



# *Krabbe Connect*

*Caring for the Caregivers:  
Sensory Self-Care in Micro-Moments Per Day*

[5.3.21]

# INTRODUCTION



**Cristol Barrett O'Loughlin**  
**Founder & CEO, ANGEL AID CARES**



*Note: Each suggestion in this presentation is backed by evidence-based research, but these are recommendations only and may need to be modified to work best for your specific medical situation. Any products, medical or otherwise mentioned or shared as part of this presentation should be vetted by your medical team. We may offer or recommend products for sale, but this education is not predicated on their purchase. This is not medical advice and all steps you take should be reviewed with your medical provider to ensure they are appropriate and safe for you and/or your patient.*



## AGENDA

1. *Grin and Barrett: A Rare Love Story*
2. 1st tool for Sustainable Self-Care
  - Breath
3. Caregiver CTSD
4. 2nd tool for Sustainable Self-Care
  - Rainbow
5. *5 More Tools for Sensory Self-Care: In Micro-Moments A Day*
  - Daily Rituals ~ Taste, Touch, Sound, Smell & Sight
6. 5 min Q&A



*My parents are the strongest people I know.*



*Richard & Phyllis Barrett circa 1964*



*Five kids: Richard Adam, Jared, Randy, David, Cristol*



*They did their very best with the resources and options available.*



**David, Jared & Randy Barrett**

*[Divorced in 1975]*



*Randy (passed away at 12)  
David (passed away at 18)  
Jared (passed away at 19)*


*The boys were always together.*



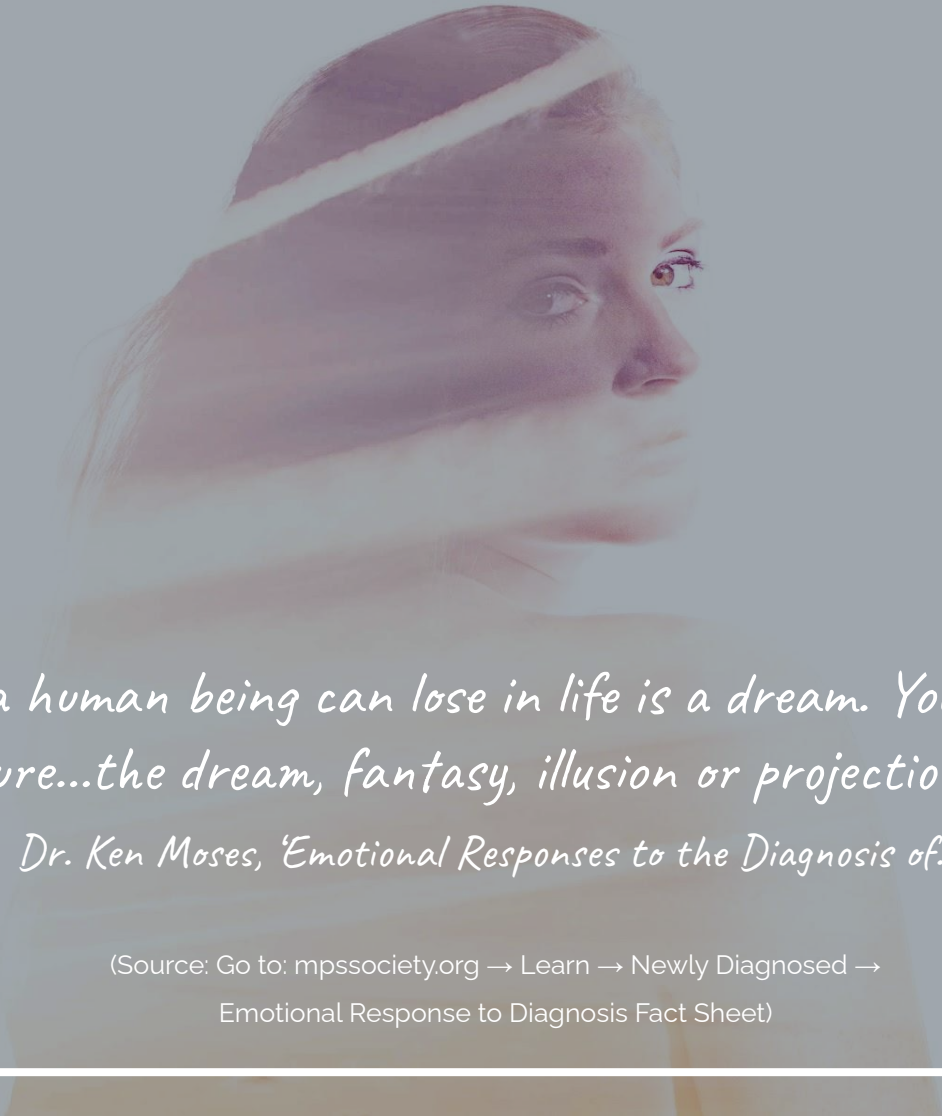
*Why me?*







*"Suffering sows the  
seeds of Empathy."  
-Cristol Barrett  
O'Loughlin*

A woman with long brown hair and a white headband is shown in profile, looking towards the right. She has a thoughtful expression. The background is a soft, out-of-focus grey.

*“The only thing a human being can lose in life is a dream. You don’t lose the past, only the future...the dream, fantasy, illusion or projection of the future.”*

*- Dr. Ken Moses, ‘Emotional Responses to the Diagnosis of...’*

(Source: Go to: [mpssociety.org](http://mpssociety.org) → Learn → Newly Diagnosed →  
Emotional Response to Diagnosis Fact Sheet)



Cristol - Chloe - Phyllis  
*Three Generations of MPS Carriers*

=



ANGEL AID

Founded in 2000  
*20th Anniversary*



“It is not unworthy,  
but it is very uncomfortable -  
to ask for help.”

- Sarah Chisholm, Rare Mother



*Self-Care.*



*Triggers our capacity for...*

LOVE





*"There are so many hearts to heal."*


*- Lynn Hopkins, MPS SuperMom*



*Empathy. Makes us human.*







**YOU ARE  
WORTHY  
OF LOVE**



Breathe

A woman with dark, curly hair and her eyes closed, looking upwards. She is wearing a light-colored, off-the-shoulder top. The background is a blurred forest with green and brown leaves, and several leaves are falling around her. The text "Heal thyself first." is written in a white, cursive font across the middle of the image.

*Heal thyself first.*



A light brown dog, possibly a pit bull mix, is standing on its hind legs and reaching up with its front paws. The dog is looking upwards and to the left. It is wearing a dark collar with a red tag. The background is a plain white wall with some peeling paint at the bottom. The floor is made of light-colored tiles.

# How?



*There is a clear path.*

**SUSTAIN  
ABLE**

**SELF**

**CARE**







*"You are stronger than you seem."*  
*- Winnie the Pooh*





*Enter Breast Cancer = Patient Point-of-View.*



4.5 Years Cancer Free...  
[Oct 4, 2016]



..with help from Friends, Family + UCLA Pi Beta Phi's





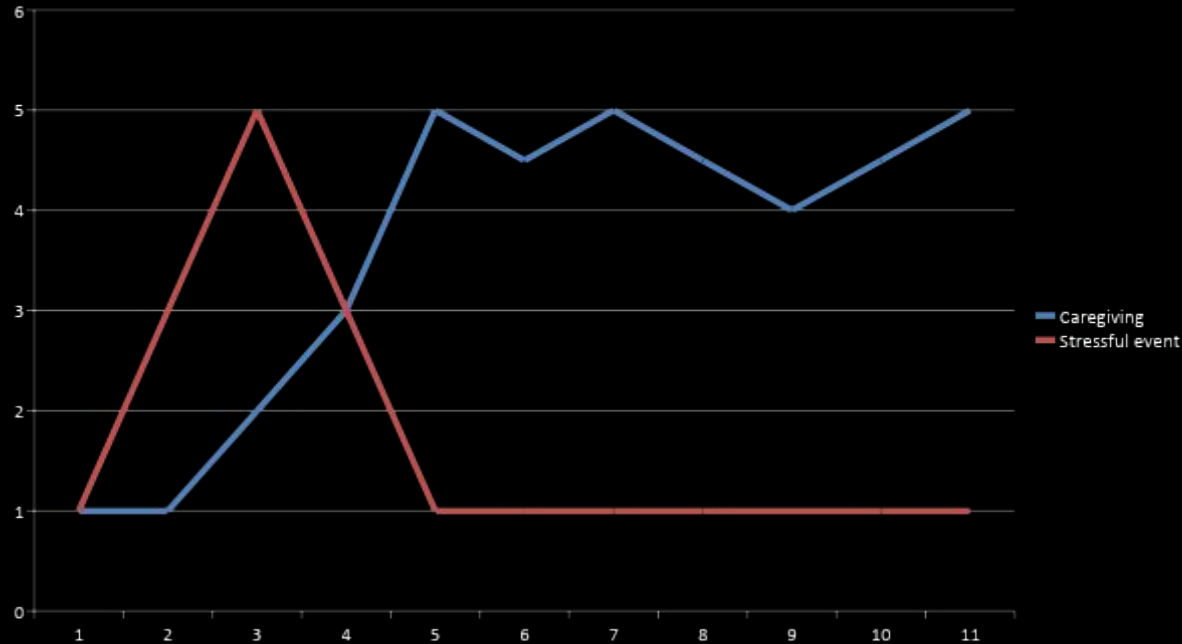
*Every life is about finding Balance.*



*The Rare Disease community suffers from CTSD, not PTSD.  
'Chronic' Traumatic Stress not 'Post'.*



# Chronic caregiving stress vs. a stressful event



**Chronic stress = Anticipation and Rumination**

© Dr. Elissa Epel, UCSF author of *The Telomere Effect*





# Four Definitions of “Support”

## **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.*

**Psychology Today**



INDIANA UNIVERSITY  
SCHOOL OF SOCIAL WORK



“ON A SCALE OF 1-10, HOW  
SUPPORTED DO YOU FEEL?”

1 = hardly supported at all, 10 = extremely supported



# 24/7 Crisis Text Line & (800)- Suicide Prevention Line



[About](#) [Resources](#) [Research](#) [News](#) [Events](#) [TEDX](#) [Contact](#)

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## CRISIS SUPPORT

### RARE DISEASE HELP LINES

Help lines in different countries that gives support and contact information for rare diseases. The help lines offer social, psychological and information solutions to rare caregivers.

## NEED HELP NOW ?

**For immediate help:** Call the National Suicide Prevention Lifeline at [1-800-273-8255](tel:1-800-273-8255).

OR text [SIGNS to 741741](#) for the Crisis Text Line.

Both services are free and available 24/7.



INDIANA UNIVERSITY

SCHOOL OF SOCIAL WORK

Phase 1: US Caregivers  
Phase 2: Global Caregivers

**Connection:** *"A listening ear without judgement."*

**Storytelling:** *"I want to hear stories that are similar to mine. I need to know I'm not crazy!"*

**Self-Care:** *"I just need time to help me do a little for myself."*

*Researchers:*

*Jennifer Ghidinelli, Yeji Jang, Janet Miodragovic*





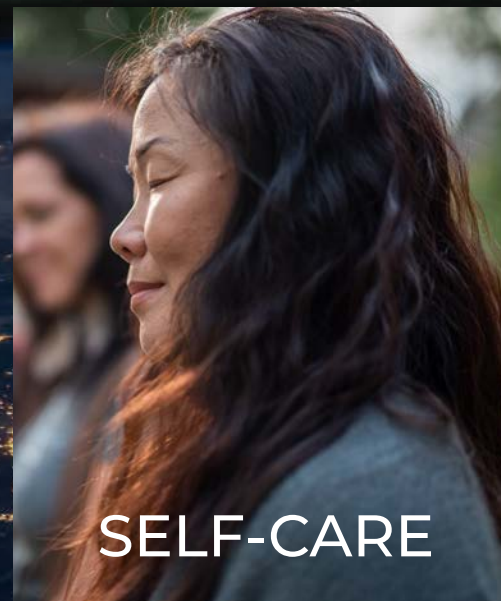
ANGEL AID



CONNECTION



STORYTELLING



SELF-CARE

[ANGELAIDCARES.ORG](https://ANGELAIDCARES.ORG)

Relaunched 2018 ~ [angelaidcares.org](https://angelaidcares.org)



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## RELIEF FOR MOTHERS WHO NEED IT MOST

Connect with other Rare Mothers, learn the tools of self-care, and be listened to without judgement

[JOIN OUR COMMUNITY](#)





Our beliefs...





1 + 1 = YOU

*...a formula for Sustainable Self Care*







*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  
Color?*

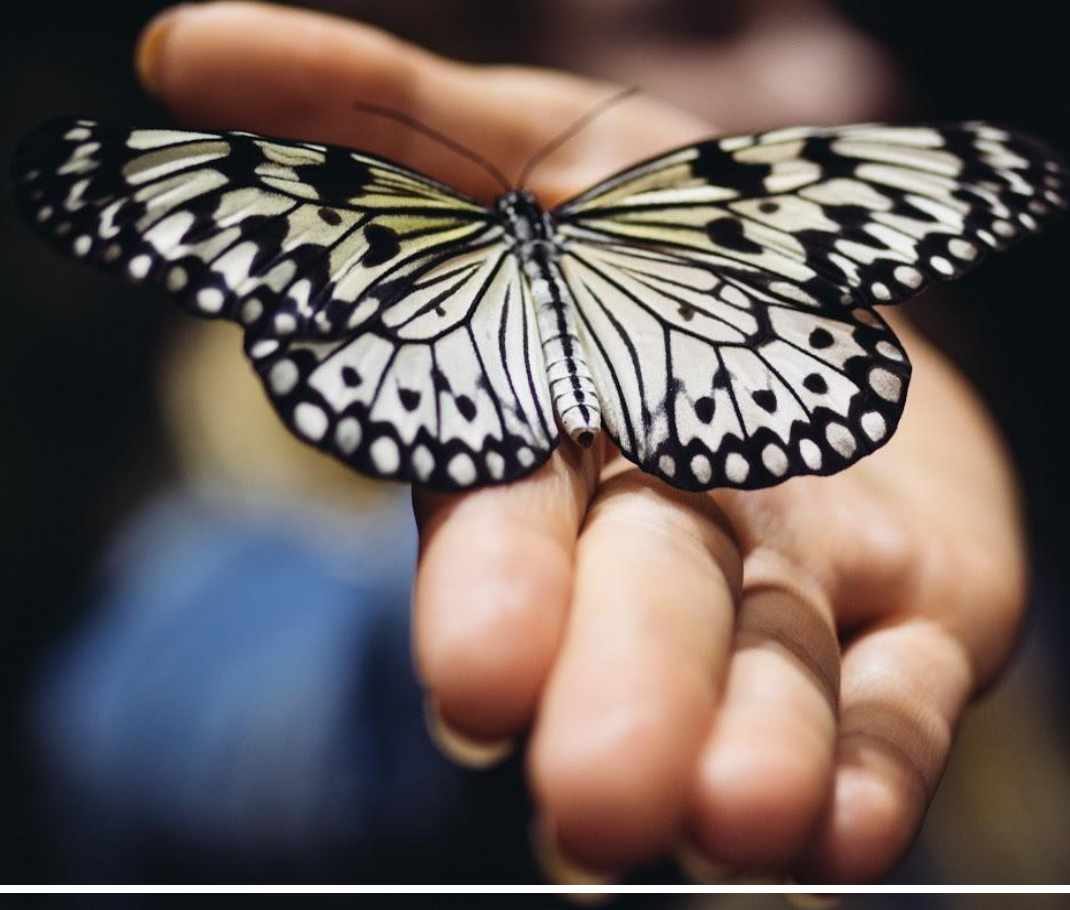


# Share





*Formula for Sustainable Self Care*  
*Breathe + Rainbow= YOU*





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





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 and a distant landmass under a warm, golden light.

Touch





Wrap Up by VP

*Pearl Maximum Robe*

LUXURIOUSLY SOFT MICROFIBER,  
CREATE A COZY END OF DAY RITUAL

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



A photograph of a white ceramic cup filled with coffee, featuring a heart-shaped latte art design on the surface. The cup sits on a matching white saucer, which also holds a silver spoon. The entire set is placed on a dark, textured wooden surface. The lighting is soft, creating a warm and inviting atmosphere.

**Taste**





WILDFLOWER  
APOTHECARY



### *Turquoise River Tea*

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

<http://wildflowerapothecary.com>



A person with long brown hair, wearing a light-colored cardigan over a collared shirt, is playing a violin. The violin is a warm, reddish-brown color. The person's hands are positioned to play, with the bow held in the right hand and the violin in the left. The background is blurred, suggesting an outdoor setting. The word "Sound" is overlaid in white text at the bottom center.

# Sound

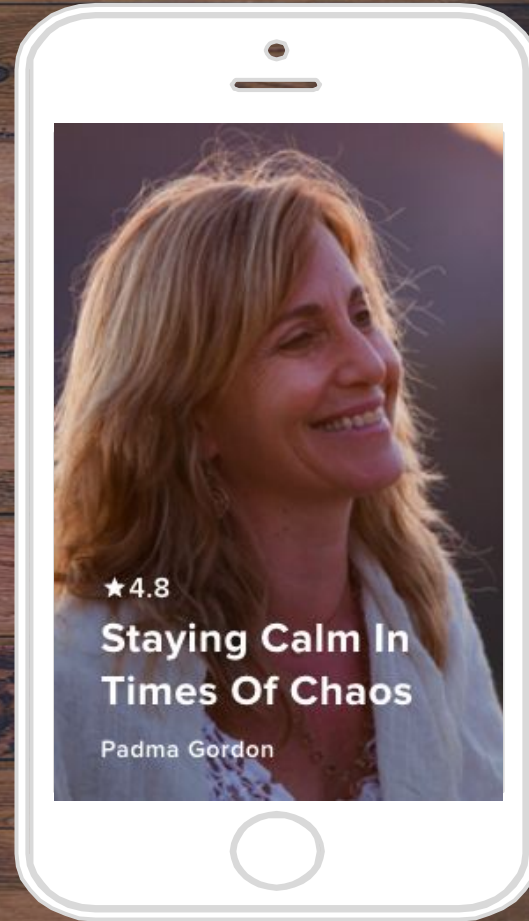




*Padma Gordon*

Quiet the mind and open the heart with  
Padma's embodied audio Insight Timer  
- the world's most use Meditation App.

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



A close-up photograph of a person's hands. The right hand is holding a small, clear glass bottle tilted downwards, with a single drop of liquid falling from its opening. The left hand is positioned below the bottle, palm up, to catch the drop. The background is dark and out of focus. The word "Smell" is overlaid in white text on the left hand.

Smell





## *Essential Oils*

Aromatherapeutic experiences with  
certified organic essential oils.

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

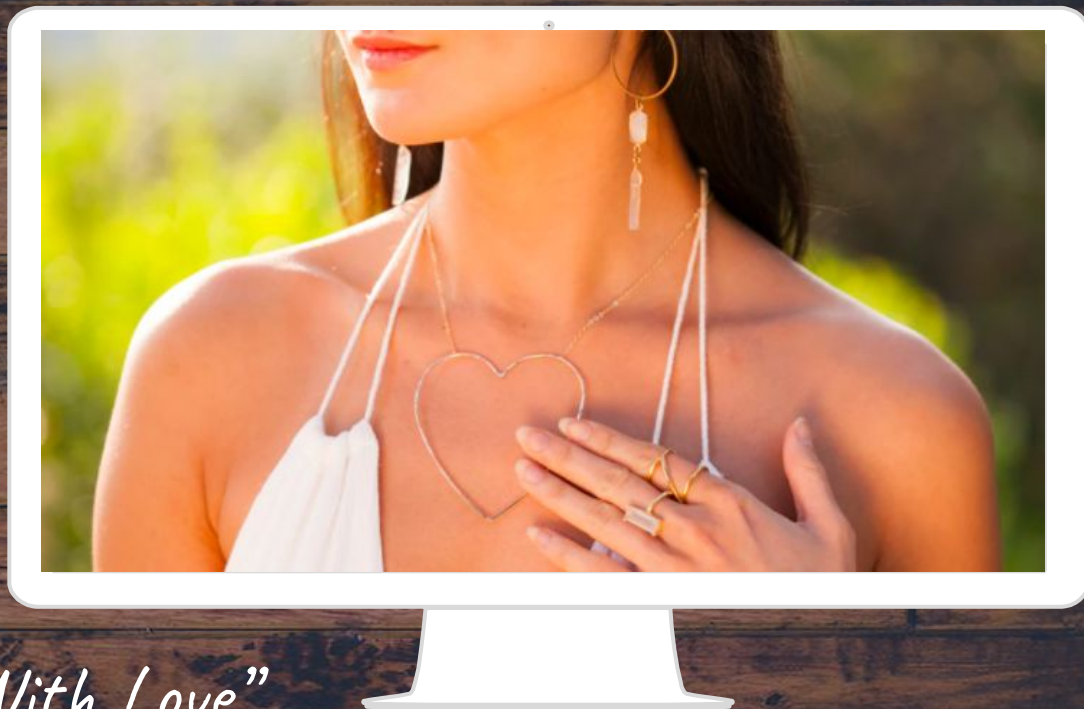


A close-up, cinematic shot of Wonder Woman. She is looking directly at the camera with a determined, intense expression. Her face is partially obscured by her golden gauntlets, which are held up in front of her. The lighting is dramatic, with a strong blue and purple hue on the right side of the frame and a warmer, reddish-orange glow on the left. The background is dark and out of focus.

Sight



COLLECTIVE  
HEARTS



*“Armed With Love”*

Heart-centered designs as a symbol  
of strength and connectedness

<http://collectivehearts.co>



*Empathy starts with you...*

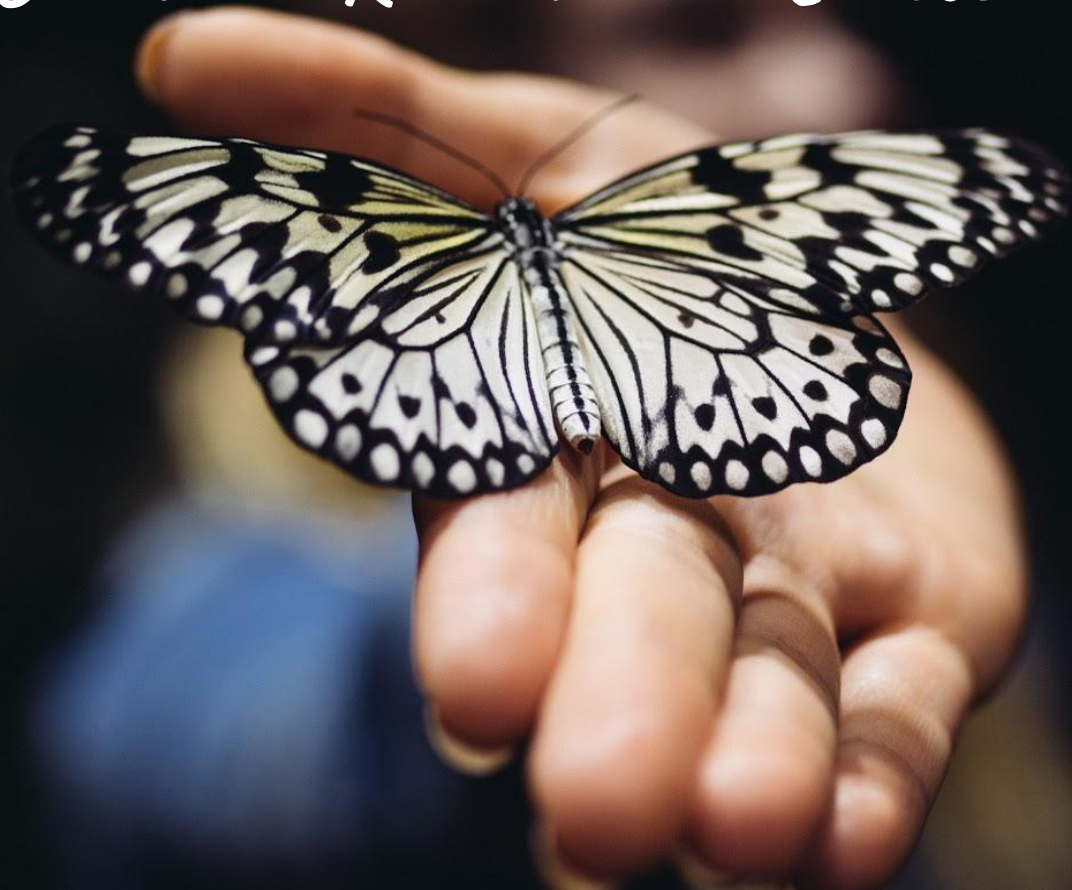
**SUSTAIN  
ABLE**

**SELF**

**CARE**



*Formula for Sustainable Self Care*  
*Breathe + Rainbow + 5 Senses= YOU*





*Daily Rituals =  
Micro-Moments  
Per Day*



*Love*



*Richard & Phyllis Barrett*



# *Love and Empathy.*



*Richard & Phyllis Barrett ~ Together Again (after 35 years apart).*



# *Life Full Circle: Advocacy, Fundraising, Research*



## 5 Minute Q&A



- Join Our Community of #RareMothers  
[raremothers.org](https://raremothers.org)

- Rare Mothers Wellness Retreat  
[\*Fall 2021\*](#)

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

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Cristol O'Loughlin

**TEDx**

*Caring for the Caregivers*

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



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