

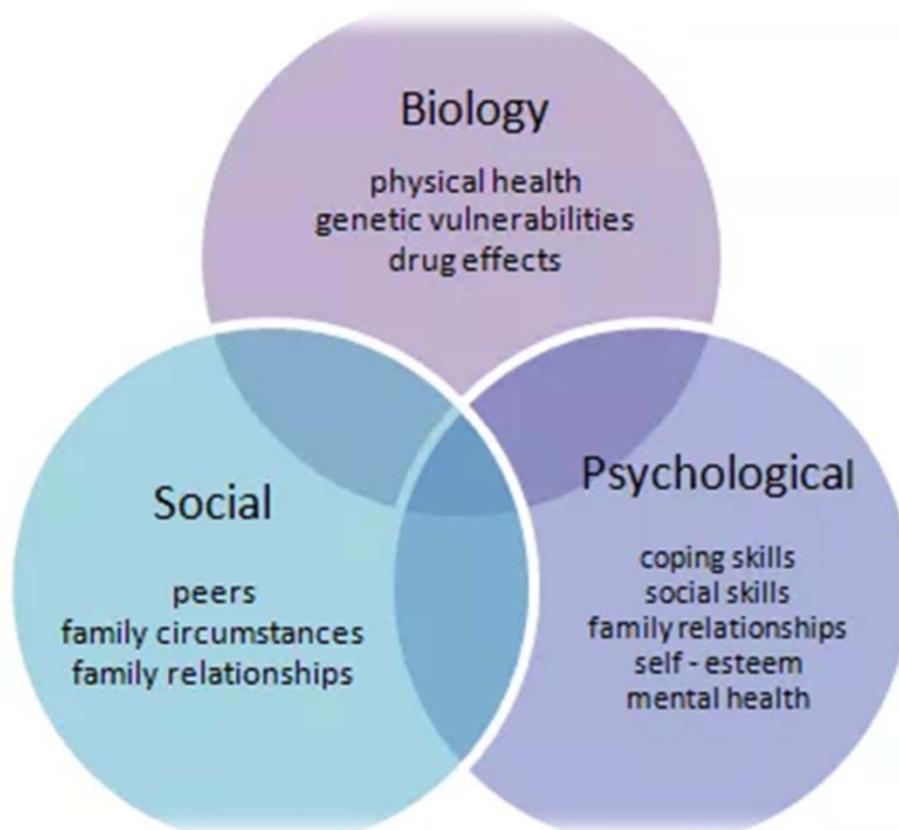


Living with Cystinosis and Meeting Your Mental Health Needs: What does it mean to “get help”?

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How do health and mental health fit together?



What is "Health"?



What does it mean to be healthy with a chronic health condition?



What is "Mental Health"?



What is "Wellness"?



What does it mean to "get help?"

Stress and Coping

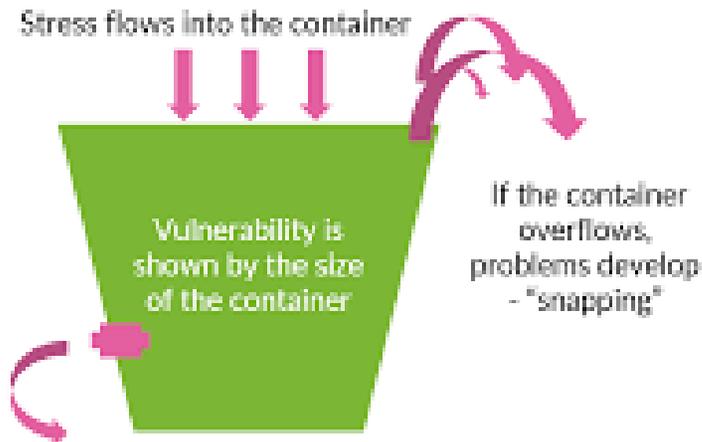


Stress as balance or imbalance



Stress is your alarm system!
Stress actually helps you survive,
if you listen to the signals.

What's in your Stress Container?



Helpful coping strategies = tap working lets the stress out
Unhelpful coping strategies = tap blocked so water fills up and overflows

(Source: [Babbies & Turkington, 2009](#))

How do we cope?

Types of support

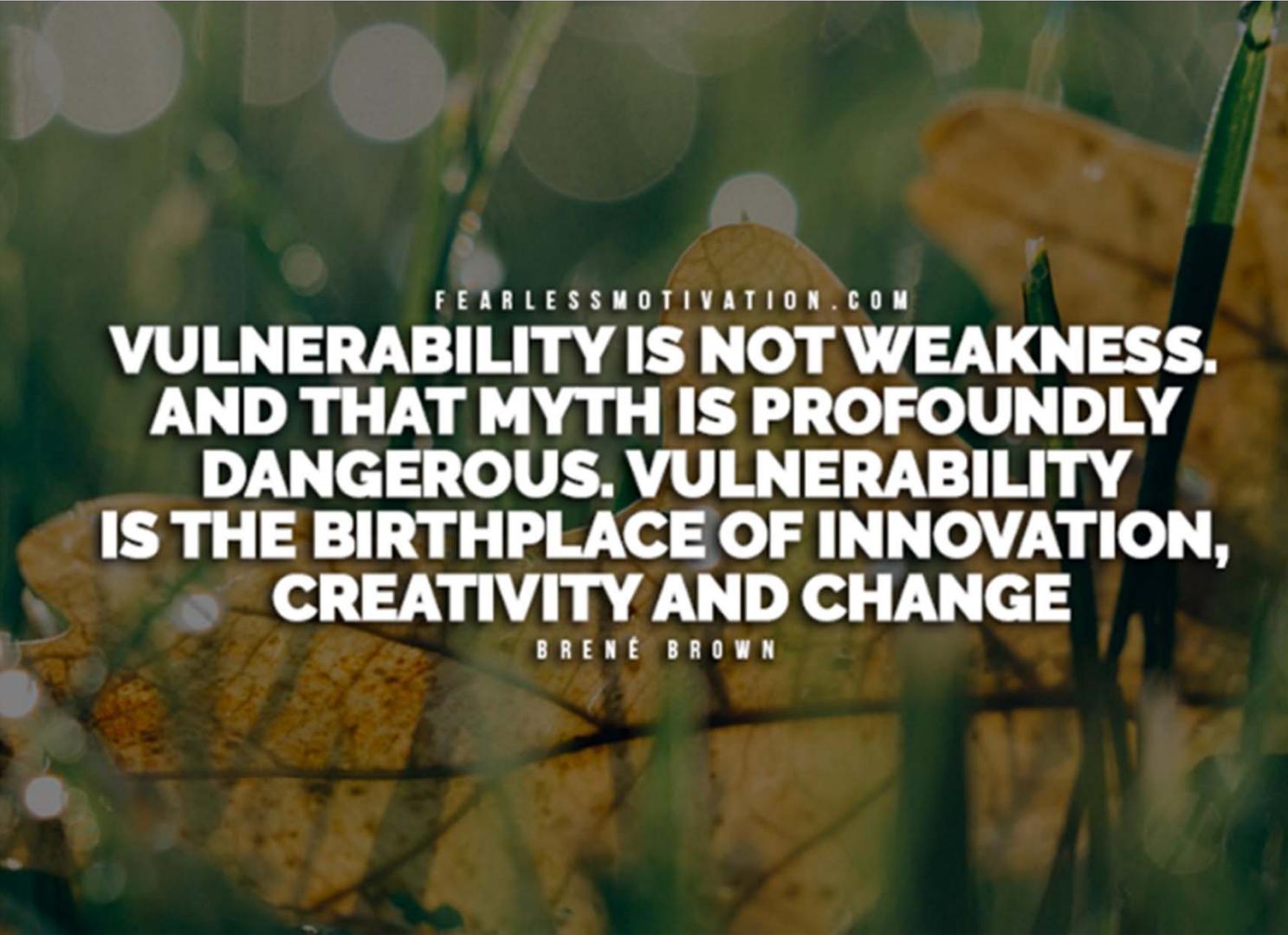


- ▶ Self-help and self-care
- ▶ Peer support, friends, family & community
 - ▶ In-person
 - ▶ Online
- ▶ Professional support





Don't let shame or embarrassment stop you from getting the support you need or want.



FEARLESSMOTIVATION.COM

**VULNERABILITY IS NOT WEAKNESS.
AND THAT MYTH IS PROFOUNDLY
DANGEROUS. VULNERABILITY
IS THE BIRTHPLACE OF INNOVATION,
CREATIVITY AND CHANGE**

BRENÉ BROWN



You are imperfect,
you are wired for struggle,
but you are worthy
of love and belonging.

– Brené Brown

aimhappy.com

Reasons for referral for “Professional Help”

- ▶ Depression
- ▶ Anxiety
- ▶ “adjustment”
- ▶ Grief
- ▶ Family/parenting issues
- ▶ School issues
- ▶ Attention Problems/Hyperactivity
- ▶ Behavior and social-emotional regulation
- ▶ Substance/Alcohol use or concerns
- ▶ Other “behaviors” (adherence to medical regimen?)
- ▶ Suicidality/Crisis
- ▶ Post-traumatic Stress (veterans, violence, etc. AND related to medical experience)
- ▶ Chronic MH diagnoses - schizophrenia, bipolar disorder, major depression, anxiety disorders, phobia etc - need for ongoing management/treatment/meds

Professional Helpers

- ▶ Marriage and Family Therapist
- ▶ Counselor
- ▶ Certified Addiction (or Recovery) Specialist
 - Social Workers – school, hospital, mental health setting
 - More than 75% of all mental health services are provided by master level clinical social workers in the US.
- ▶ Clinical Psychologist
- ▶ School Psychologist – testing and IEPs, some intervention
- ▶ Psychiatrist – MDs who can diagnose and prescribe meds, some talk therapy
- ▶ Agencies or Private Practice

Screening for anxiety and depression

- ▶ Screening, Brief Intervention, Treatment (SBIRT) becoming more common in healthcare settings and schools

Patient Health Questionnaire (PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems?

Little interest or pleasure in doing things	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input checked="" type="radio"/> N/A
Feeling down, depressed, or hopeless	<input type="radio"/> 0	<input checked="" type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Trouble falling or staying asleep, or sleeping too much	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Feeling tired or having little energy	<input checked="" type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Poor appetite or overeating	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Feeling bad about yourself	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Trouble concentrating on things	<input checked="" type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> N/A
Moving or speaking so slowly or the opposite	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input checked="" type="radio"/> N/A
Thoughts that you would be better off dead	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input checked="" type="radio"/> N/A

.....

OK Cancel

GAD-7 - Generalized Anxiety Disorder Scale

Over the last two weeks, how often have you been bothered by the following problems?

	Not at all	Several days	Over half the days	Nearly every day
Feeling nervous, anxious, or on edge	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3
Not being able to stop or control worrying	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3
Worrying too much about different things	<input type="radio"/> 0	<input checked="" type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
Trouble relaxing	<input type="radio"/> 0	<input type="radio"/> 1	<input checked="" type="radio"/> 2	<input type="radio"/> 3
Being so restless that it's hard to sit still	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input checked="" type="radio"/> 3
Becoming easily annoyed or irritable	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 2	<input checked="" type="radio"/> 3
Feeling afraid as if something awful might happen	<input type="radio"/> 0	<input checked="" type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3

How difficult have those problems made it for you to do your work, take care of things at home, or get along with other people?

Somewhat difficult

Score: 14
Difficulty Level: Somewhat difficult
Severity Level: Moderate Anxiety

Add to Chart

PHQ-9 and GAD-7

Depression is shame
and pain from the past.

Anxiety is fear
for the future.



The NOW
is that perfect space
in between

Making Change

...and learning to do things differently

▶ Motivational

Interviewing and

Stages of Change

▶ The 12 Steps and similar -Anon programs

▶ Solution-Focused Brief Therapy

▶ Cognitive Behavior Therapy (CBT)

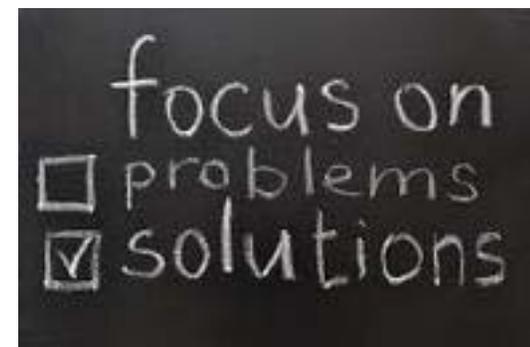
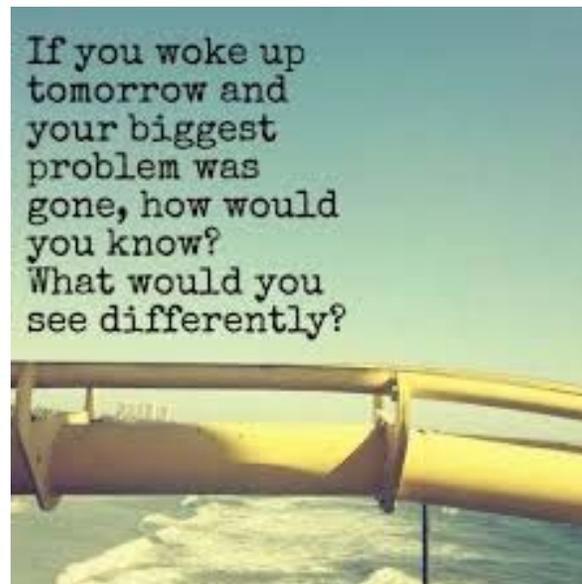
▶ Dialectical Behavior Therapy(DBT)



Solution-focused brief therapy

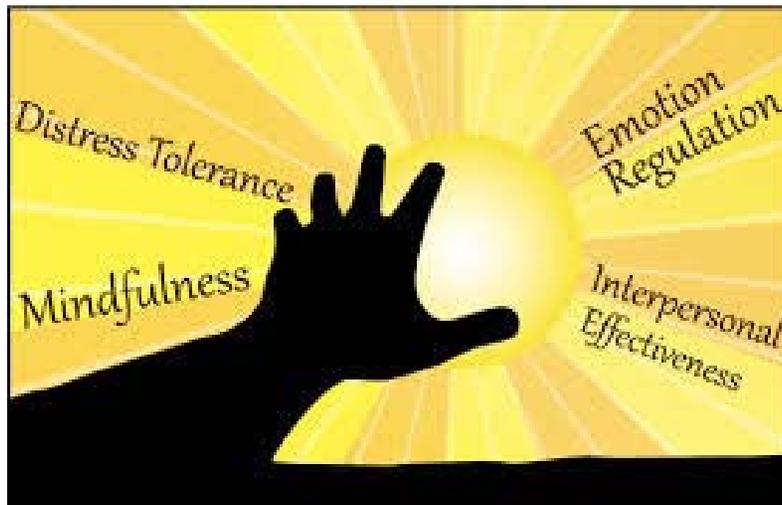
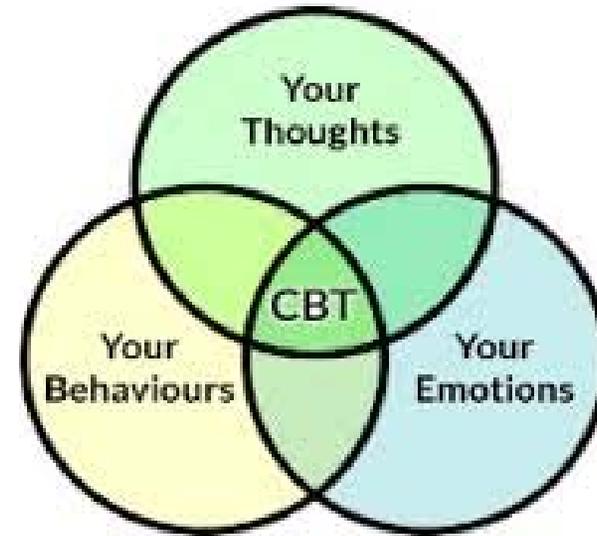
Focuses on how individuals can identify their own solutions. Therapy is firmly in the present while working towards a future in which your current problem or problems have less of an impact on your life.

**The
MIRACLE
question



Making Change

- ▶ Cognitive Behavioral Therapy (recognizing what triggers feelings and behavior)
- ▶ Dialectical Behavior Therapy (changing high-risk and self-harming behaviors)



The 3 C's of Cognitive Therapy

- C**atch
Identify the thought that came before the emotion
- C**heck
Reflect on how accurate and useful the thought is
- C**hange
Change the thought to a more accurate or helpful one as needed

Family Therapy

- ▶ Working together to address issues in the family system (attachment, alliances and triangles)



- ▶ Psychotherapy - Working individually to understand how family history and structure has influenced you

If you are in **CRISIS**:

- ▶ Reach out!!
- ▶ Healthcare team
- ▶ Local and national hotlines or text-lines
- ▶ Emergency room or 911
- ▶ Many states have mobile response teams

NATIONAL
SUICIDE
PREVENTION
LIFELINETM
1-800-273-TALK (8255)
suicidepreventionlifeline.org

SUICIDE WARNING SIGNS

TALK (Icon: speech bubble)

- Being a burden to others
- Experiencing unbearable pain
- Killing themselves
- Having no reason to live
- Feeling trapped

BEHAVIOR (Icon: martini glass)

- Increased use of alcohol or drugs
- Acting recklessly
- Withdrawing from activities
- Looking for a way to kill themselves, such as searching online for materials or means
- Isolating from family and friends
- Sleeping too much or too little
- Visiting or calling people to say goodbye
- Giving away prized possessions
- Aggression

MOOD (Icon: sad face)

- Loss of interest
- Irritability
- Depression
- Rage
- Humiliation
- Anxiety

AMERICAN FOUNDATION FOR Suicide Prevention

Text HOME
to 741741

for free, 24/7 crisis support in the US.

Being a support to others

- ▶ ...can help you too
- ▶ Formal and informal ways to do this
- ▶ Connect others to forms of support
- ▶ Be aware of your own boundaries
- ▶ Educate yourself
- ▶ <https://www.mentalhealthfirstaid.org/>

Mental Health First Aid

- ▶ 8-12 hour adult and youth first aid courses
- ▶ #bethedifference
- ▶ Worthwhile for first responders, school staff, and anyone involved in providing peer support, or involved in community organizations.



- ⚠ Assess for risk of suicide or harm
- 👂 Listen nonjudgmentally
- 🗣 Give reassurance and information
- 👥 Encourage appropriate professional help
- 🏠 Encourage self-help and other support strategies

Psychological First Aid

CORE ACTIONS



Contact & Engagement



Safety & Comfort

REMEMBER:

- Work within a team.
- Protect survivors from harm.
- Be calm and compassionate.
- Listen and be flexible.
- Respect culture and diversity.
- Give clear and reliable information.
- Know local available resources.
- Help survivors help themselves.
- Know your limits.
- Take care of yourself.

PSYCHOLOGICAL FIRST AID

Are you ready to respond?

GET **P**REPARED
GET **F**OCUSED
GET INTER**A**CTIVE



GET **PFA**

NCTSN The National Child Traumatic Stress Network



PFA Mobile™ can be downloaded on mobile Apple and Android devices

This project was also funded by SAMHSA, US Dept. of Health and Human Services
Illustrations by Dr. Bob Seaver

Responding to disaster

<https://learn.nctsn.org/course/index.php?categoryid=11>

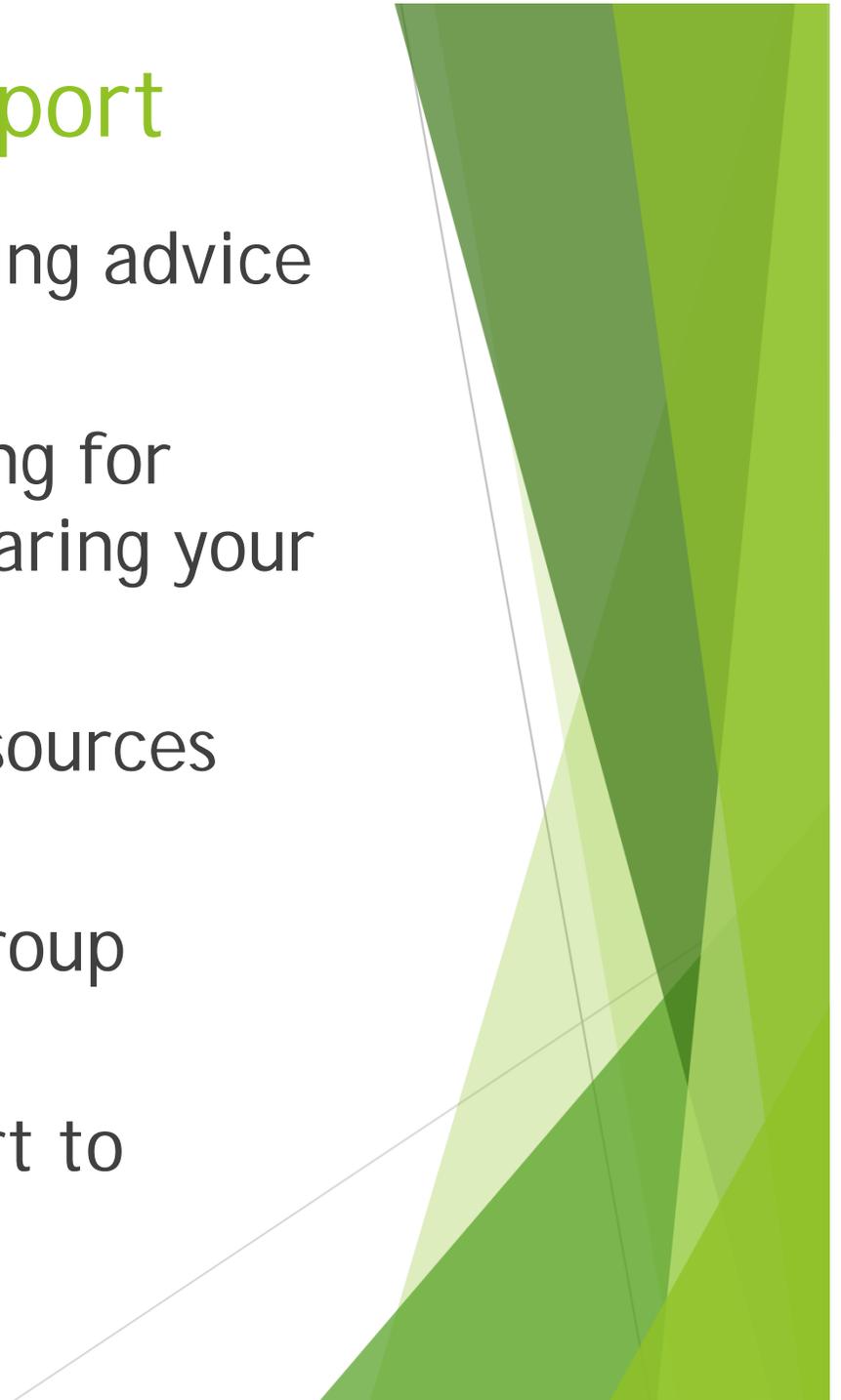
CORE ACTIONS	CORE ACTIONS	CORE ACTIONS
 <p><i>Stabilization</i></p>	 <p><i>Practical Assistance</i></p>	 <p><i>Information on Coping</i></p>
 <p><i>Information Gathering</i></p>	 <p><i>Connection with Social Supports</i></p>	 <p><i>Linkage with Collaborative Services</i></p>

Resources

- ▶ Suicide and Mental health hotlines
- ▶ Depression/anxiety self-assessments
- ▶ Advocacy groups like CRN and NAMI
- ▶ Medical team
- ▶ Mental health providers and/or integrated behavioral health
- ▶ School (IEP?) or Work (employee assistance programs)
- ▶ State and local agencies
- ▶ Online listings

Elements of Peer Support

- ▶ Emotional Support - Wanting advice or just ventilation
- ▶ Shared experience - looking for other's experience and sharing your own
- ▶ Instrumental Support - resources and how-to's
- ▶ Maintaining connection/group membership
- ▶ Mentorship - giving support to others, giving back



Strategies of Successful Families

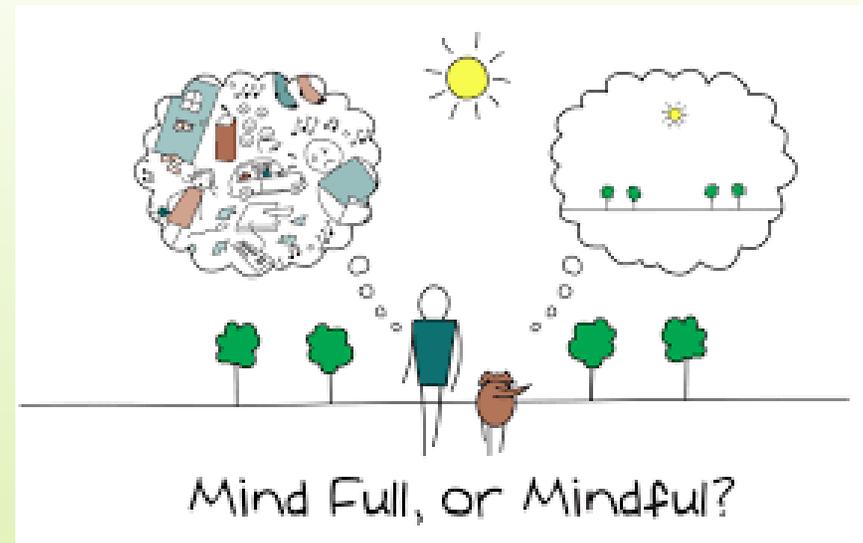
from adult patients and families reflecting back on childhood and adolescence

- ▶ Educating - coming to understand, and using what you know
- ▶ Regimenting - organizing life to manage illness
- ▶ Protecting and Pushing - setting and surpassing boundaries
- ▶ Connecting - the power of the social network
- ▶ Coming to Terms and Finding a Fit
- ▶ Living in the Now

- ▶ In your packet: Doyle, M., & Werner-Lin, A. (2016). Family Strategies for Living with Rare Disease: The Experience of Cystinosis. *Journal of the Society for Social Work and Research*, 7(3), 547-567.

Self-Care and Mindfulness Practices

- ▶ Being in the Now
- ▶ Being “in your body”
- ▶ Time for self
- ▶ Meditation
 - ▶ (Mediation? Medication? Media-vacation?)
- ▶ Relaxation/Centering
- ▶ Breathing
- ▶ Yoga and other physical practices
- ▶ Cultivating Gratitude
- ▶ Writing/journaling
- ▶ Apps like CALM



Coping and Resilience

- ▶ Recognizing your current strengths and supports
- ▶ “Who are the people in your neighborhood?”
- ▶ Positive messages, theme songs, humor :)
- ▶ Identifying and asking for what you need
- ▶ Self Care
 - ▶ Creating healthy habits
 - ▶ Small changes





Thanks to:

- ▶ Cystinosis Research Network
- ▶ ALAB
- ▶ Patients and families living with cystinosis and sharing their stories
- ▶ Clinicians, researchers, advocates, government, and industry addressing the challenges of rare disease
- ▶ Faculty and MSW students from Quinnipiac University