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”?  

How do health and mental health fit together? [Diagram]
Stress and Coping

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

What’s in your Stress Container?

- Stress flows into the container
- Vulnerability is shown by the size of the container
- If the container overflows, problems develop - “snapping”

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

(Source: Rodham & Taokeliner, 2002)
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.
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
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
  - Feeling down, depressed, or hopeless
  - Trouble falling or staying asleep, or sleeping too much
  - Feeling tired or having little energy
  - Poor appetite or overeating
  - Feeling bad about yourself
  - Trouble concentrating on things
  - Moving or speaking so slowly or the opposite
  - Thoughts that you would be better off dead

**Generalized Anxiety Disorder Scale (GAD-7)**

- Over the last two weeks, how often have you been bothered by the following problems?
  - Feeling nervous, anxious, or on edge
  - Not being able to stop or control worrying
  - Worrying too much about different things
  - Trouble relaxing
  - Being so restless that it’s hard to sit still
  - Becoming easily annoyed or irritable
  - Feeling afraid as if something awful might happen

- 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?

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

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**

If you woke up tomorrow and your biggest problem was gone, how would you know? What would you see differently?
Making Change

- Cognitive Behavioral Therapy (recognizing what triggers feelings and behavior)
- Dialectical Behavior Therapy (changing high-risk and self-harming behaviors)
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
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
- #betheedifference
- Worthwhile for first responders, school staff, and anyone involved in providing peer support, or involved in community organizations.
Psychological First Aid

Responding to disaster

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

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
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