Raregivers™ Emotional Journey Map
A cycle of hope and grief for caregivers, patients and professionals.

1. NOTICING CHANGES
   - "Something isn't right"
   - Desire for diagnosis
   - Engage Healthcare/ Bureaucracy
   - Lack of disease-specific info
   - Fear, anxiety, shame, "Savior"

2. ADJUSTING +/- DIAGNOSIS
   - Managing symptoms
   - Learning about genetics
   - Lack of treatment
   - Complex care coordination
     - Overwhelm, fatigue, "Hero"

3. SHIFTING RESPONSIBILITIES
   - Role strain/identity change
   - Learning about the disease
   - Becoming the expert/advocate
   - Need to learn nursing skills
   - Resistance to role, "Expert"

4. FULL TIME CARE
   - Costs of time off/Loss of income
   - Relationship impact—siblings, spouse, family, friends, colleagues
   - Need for/seeking social support
     - Isolation, insecurity, "Advocate"

5. END OF LIFE
   - Acknowledgment
   - Preparation / Bereavement
     - Stages of Grief (denial, anger, bargaining, depression, acceptance), "Navigator"

6. SURVIVORSHIP
   - Redefining identity
   - Processing trauma/reflecting
     - Exploring purpose/giving back
     - Bitterness, enlightenment, recovery, empathy, "Angel"

EVERY DAY STRESSORS

RELIEF

Self-Care Skill-Building
Counseling / Therapy
Emotional Support
Social Connection
Physical Activity
Mindfulness
Nutrition
Nature
Sleep

ONGOING HEALTH & FINANCIAL NAVIGATION

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The Ehlers-Danlos Society

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biocryst