

Caring for the Caregivers:  
From Brokenhearted to Belonging  
by Cristol Barrett O'Loughlin | 6.23.23

Raregivers<sup>™</sup> by



Empathy.

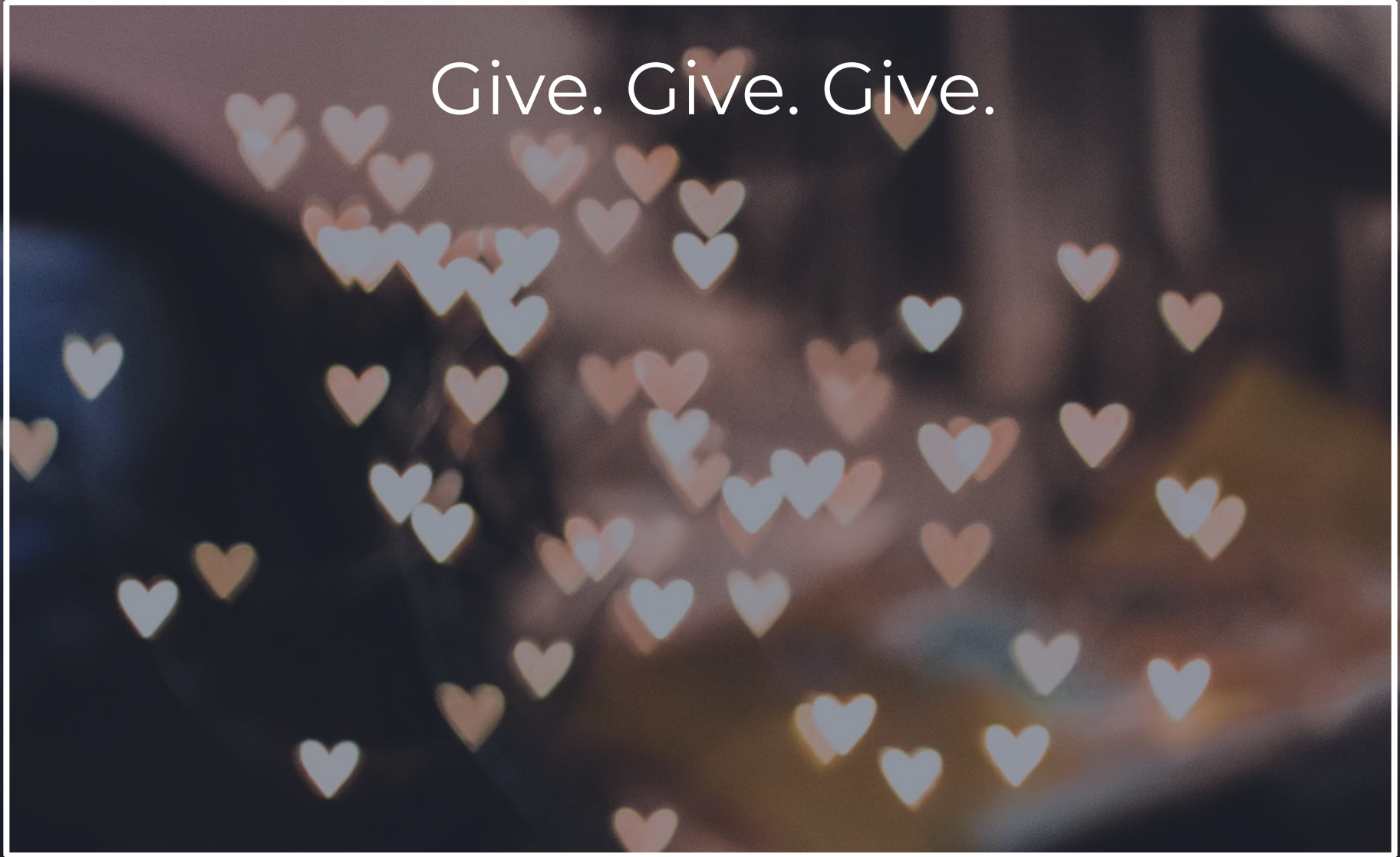
A baby's cry.



Triggers our capacity for...




Give. Give. Give.



Empathy. Makes us human.



A photograph of a white rectangular sign with bold black text, mounted on a weathered wooden utility post. The sign is positioned outdoors, next to a paved path and some green foliage. The background is softly blurred, showing more trees and a path. The entire image is framed by a thin white border.

**YOU ARE  
WORTHY  
OF LOVE**

Breathe



A woman with long, dark, curly hair is shown from the chest up, wearing a light-colored, off-the-shoulder top. Her eyes are closed, and she has a serene expression, looking slightly upwards. The background is a soft-focus forest scene with green and brown leaves, and several leaves are captured in motion, falling around her. The overall mood is peaceful and contemplative.

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.

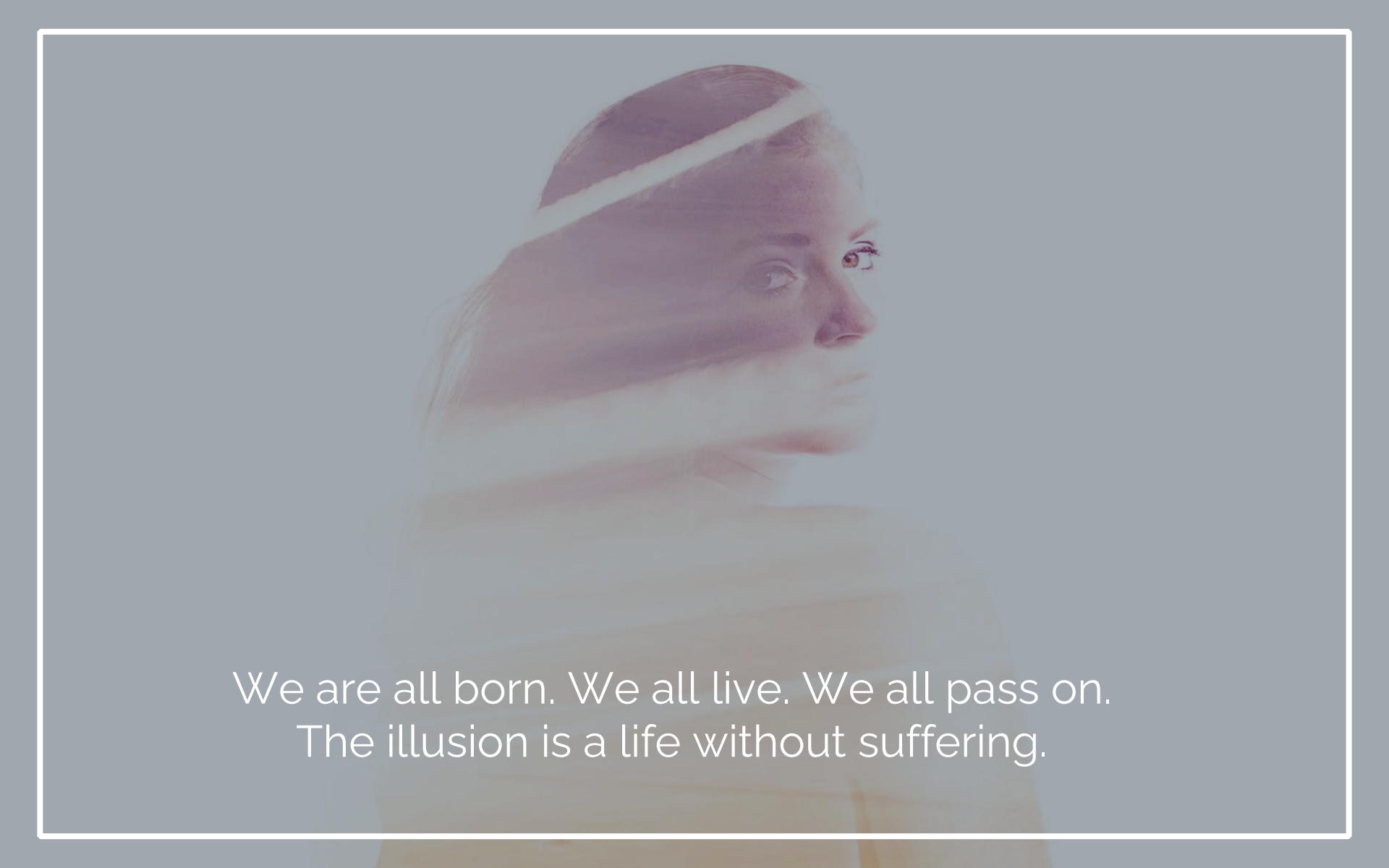


David, Jared & Randy Barrett


Randy ~ passed away at 12 years old  
David ~ passed away at 18 years old  
Jared ~ passed away at 19 years old

Why me?



A woman is shown from the chest up, wrapped in white bandages that cover her face and body. She is looking towards the right of the frame with a neutral expression. The background is a solid, light blue-grey color. The entire image is enclosed within a thin white border.

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 8.





ANGEL AID

**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.)

There are **0** cures.

Empathy Math 8

(350M patients)

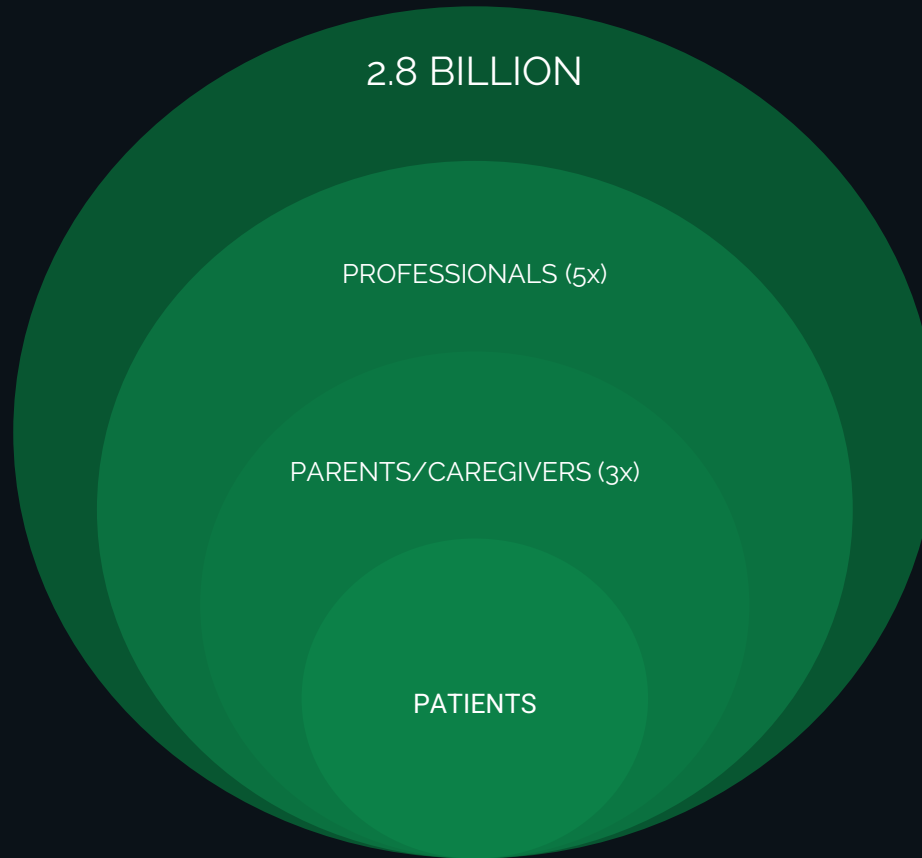
x

0 cures

=

*Global Mental Health Crisis*

An estimated 2.8B patients, parents and professionals  
in deep emotional distress.



Raregivers™ by



Raregivers™ often suffer from CTSD, not PTSD.  
'Chronic' Traumatic Stress not 'Post'.

*- Cristol Barrett O'Loughlin, CEO ANGEL AID*



Research.

# Psychology Today

An iceberg floating in a blue ocean under a blue sky. The tip of the iceberg is above the water, and the much larger base is submerged below the surface. A vertical white line divides the image into two halves, corresponding to the two columns of text.

## 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.*

# Psychology Today

## 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

  
ANGEL AID

## 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

 ANGELAIDCARES.ORG

# 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





# Weekly Support Groups

JOIN OUR ONLINE COMMUNITY OF  
RARE MOTHERS



 ANGELAIDCARES.ORG



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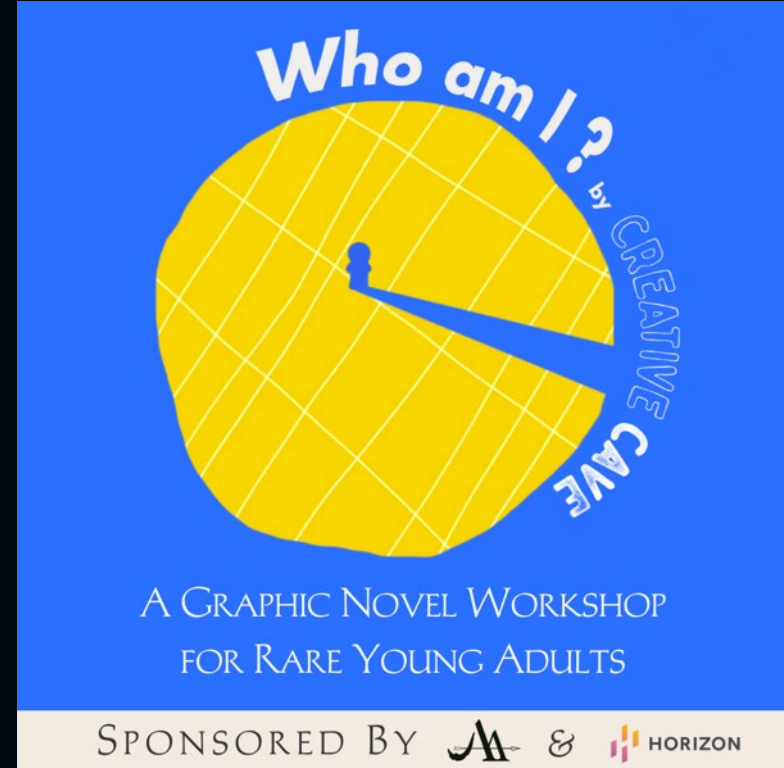


# Young Adult Patient Programs

ORDER YOUR FREE  
TRAUMA-LESS NEEDLE POKES KIT  
FEATURING THE BUZZY





 [ANGELAIDCARES.ORG/MIGHTY-KITS](https://www.angelaidcares.org/mighty-kits)



Who am I?  
by CREATIVE CAVE

A GRAPHIC NOVEL WORKSHOP  
FOR RARE YOUNG ADULTS

SPONSORED BY  &  HORIZON



# Virtual & In-Person Retreats


FIND RELIEF WITH MEDITATION



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

 ANGELAIDCARES.ORG



 ANGELAIDCARES.ORG

Witness.



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



IONIS



The Ehlers Danlos Society



#MentalHealthMattersGiveaway

*Win \$150 Amazon Gift Card!*  
*(through June 30)*



# #MentalHealthMattersGiveaway

Visit, Share, Donate, Repost: <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.

ENTER TO WIN



## REPOST OUR GIVEAWAY

Repost about our giveaway on your instagram or facebook.

ENTER TO WIN



## JOIN OUR COMMUNITY

Sign up for our weekly emails and support groups in the link below.

ENTER TO WIN



## 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

Be Seen.



Close your eyes...



Picture a Rainbow



## Red

Symbolizes life, vitality, action and wealth. Emanating red reflects physical strength, love, courage and passion.



## 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.



## 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.



## Blue

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

Your  
Cdr?

Share





Be Heard.



Use your five senses to 'reframe' daily rituals:  
micro-moments of each day centered around  
Touch, Taste, Sound, Smell, Sight

# Hammam

A woman is shown in profile, relaxing in a hammam. She has her eyes closed and a serene expression, looking upwards. Her right leg is extended, and her foot is resting on a chrome faucet. Water is flowing from the faucet onto her foot. The background is dark and slightly out of focus, showing the interior of the hammam with stone walls and some fixtures. The overall mood is peaceful and relaxing.

A close-up photograph of two hands clasped together on a beach at sunset. The word "Touch" is overlaid in white text. The background shows the ocean waves and a sandy beach under a warm, golden light. The hands are the central focus, with one hand resting on top of the other. The overall mood is intimate and peaceful.

**Touch**



*Ultra-Plush Comfort Blanket*

LUXURIOUSLY SOFT MICROFIBER,  
CREATE A COZY END OF DAY RITUAL

<http://angelaidcares.org/products>



A white ceramic cup filled with coffee and latte art, sitting on a matching saucer. A silver spoon is placed on the saucer. The background is a dark, textured surface, possibly wood. The word "Taste" is overlaid in white text on the cup.

**Taste**



WILDFLOWER  
APOTHECARY



## Turquoise River Tea

Herbs and flowers to aid, repair and  
ignite healing from the inside out.

<https://www.wildflowerapothecary.com/>



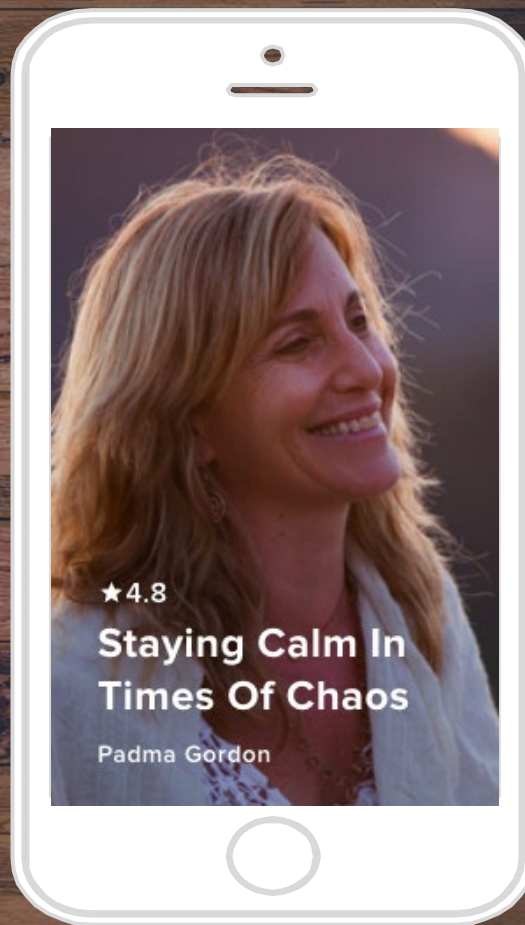
Sound





## Padma Gordon

Quiet the mind and open the heart with  
Padma's embodied audio via  
@angelaidcares on YouTube.  
[www.padmagordon.com](http://www.padmagordon.com)



A close-up photograph of a hand holding a small, clear glass bottle. A single drop of liquid is falling from the bottle's opening. The background is dark and out of focus. The word "Smell" is overlaid in white text in the lower center of the image.

**Smell**



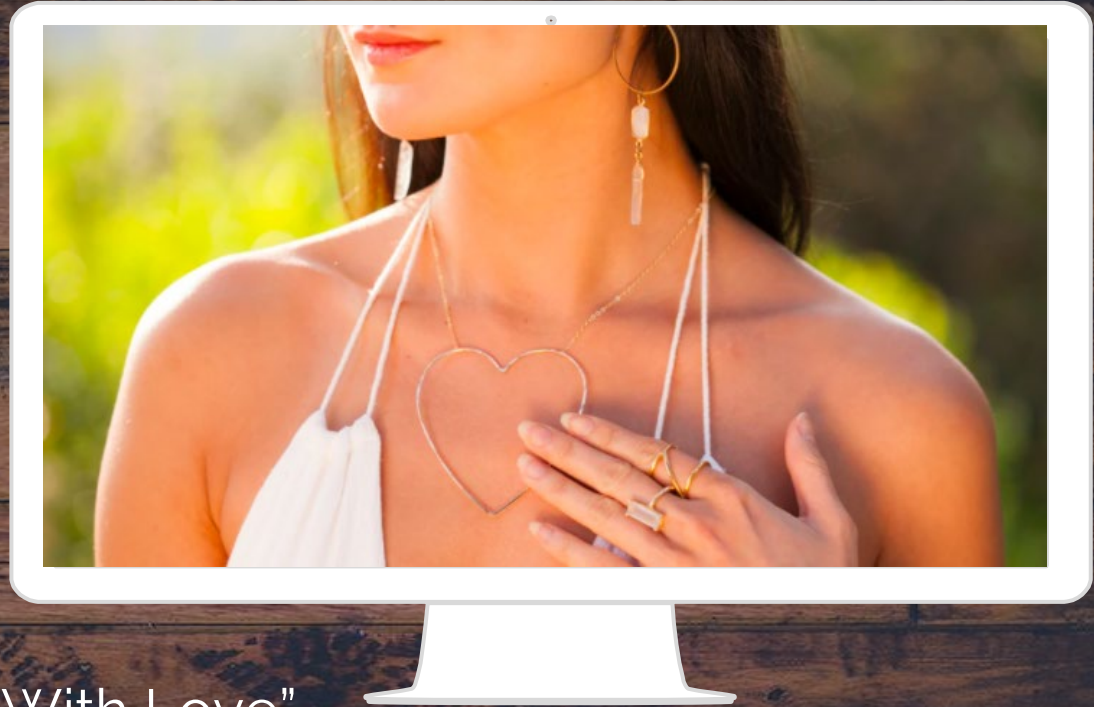
Doterra Essential Oils  
Aromatherapeutic experiences with  
certified organic essential oils.  
<https://www.angelaidcares.org/products>



A close-up, dramatic portrait of Wonder Woman. She is looking directly at the camera with a serious, intense expression. Her face is partially framed by her golden, intricately detailed armor, which includes a tiara with a star emblem on her forehead and gauntlets on her hands. The lighting is moody, with a strong blue and purple gradient on the right side of the frame, contrasting with the warmer tones of her skin and armor. The word "Sight" is written in a clean, white, sans-serif font across the lower center of the image.

**Sight**

# COLLECTIVE HEARTS



“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



Richard & Phyllis Barrett. Married 1963.





Richard & Phyllis Barrett. Married Again – 60 Years Later. (2023)



Cristol O'Loughlin

**TEDx**

*Caring for the Caregivers*

Share the Video!  
[angelaidcares.org/tedx](https://angelaidcares.org/tedx)



ANGEL AID

Visit [angelaidcares.org](https://angelaidcares.org)  
Click 'Join Our Community'

General: [info@angelaidcares.org](mailto:info@angelaidcares.org)

Programs: [grants@angelaidcares.org](mailto:grants@angelaidcares.org)

[@angelaidcares](#)

[Facebook/Twitter/Instagram]

Linkedin: [Cristol O'Loughlin](#)

Linkedin: [ANGEL AID](#)

# Ways to connect and continue learning...



- Visit [angelaidcares.org/events](https://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](https://www.raregivers.global)



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



The Ehlers Danlos Society