

Raregivers™ Emotional Journey Map

A cycle of hope and grief for caregivers, patients and professionals.

EVERY DAY STRESSORS

RELIEF

www.raregivers.global

TYPICAL

RARE



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"



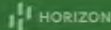
6. SURVIVORSHIP

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

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