Caring for the Caregivers: From Brokenhearted to Belonging
by Cristol Barrett O’Loughlin | 6.23.23
Empathy.
A baby’s cry.
Triggers our capacity for...
YOU ARE WORTHY OF LOVE
Heal thyself first.
Life.
My parents are the strongest people I know.

Richard & Phyllis Barrett. Married 1963.  5 Children: Adam, Jared, Randy, David, Cristol
Barrett Family - Lost 3 Sons

Mucopolysaccharidosis
MPS II (Hunter Syndrome) claimed the life of my 3 older brothers.

Randy ~ passed away at 12 years old
David ~ passed away at 18 years old
Jared ~ passed away at 19 years old
Why me?
We are all born. We all live. We all pass on. The illusion is a life without suffering.
“Suffering sows the seeds of empathy.”

~Cristol Barrett O’Loughlin, Founder & CEO, ANGEL AID
Empathy Math
There are 0 cures.

7000 Types of Rare Diseases

RARE

Diseases Impact More People Than Cancer and AIDS Combined

350 Million People Suffer From a Rare Disease Globally (greater than the population of the U.S.)
Empathy Math

(350M patients) x 0 cures = Global Mental Health Crisis
An estimated **2.8B** patients, parents and professionals in deep emotional distress.
Raregivers™ often suffer from CTSD, not PTSD. ‘Chronic’ Traumatic Stress not ‘Post’.
- Cristol Barrett O’Loughlin, CEO ANGEL AID
Research.
Informational Support: education about the disease and referrals for medical care.

Tangible Support: practical things such as child-care or help with daily living tasks.
Informational Support: education about the disease and referrals for medical care.

Tangible Support: practical things such as child-care or help with daily living tasks.

Emotional Support: involves feeling validated and understood by others.

Companionship Support: engaging in activities with others, resulting in a sense of belonging.
Why Us?
ANGEL AID is a **global network** that provides **emotional support** and **personal connection** to patients, caregivers and professionals in **rare, chronic and complex** disease ~ individuals who feel isolated and overwhelmed ~ who now experience **daily** compassion and relief.

**Goal: Support 3.5 million Raregivers™ by 2026.**
Sustainable Relief.
Education & Training

**The Sustainable Mom**

A GUIDEBOOK FOR RARE MOTHERS

Building a Stronger Family Through Self Care

Laura Riordan, Ph.D.

Sponsored by ANGEL AID CARES, INC

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**Voice of the Rare Carrier**

JOIN US FOR A 6-PART WORKSHOP WHERE WE WILL:

MEET & BOND WITH OTHER RARE CARRIERS AS WE DISCUSS GENETIC TESTING, DATING, FAMILY PLANNING & MORE

ANGELAIDCARES.ORG
Weekly Support Groups

Join Our Online Community Of Rare Mothers

Australia Raregivers™ Support Group
Featuring Megan Loden

angelaidcares.org

angelaidcares.org
ORDER YOUR FREE
Trauma-Less Needle Pokes Kit
featuring The Buzzy

Who am I? by CREATIVE CAVE

A Graphic Novel Workshop
for Rare Young Adults

Sponsored By ANGEL AI & HORIZON

ANGELAIDCARES.ORG/MIGHTY-KITS
Virtual & In-Person Retreats

Find Relief with Meditation

A FREE Meditation Series Created Especially for Mothers of Children with Rare Disease

A Rare Weekend of Wellness

Orange County, CA

ANGELAIDCARES.ORG
Witness.
Raregivers
Emotional Journey Map

A cycle of hope and grief for caregivers, patients and professionals.

EVERY DAY STRESSORS

RELIEF

1. NOTICING CHANGES
   “Something isn’t right”
   Desire for diagnosis
   Engage Healthcare / Bureaucracy
   Lack of disease-specific info
   Fear, anxiety, shame, ‘Savior’

2. ADJUSTING +/− DIAGNOSIS
   Managing symptoms
   Learning about genetics
   Lack of treatment
   Complex care coordination
   Overwhelm, fatigue, ‘Hero’

3. SHIFTING RESPONSIBILITIES
   Role strain/identity change
   Learning about the disease
   Becoming the expert/advocate
   Need to learn nursing skills
   Resistance to role, ‘Expert’

4. FULL TIME CARE
   Costs of time off / Loss of income
   Relationship impact — siblings, spouse, family, friends, colleagues
   Need for seeking social support
   Isolation, insecurity, ‘Advocate’

5. END OF LIFE
   Acknowledgment
   Preparation / Bereavement
   Stages of Grief [denial, anger, bargaining, depression, acceptance], ‘Navigator’

6. SURVIVORSHIP
   Redefining identity
   Processing trauma / reflecting
   Exploring purpose / giving back
   Bitterness, enlightenment, recovery, empathy, ‘Angel’

ONGOING HEALTH & FINANCIAL NAVIGATION

SELF-CARE SKILL-BUILDING
Counseling / Therapy
Emotional Support
Social Connection
Physical Activity
Mindfulness
Nutrition
Nature
Sleep
#MentalHealthMattersGiveaway

Win $150 Amazon Gift Card!
(through June 30)
#MentalHealthMattersGiveaway

Visit, Share, Donate, Repost: [https://www.angelaidcares.org/mental-health-matters-giveaway](https://www.angelaidcares.org/mental-health-matters-giveaway)

**FOLLOW US ON OUR SOCIAL**
Follow us on Instagram @angelaidcares and tag 2 caregivers in our comments.

**REPOST OUR GIVEAWAY**
Repost about our giveaway on your Instagram or Facebook.

**JOIN OUR COMMUNITY**
Sign up for our weekly emails and support groups in the link below.

**DONATE IN HONOR OF A CAREGIVER**
If you would like honor a friend in our giveaway who is a caregiver, please donate in honor of their name.

**ENTER TO WIN**
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**ENTER TO WIN**
Be Seen.
Close your eyes...
Picture a Rainbow
Red
Symbolizes life, vitality, action and wealth. Emanating red reflects physical strength, love, courage and passion.

Orange
Reflects creativity, joy, youth, vibrancy, happiness, balance. Orange is a power color as it combines Red and Yellow.

Yellow
Naturally associated with life-giving energy of the sun. Yellow also symbolizes keen intellect and wisdom.

Green
Is the color of money and Mother Earth, representing the balance of wealth, well-being and nature.

Violet
A color of good judgement, preciousness and noble thought. A symbol of sacred energy.

Indigo
Implies infinity, spiritualism, grace and personal thought. Turns the blue inside for profound insight.

Blue
The hue of security, trust, compassion, stability. Blue promotes peace, calmness and relaxation.

Your Color?
Be Heard.
Use your five senses to ‘reframe’ daily rituals: micro-moments of each day centered around Touch, Taste, Sound, Smell, Sight
Touch
Ultra-Plush Comfort Blanket

LUXURIOUSLY SOFT MICROFIBER,
CREATE A COZY END OF DAY RITUAL

http://angelaidcares.org/products
Taste
Turquoise River Tea
Herbs and flowers to aid, repair and ignite healing from the inside out.
https://www.wildflowerapothecary.com/
Sound
Padma Gordon

Quiet the mind and open the heart with Padma's embodied audio via @angelaidcares on YouTube. www.padmagordon.com
Doterra Essential Oils
Aromatherapeutic experiences with certified organic essential oils.
https://www.angelaidcares.org/products
Sight
“Armed With Love”
Heart-centered designs as a symbol of strength and connectedness
https://www.angelaidcares.org/products
Relief.
Formula for Sustainable Self Care
Breathe + Rainbow + 5 Senses= YOU
Visit angelaidcares.org
Click ‘Join Our Community’

General: info@angelaidcares.org
Programs: grants@angelaidcares.org

@angelaidcares
[Facebook/Twitter/Instagram]

Linkedin: Cristol O’Loughlin
Linkedin: ANGEL AID
Ways to connect and continue learning...

- Visit angelaidcares.org/events to
  - Join Our Community of #Raregivers
  - Register for Weekly Support Groups: Tuesdays & Thursdays @ 10am PST
  - Subscribe to our newsletter

- Follow @AngelAidCares on Facebook, Instagram, Twitter and Linkedin

- Join Raregivers Coalition™ at Raregivers.global
Raregivers Emotional Journey Map

A cycle of hope and grief for caregivers, patients and professionals.

1. NOTICING CHANGES
   - "Something isn't right"
   - Desire for diagnosis
   - Engage Healthcare/ Bureaucracy
   - Lack of disease-specific info
   - Fear, anxiety, shame, 'Savior'

2. ADJUSTING +/- DIAGNOSIS
   - Managing symptoms
   - Learning about genetics
   - Lack of treatment
   - Complex care coordination
   - Overwhelm, fatigue, 'Hero'

3. SHIFTING RESPONSIBILITIES
   - Role strain/identity change
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   - Becoming the expert/advocate
   - Need to learn nursing skills
   - Resistance to role, 'Expert'

4. FULL TIME CARE
   - Costs of time off/Loss of income
   - Relationship impact—siblings, spouse, family, friends, colleagues
   - Need for/seeking social support
   - Isolation, insecurity, 'Advocate'

5. END OF LIFE
   - Acknowledgment
   - Preparation / Bereavement
   - Stages of Grief [denial, anger, bargaining, depression, acceptance], "Navigator"

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   - Redefining identity
   - Processing trauma/reflecting
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Social Connection
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Nutrition
Nature
Sleep

www.raregivers.global