

Discovering Wellness

NAVIGATING LIFE WITH A RARE DISEASE

Living with a rare disease is like being in a constant storm at sea.

You need the strength to power through and still keep the sail steady, every day. Learning emotional resilience is accepting the fact that you need to continue to grow even while handling crisis situations.

COMPONENTS OF RESILIENCE

- Confidence
- Social Support
- Purposefulness
- Adaptability

DEVELOP A WISE MIND THROUGH MINDFULNESS

Mindfulness is a state of awareness characterized by nonjudgmental observation of and interaction with the present moment.

ELEMENTS OF THE 3 MINDS

- 1 Reasonable Mind**
When we view the world rationally and pay attention to observable facts and phenomenon
- 2 Emotional Mind**
When we experience a state when logical thinking becomes difficult. We may notice the facts but find ourselves distorting or amplifying them based on our current emotional state
- 3 Wise Mind**
When we balance between reasonable mind and emotional mind. The core of the wise mind involves a deep sense of intuitive knowing, otherwise known as using your "gut" feeling

DEVELOPING EMOTIONAL RESILIENCE

One needs to look at:

- **COGNITION:** the way we think
- **PERCEPTION:** the way we analyze and evaluate things
- **ACTION:** the way we react to it

THE 7 C'S OF EMOTIONAL RESILIENCE

- 1 COMPETENCE:** knowing you can handle difficult situations
- 2 CONFIDENCE:** believing in your abilities
- 3 CONNECTION:** maintaining ties with loved ones
- 4 CHARACTER:** developing a strong set of values
- 5 CONTRIBUTION:** using your strengths to help others
- 6 COPING:** handling stress in a healthy way
- 7 CONTROL:** knowing you can make choices

PSYCHOLOGICAL FLEXIBILITY

The ability to stay in contact with the present moment regardless of unpleasant thoughts, feelings, and bodily sensations. Although this is not a state of happiness, it is the ability to flexibly navigate through changing demands of life and when difficult thoughts and feelings arise.

Elements include:

- THE PRESENT MOMENT:** be here now
- VALUES:** know what matters
- COMMITTED ACTION:** do what it takes
- SELF-AS-CONTEXT:** pure awareness
- DEFUSION:** what you're thinking
- ACCEPTANCE:** open up

Advocating for yourself is one of the most important aspects of living with a rare disease.