

Caring for the Whole Family

Mitochondrial disease may be one of the most complex disorders that EI clinicians encounter. Mitochondrial disease, or “Mito,” affects every body system in varying degrees, with the severity of symptoms ranging from barely perceptible to life-threatening. Children with moderate to severe complications may even be followed by or have been referred to every specialty available in your program, the public school system, and your local children’s hospital. Making a definitive diagnosis is often difficult, and may take months to years of intensive diagnostic testing to identify the specific genetic defect. In many cases, the specific defect is never identified and the diagnosis is made based on clinical signs and symptoms, family history, and supportive lab results. To make matters worse, a specific genetic diagnosis may not significantly contribute to the child’s treatment plan and prognosis. Due to the genetic transmission of some types of mitochondrial disorders, your child client may have siblings, parents, and other family members with the same disorder. Morbidity and mortality varies widely among family members, and response to supportive treatment is difficult or impossible to anticipate. As you can imagine, this can be frustrating and frightening to the child’s family. Support provided by EI clinicians, working in harmony with other medical, developmental, and educational services, can have a profound impact on the family and child’s quality of life.

Palliative Care, Hospice, and Quality of Life

What Is Palliative Care?

If a family chooses palliative care for their child, does that mean they’re “giving up”? Are Palliative Care and Hospice the same thing? An Expert Committee of the World Health Organization in 2002 approved this revised definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care is not about dying, it is about *living!* Medical care is not withdrawn, it is modified to support quality vs. quantity of life. Parents work with the child’s medical team to review current and future medication, treatments, and support to determine the best way to assist the child and family.

Can Early Intervention services play a role in palliative care? Absolutely! Every child is unique, and every family’s needs are unique as well. EI clinicians have much to offer to children and families: organization, play, social interaction, family support, integration of siblings into the child’s care, and more. Working with the chronically and terminally ill is an emotional experience. Be sure to find a professional, appropriate way to discuss your experiences and gain support. *You are not alone!*

Family Support Resources:

<http://www.patientadvocate.org/index.php> Patient Advocate Foundation: provides mediation and arbitration services to patients to remove obstacles to healthcare, including medical debt crisis, insurance access issues and employment issues for patients with chronic, debilitating, and life-threatening illnesses.

http://caregiver.org/caregiver/jsp/fcn_content_node.jsp?nodeid=2083 The Family Caregiver Alliance was developed to provide a “one-stop” source of information and support for families caring for a loved one with disabilities or chronic/severe illness. The Family Care Navigator provides resources organized by state.

<http://www.rosalynncarter.org/> Rosalynn Carter Institute for Caregiving: information and support for caregivers of all kinds. Includes an extensive, well-organized resource section.

http://www.comeunity.com/special_needs/ Articles, resources, and online support for parents of children with disabilities and special needs.

Sibling resources:

www.siblingsupport.org Ongoing support for children who have a sibling with a chronic, life-threatening, or terminal illness, or disabilities of any kind. Program includes "Sibshops" workshops, follow-up info given to the pedi, therapist, or parent to continue expressing emotions and channeling energy in a positive way; email "pen-pals" available as well.

<http://www.autismsiblings.org/> Charity designed to help the brothers and sisters of autistic kids (and adults too).

Books

"What About Me? When Brothers and Sisters Get Sick" http://www.amazon.com/What-About-Me-Brothers-Sisters/dp/0945354495/ref=pd_sim_b_95

"When Molly Was In The Hospital," a book for siblings http://www.amazon.com/When-Molly-Was-Hospital-Hospitalized/dp/1877810444/ref=pd_sim_b_2

"Hi, My Name is Jack," a book for healthy siblings of chronically ill children http://www.amazon.com/Hi-Name-Jack-Christina-Beall-Sullivan/dp/0975971808/ref=pd_sim_b_24

"The Sibling Slam Book; What it's Really Like to have a Brother or Sister with Special Needs" http://www.amazon.com/Sibling-Slam-Book-Brother-Special/dp/1890627526/ref=pd_sim_b_7

Family Ties book of resources: <http://massfamilyties.org/info/directory.php>

"Working with Children with Special Health Care Needs: What Families want Health Care Providers to Know" http://www.fcsn.org/provider_guide.pdf

"Activity: Pathways Challenge" <http://woodnbarnes.com/?p=1438>

Palliative Care Information for Families:

<http://www.childrenshospice.org> The Children's Hospice and Palliative Care Coalition (written for children in California but principles apply in all areas).

<http://www.partnershipforparents.org> Partnership for Parents provides a wealth of information, support, and resources for the families of children with life-threatening and chronic illnesses. Although the site was written by individuals from California, the suggestions and resources offered are applicable worldwide.

<http://www.hospicefed.org> The Hospice and Palliative Care Federation of Massachusetts: Provides basic information about Hospice and Palliative Care, including a list of service providers statewide.

<http://www.endoflifecommission.org> The Massachusetts Commission on End of Life Care: This MA-based service commission has participated in several programs that directly benefit MA adults and children and their families in making end-of-life decisions as well as providing a resource database to enable families to locate and utilize local financial, educational, emotional, and other support services.

<http://www.mitoaction.org/blog/palliative+care+in+mitochondrial+disease> Palliative Care in Mitochondrial Disease: (audio recording) Dr. Pat O'Malley from Massachusetts General Hospital talks about long-term care and quality of life support for adults and children with mitochondrial disease.

Palliative Care Information for Professionals:

<http://www.capc.org> The Center to Advance Pediatric Palliative Care resource site includes toolkits, policy statements, teaching/training materials, organization listing and information about publications, books, and videos.

<http://www.chionline.org> Children's Hospice International provides education, training, and technical assistance to those who care for children with life-threatening conditions and their families.

<http://www.ippcweb.org> The Initiative for Pediatric Palliative Care is an education and quality improvement effort, aimed

at enhancing family-centered care for children living with life-threatening conditions. IPPC's comprehensive, interdisciplinary curriculum addresses knowledge, attitudes, and skills that health care professionals need in order to better serve children and families.

<http://www.rwjf.org> Pediatric palliative care project sponsored by Robert Wood Johnson Foundation includes resources, reports, parents' stories, and video clips.

Child and Family Support:

<http://www.sharenetwork.org/wish.htm> National/international database of wish-granting organizations.

<http://angelsforhope.org> crocheted angels, smiley faces, and seasonal items sent to people who could use some "happy mail." Don't forget to check out their extensive links section!

<http://elisangels.net> A program for children with mitochondrial or metabolic diseases, infants through age 10, "happy mail" and care packages for birthdays and holidays.

www.songsoflove.org provides personalized songs for children or teens currently facing tough medical, physical, or emotional challenges, free of charge.

<http://www.littlestheroesproject.org/> provides free professional portraits for children with serious illnesses or disabilities.

<http://www.acpcg.com/mission.htm> The American Child Photographers Charity Guild of professional photographers who provide complimentary portrait sessions (taken in NICU, PICU, Hospice, etc.). Able to respond on a moment's notice.

<http://www.nowilaymedowntosleep.org/> Complimentary heirloom photographs of infants and children who are seriously ill, stillborn, or experiencing other dire circumstances.

www.shareacard.org cards sent to people with illnesses, injuries, disabilities, etc., who could use "happy mail" to brighten their day.

www.hugsandhope.org cards sent as "happy mail" much like share-a-card.

www.makeachildsmile.org cards, small gifts, and other "happy mail" for sick children.

www.nathanielshope.org Christian support organization that sends cards and care packages, prayer chain as well.

www.projectlinus.org Donated, handmade blankets for children who are seriously ill, disaster victims, foster care, any traumatic situations.

www.icingsmiles.org "We are Baking a Difference" Deluxe cakes for kids with terminal illnesses.

http://www.famousfonefriends.org/Home_Page.php Hospitalized children can receive a phone call from a celebrity or a cartoon character. See site for information.

Financial Assistance

<http://tiny.cc/79bW3> The **Financial Resources (Possible) Fact Sheet** lists organizations/groups that have been known to assist those in need, or whose mission is to provide assistance. One of the more frequent requests information specialists receive are those for financial assistance. Beyond the regular assistance provided by Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), there is precious little money available for people with disabilities. However, on occasion charities and organizations have been known to provide assistance if they can. Catholic Charities and Salvation Army organizations help elders, families, and children in need. (New England INDEX)

<http://www.mass.gov/cicrf/> The Catastrophic Illness in Children Relief Fund (CICRF) helps families bear the excessive financial burdens associated with the care of children with special health care needs and disabilities. CICRF is a payer of last resort. It provides financial assistance for Massachusetts families with children experiencing a medical condition requiring services that are not covered by a private insurer, federal or state assistance, or any other financial source.

<http://andriveroflife.org> The Andre Sobel River of Life Foundation provides emergency financial support to single parents with a child enrolled in a hospice program. This amazing agency can provide critical support exactly when it is needed most, even within 24 hours of being contacted.

www.dcrf.com Disabled Children's Relief Fund: provides up to \$500/year for equipment or services not covered by insurance. Accepts applications annually between April and September.

www.wheeltowalk.com The Wheel to Walk Foundation provides funding for medically necessary equipment, therapies, in-home services/respite not covered by insurance.

Final Expenses

<http://kidswishnetwork.org/faq/funeral-faq/> Funeral expenses for children through 21 years of age. *NOTE: You must contact within 30 days of child's death.

www.funerals.org Non-profit consumer advocate organization.

<http://www.afoofa.org/> All For One-One For All Foundation assists financially burdened families who cannot afford the burial expenses for their child.

<http://www.dreamcometrue.org> Dream Come True: wish-granting anywhere in the US. Also includes services for scholarships and funeral arrangements for children who previously received a wish.

Grief Support for Parents and Families

<http://compassionatefriends.org> National organization with hundreds of local chapters provides support to families who have lost a child.

www.missfoundation.org Mothers In Sympathy and Support; support for families after the death of an infant or young child.

<http://www.rowantreefoundation.org/> Rowan Tree Foundation, helping families heal after the loss of a precious child. EXCELLENT articles!

www.ekrfoundation.org The Elisabeth Kubler-Ross Foundation.

http://compassionatefriends.org/resources/ways_you_can_help.aspx

<http://www.missfoundation.org/pro/articles/effective.html> The Do's and Don't's of Grief Support.

Grief Support for Siblings

http://compassionatefriends.org/resources/grief_support_for_siblings.aspx

www.missfoundation.org/kids/pdf/kaleidoscope.pdf _Journal/coloring book for grieving kids.

www.hellogrief.org resources for grieving children and their families.

www.comfortzonecamp.org weekend retreats (free) for grieving children.

www.childrensroom.org The Children's Room offers hope and quality of life to bereaved children and those who are part of their lives. In this safe and caring environment, children, teenagers, and their families can receive the support they need while grieving the death of a loved one.

www.ekrfoundation.org/HelpingGrievingChildren.pdf

<http://www.dougy.org/grief-resources/help-for-kids/> Activities and articles to help support grieving children.

<http://counselingstlouis.net/> The Sibling Connection: Resources for anyone who has lost a brother or sister.