMB children’s support programs, books, videos

**www.lookingglass.org/parents** “TLG provides direct services, information and referral to a diverse group of parents with disabilities and their families.” No specific info for parents with a life-threatening illness.

**Hallmark recordable children’s books**

Hallmark Corporate Information for list of titles, [www.hallmark.com](http://www.hallmark.com) for ordering.

**Organizations that assist families with recording legacies**

**Mother’s Living Stories**

http://www.motherslivingstories.org

The Mothers’ Living Stories Project (MLS) brings compassion, support in parenting, and dignity to mothers who have a life-threatening or chronic illness by helping them record life stories and personal legacies for their children and loved ones.

**Association of Personal Historians**

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

The APH is “dedicated to helping others preserve their personal histories and life stories.” Listings of professional personal historians working in different media around the country.

Tips on recording personal histories. Conference for professionals.

**Center for Journal Therapy**

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

“The mission of The Center for Journal Therapy is to make the healing art of journal writing accessible to anyone who desires self-directed change. Our vision is to heal body, psyche and soul through writing.” The Center offers workshops, books and tapes designed to help you engage in journal therapy.
Center for Life Stories Preservation  
http://www.storypreservation.com  
A resource for helping people capture their family and life stories.

Ethical Wills  
http://www.ethicalwill.com  
Ethical wills are a way to preserve and pass on your values, beliefs, life lessons, hopes for the future, love, and forgiveness. It is one of the most cherished gifts that you can give to your family and community. Provides information, resources, materials and a facilitators’ network.

Healing Legacies  
http://www.healinglegacies.org  
Art & writing by women who have faced breast cancer. Art and healing resources

Healing Story Alliance  
http://www.healingstory.org  
Explores and promotes the use of storytelling in healing. Has special story-based project for children in crisis.

The Legacy Center  
www.thelegacycenter.net  
Has a network of Legacy Center Associates that can help you explore, document and share the stories and lessons of your own life.

StoryCorps  
http://www.storycorps.net  
“A national project to instruct and inspire people to record each others' stories in sound.” Has a recording booth in New York City and also Mobile Booths for hour-long recording sessions.

Turning Memories Into Memoirs  
http://www.turningmemories.com  
Memoir writing and teaching resources (workshops, books, editors, coaches, etc.).

Books, Web Sites, and workshops for families

Compassion Books  
http://www.compassionbooks.com  
An online bookstore, Compassion Books has hundreds of excellent books, audiotapes and videotapes on loss, grief, death and dying.

Courage to Choose/Courage to Care  
http://www.couragetochoose.com
Consultation, workshops, and educational offerings for professionals and the public related to essential conversations about end-of-life wishes.

**Dying Well**  
[http://www.dyingwell.org](http://www.dyingwell.org)  
This web site of Ira Byock, MD is filled with valuable information about death and dying, including an extensive list of books and resources.

**Arts and Healing Network**  
[http://www.artheals.org](http://www.artheals.org)  
“An international resource for anyone interested in the healing potential of art, especially environmentalists, social activists, artists, art professionals, health care practitioners, and those challenged by illness.”

**Healing Environments**  
[http://www.healingenvironments.org](http://www.healingenvironments.org)  
Offers ideas, tools, resources, and a free newsletter for patients and caregivers on how to create healing environments that nourish the soul and relieve suffering.

### Adult Wish-Granting Organizations

**Inheritance of Hope**  
[http://inheritanceofhope.org](http://inheritanceofhope.org)  
Provides all expense paid retreats, scholarships, resources, and other support to young families with a parent who has a life-threatening illness.

**The Dream Foundation**  
[http://www.thedreamfoundation.org](http://www.thedreamfoundation.org)  
The Dream Foundation grants final wishes to adults suffering life-limiting illness. Our focus is on providing those at the end of life’s journey with a sense of resolution and completion. We provide a non-traditional, palliative form of healthcare. Although there is no cure for the catastrophic illnesses afflicting the lives of our dream recipients, we help by improving the quality of their lives in a way that medicine cannot.

**The Adult Wish Foundation**  
[http://www.adultwishfoundation.org](http://www.adultwishfoundation.org)  
The foundation’s mission is “To grant reasonable wishes to adults; 18 and above with life-threatening illnesses, while supporting surviving family members. To enrich their lives with respect, love, and hope.

**Memories Of Love**  
[http://www.memoriesoflove.org](http://www.memoriesoflove.org)  
Florida vacations for families with a chronically ill parent and children under age 16
Her Heart’s Wish Foundation
http://www.herheartswish.org
Wishes granted for women age 18 to 78 with life-threatening illnesses who are in their last 24 months of life

Never Too Late
http://nevertoolate.org
Grants wishes to people regardless of age (although they give priority to individuals age 65 and up). Wishes are granted to people who are in nursing homes, hospices, adult day care, and extensive home support. Be sure to document any home nursing and PCA services, long and short term rehab facility stays, palliative care/hospice programs, etc.

The Dream Lives On
http://thedreamliveson.org
Grants dreams to adults, age 18 years and older, who have been diagnosed with a year or less to live. We believe that everyone has a dream and we are dedicated to making that dream come true while helping to create lasting memories.

The Granted Wish Foundation
http://grantedwish.org
Grants wishes to people in three categories: disabled, disadvantaged, and deserving. Highly competitive program, applicants do not need to be terminally ill.

Grants Open To Adults

www.modestneeds.org grants for up to the cost of 1 month’s rent or mortgage, see website for grant requirements

www.smallcomforts.org $250 grant for comfort items, also family financial assistance for Tompkins County, NY only

www.pennies-from-heaven.org pay incidental, non-medical expenses for families experiencing a severe health crisis.

http://wishuponahero.com small, quick, online grants

The Weber Foundation of Helping Hands Inc.
The Weber Foundation grant is only open to Northeast US states, requires a lot of documentation, and takes 6 to 8 months before approving a grant, but gives significant amounts and could possibly pay for quite a bit of private duty nursing.

www.raytyemedicalaidfoundation The Ray Tye Medical Aid Foundation's charter and mission is dedicated to funding in-hospital life saving medical treatment and surgeries
for those who do not have medical insurance, and for which no other financial resources are available.

**www.netwish.org** small, anonymous wishes for a variety of items, no cash given, vouchers, purchase orders, gift cards, and actual items.

**www.faithshopefoundation.org** open to any age, pays for household expenses that go unpaid while caring for a sick family member

**http://mayerfoundation.org**
The Mayer Foundation provides "economic relief" grants to individuals who need assistance paying for equipment or services related to severe illness, accident, or disability, along with a few other situations. The grants range from $2500 to $5000 and are reviewed and awarded on a rolling basis.

**www.joniandfriends.org**
Joni and Friends Grants for Disabled Individuals is a Christian charity that will provide a grant of up to $2500 for an individual with a disability who needs financial assistance. They request that the applicant's church match funds for the donation. This fund can be accessed very quickly, if needed.

**www.mesa-angels.com** The Mesa Angels foundation gives grants to individuals in crisis due to a health emergency, natural disaster, etc. The fund seems to focus on acute needs rather than ongoing chronic illness needs, but a recent and drastic change in condition may qualify.

**www.thedreamsociety.org** It is the goal of "The Dream Society" to assist people with moderate to severe physical challenges in becoming independent, productive citizens. By enhancing their lives with the tools to assist them, they will be able to give back to themselves and their community. We hope to give people with physical challenges the strength, courage, and financial opportunity to accomplish their dreams of a more fulfilled and independent life. FL only

A few sources of state-specific info are:
**www.ucp.org/ucp_generaldoc.cfm/1/3/43/43-43/5807** UCP One-Stop Resource Guide
**www.disabilityresources.org/pennsylvania.html** (insert any state name)
**www.patientadvocate.org/report.php**

A few non-specific financial resource pages are:
**www.disabilityresources.org/FINANCIAL.htm**
**www.familyvillage.wisc.edu/general/adults.htm**
**http://foundationcenter.org/getstarted/guides/disabilities_indiv.html**
**http://www.nonprofitexpert.com/assistance.htm**

*Non Profit Expert.com: Individual Assistance*
Lists some sources of individual funding.

Missouri Vocational Rehabilitation  
_http://dese.mo.gov/vr/_

Kansas Dept. of Social & Rehab Services  
_http://www.srsksansas.org/_

Illinois Dept. of Human Services  
_http://www.dhs.state.il.us/page.aspx?item=29736_

Tennessee Vocational Rehabilitation  
_http://www.state.tn.us/humanserv/rehab/vrs.html_

Missouri Assistive Technology  
_http://www.at.mo.gov/bkgrnd_mission.html_

Elk’s (national)  
_http://www.elks.org/enf/default.cfm_
find a local lodge to ask for assistance

Missouri Dept of Mental Health Division of Developmental Disabilities  
_http://www.dmh.missouri.gov/mrdd/progs/waiver/factsheet.htm_

Kansas Assistive Technology Corporation  
_http://www.katco.net/_

Veteran Affairs (adults)  
_http://www.va.gov/_

Friends of Man  
_http://www.friendsofman.org/_

Helping Hand Foundation(Kansas)  
_http://www.helpingfoundation.org/_

www.givetech.org  Does not give grants, but will provide free “hands-free” computer hardware for people who cannot use adapted keyboards.


http://fdncenter.org/


There are several sources of caregiver support that can be located and contacted online. Two groups that may be helpful are: The National Family Caregivers Association [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org), Care Community [www.mycarecommunity.org](http://www.mycarecommunity.org)

If the patient is married or in a long-term relationship, a helpful organization is The Well Spouse Association [www.wellspouse.org](http://www.wellspouse.org).

Parents with Disabilities

[www.lookingglass.org](http://www.lookingglass.org) The National Resource Center for People with Disabilities/Through the Looking Glass

[www.wheelchairnet.org/WCN_living/parenting.html](http://www.wheelchairnet.org/WCN_living/parenting.html) A link to many, many more websites useful to parents with all kinds of disabilities, some links for parents with “invisible illnesses/disabilities” as well

[www.familyvillage.wisc.edu/general/parentswdis.html](http://www.familyvillage.wisc.edu/general/parentswdis.html) A list of websites that have articles, resources, and social/emotional support for parents with a multitude of disabilities

[www.kidstogether.org](http://www.kidstogether.org) “people first” language, self-advocacy for children and adults

[www.disabledparents.net](http://www.disabledparents.net) “the internet’s one-stop resource for parents with disabilities”

[www.disabilityresources.org/PARENTS-WITH.html](http://www.disabilityresources.org/PARENTS-WITH.html) a huge disability clearinghouse describes the list of parenting resources like this: Being a parent is never easy. When you’re a parent who happens to have a disability, the challenges are even greater. These web sites that offer information, tips, and support.

[www.mobilewomen.org](http://www.mobilewomen.org) online magazine for women in wheelchairs

[www.disaboom.com](http://www.disaboom.com) Disaboom is the leading resource for disability information and real-life articles about people with disabilities. Our broad range of topics, including health conditions, lifestyle, and helpful resources, help you create the life you want.

[www.disability.gov](http://www.disability.gov) An excellent, well-maintained federal site that can help a parent find any desired info. Separated into large sections for browsing (benefits, employment, housing, etc.)

[www.disabilityinfo.org](http://www.disabilityinfo.org) Index of services available to individuals in MA
http://www.workshopsolutions.com/ how to make your own assistive devices, also has links to AT site

http://www.abledata.com/abledata.cfm?pageid=113573&top=16046&sectionid=19326  Abledata’s list of resources, articles, organizations, conferences, studies, etc.

www.childrensdisabilities.info site has a large amount of information about both children and parents with disabilities.  The site is difficult to navigate—a bit cluttered and bursting at the seams with information.

A thoughtful story to share …

**Butterflies**

A man found a cocoon of a butterfly. One day a small opening appeared and he sat and watched the butterfly for several hours as it struggled to force its body through that little hole. Then it seemed to stop making any progress. It appeared as if it had gotten as far as it could and it could go no further. So the man decided to help the butterfly by taking a pair of scissors and snipping off the remaining bit of the cocoon. The butterfly then emerged easily, but it had a swollen body and small, shriveled wings. The man continued to watch the butterfly because he expected that, at any moment, the wings would enlarge and expand to be able to support the body, which would contract in time. Neither happened! In fact, the butterfly spent the rest of its life crawling around with a swollen body and shriveled wings. It never was able to fly.

What the man in his kindness and haste did not understand was that the restricting cocoon and the struggle required for the butterfly to get through the tiny opening were God’s way of forcing fluid from the body of the butterfly into its wings so that it would be ready for flight once it achieved its freedom from the cocoon. Sometimes struggles are exactly what we need in our life. If God allowed us to go through our life without any obstacles, it would cripple us. We would not be as strong as we could have been. We could never fly.