

# Beyond the Diagnosis Module 2: Clinical Companion Resources

## Emotional, Social, and Systemic Challenges Within the Rare Disease Community

This companion document was developed to support mental health providers participating in Module 2 of the Beyond the Diagnosis Rare Disease Training focusing on Emotional, Social and Systemic Challenges within the Rare Disease Community.

Rooted in trauma-informed care, this resource includes clinical tools and language guidance designed to:

- Normalize and validate the emotional experience of those affected by rare disease.
- Support safe, shame-sensitive client engagement
- Equip providers with practical, evidence-informed interventions

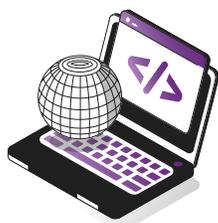
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### Contents Include:

Spectrum of Coping in Rare Disease Handout  
Chronic Uncertainty Mapping Tool  
Hope Without Guarantees: Navigating Hope Ethically

2



### Usage

This document is designed for use alongside the Module 1 slide presentation and facilitator guide. It may be distributed to CE participants, clinical trainees, or supervisors seeking to implement trauma-informed fraud recovery practices.

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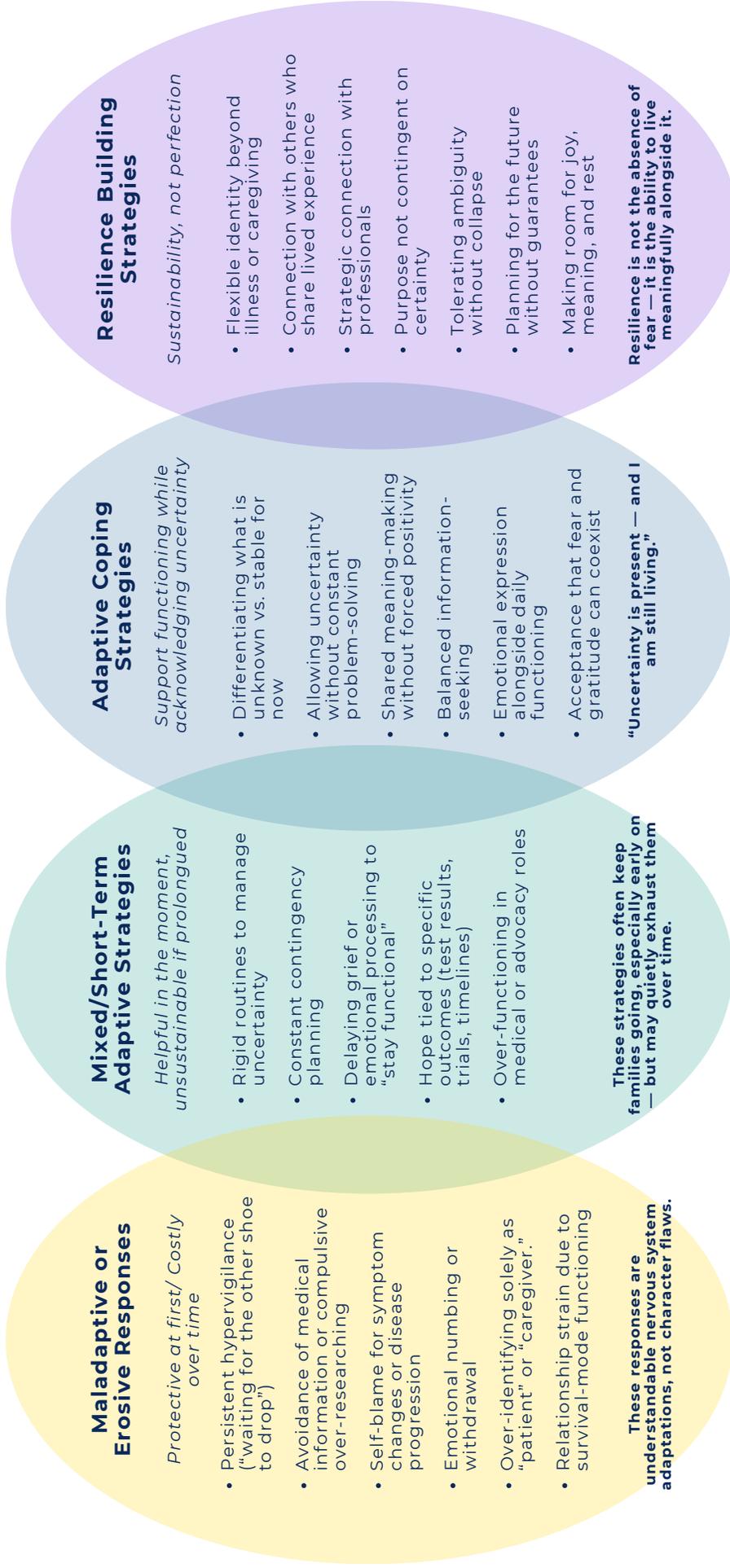
### Contributor Note

These materials were developed in collaboration with Al Freedman, PhD., Psychologist, Educator, & Rare Disease Advocate and Cheryl Simeons, M.A.

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# Spectrum of Coping with Chronic Uncertainty in Rare Disease

A non-linear model of survival, adaptation, and resilience. Coping responses shift over time. Movement along this spectrum is expected - not a measure of strength or failure



## Chronic Uncertainty Exposure Over Time

### Important Clinical Reminder:

Individuals and families may move back and forth across this spectrum depending on symptoms, stressors, losses, or transitions. Regression is not failure — it is information.

# CHRONIC UNCERTAINTY MAPPING TOOL

Externalizing Uncertainty in Rare Disease

## Who this tool is for:

- Adults living with rare or life-limiting illness
- Parents and caregivers
- Adolescents and young adults (language can be simplified)

## Clinical purpose

- To externalize uncertainty so it is no longer experienced as:
  - personal weakness
  - poor coping
  - psychological failure
  - lack of resilience

Uncertainty is framed as a persistent environmental condition, not an internal defect.

## CLINICAL FRAMING (FOR PROVIDERS)



Chronic uncertainty functions like a long-term exposure, not a discrete stressor.

The goal is orientation, not resolution.

Use this tool when:

- clients are self-blaming for anxiety or vigilance
- caregivers feel “crazy” or “obsessive”
- clinicians sense pressure to provide certainty they cannot ethically give
- uncertainty is being misinterpreted as resistance, avoidance, or pathology

# Living with Chronic Uncertainty

A mapping exercise for people navigating rare disease



The goal is not to “get over” uncertainty.  
It is to learn to live alongside it.

## IDENTIFY THE TYPES OF UNCERTAINTY PRESENT

### Existential

- Prognosis or life expectancy
- Disease progression or decline
- Impact on work, family, or independence
- Questions about fairness, meaning, or mortality
- “Who am I now?” or “What does my future look like?”

**Other:**

### Day-to-Day

- Symptoms that fluctuate unpredictably
- Waiting for tests, labs, or results
- Clinical trials
- Medication response or side effects
- Insurance, access, or scheduling instability
- Emergency planning or “what if” scenarios
- Financial concerns

**Other:**

Many people carry both kinds at once.  
That is not weakness; it is the reality of chronic illness.

# Living with Chronic Uncertainty

A mapping exercise for people navigating rare disease

## **SORT WHAT YOU'RE CARRYING**

Still Unknown	Partially Known	Stable (for now)

*“Stable for now” does not mean permanent.  
It means you are allowed to rest here without vigilance.*

## **NOTICE HOW UNCERTAINTY SHOWS UP IN YOUR BODY**

**Uncertainty is processed physically, not just mentally.  
When uncertainty increases, do you notice:**

- Constant scanning or hyper-alertness
- Trouble resting or sleeping
- Mental fatigue or brain fog
- Emotional numbness or shutdown
- Anxiety, irritability, or agitation
- Physical symptoms (tight chest, nausea, pain, headaches)

# Living with Chronic Uncertainty

A mapping exercise for people navigating rare disease

## NAME WHAT HELPS YOU STAY ORIENTED

**This is not about fixing uncertainty; it's about staying present with it.  
What helps even a little?**

- Structure or routine
- Information (at the right dose)
- Sensory grounding or movement
- Connection with others who understand
- Meaningful distraction or joy
- Professional support

**You don't need all of these.  
You only need one anchor at a time.**

## CAREGIVER PROMPT

**"What responsibility am I carrying that actually belongs to the illness, not to me?"**

**Response:**

# HOPE WITHOUT GUARANTEES

## Clinical Language Guide:

*Supporting Hope Ethically in Rare Disease Care*



### PURPOSE

To equip clinicians with language and strategies that help sustain hope while avoiding false promises, especially in the face of chronic uncertainty, medical trauma, and rare disease diagnoses.

### How to Sustain Hope Ethically:

01

#### Be Transparent & Honest

Offer hope in a realistic, clear, and genuine manner, acknowledging the challenges and uncertainties while recognizing the clients resilience.

Example phrases:

- “I can’t predict exactly what will happen, but I believe you have options, and we will support you through this journey.”
- “We’re in uncharted territory, and it’s normal to feel unsure. But we’re in this together.”

02

#### Recognize the Client’s Agency

Empower clients by emphasizing their active role in decision-making and coping, even when the medical path is unclear.

Example phrases:

- “You are an important part of this process, and we will find the best way forward with you.”
- “Although the future is uncertain, your strength and choices today will make a difference.”

03

#### Use Hope with Flexibility

Emphasize that hope is dynamic and that it may evolve over time, especially as new information becomes available.

Example phrases:

- “It’s important to hold onto hope, but that might mean adjusting our expectations as we learn more about your condition.”
- “There may be ups and downs, but maintaining hope through the changes can provide strength.”

### Phrases to Avoid!

**Avoid offering guarantees or absolutes that cannot be substantiated.**

*“This treatment will definitely work for you.”*  
*“We’ll find a cure, no matter what.”*  
*“Everything will be fine.”*

**Avoid minimizing the client’s experience of uncertainty and grief.**

*“Don’t worry, it’ll all work out in the end.”*  
*“You’ll get through this easily.”*  
*“At least you’re not in pain anymore.”*

**Avoid using overly simplistic language that doesn’t acknowledge the complexity of the situation.**

*“Everything happens for a reason.”*  
*“Just stay positive, and everything will be okay.”*

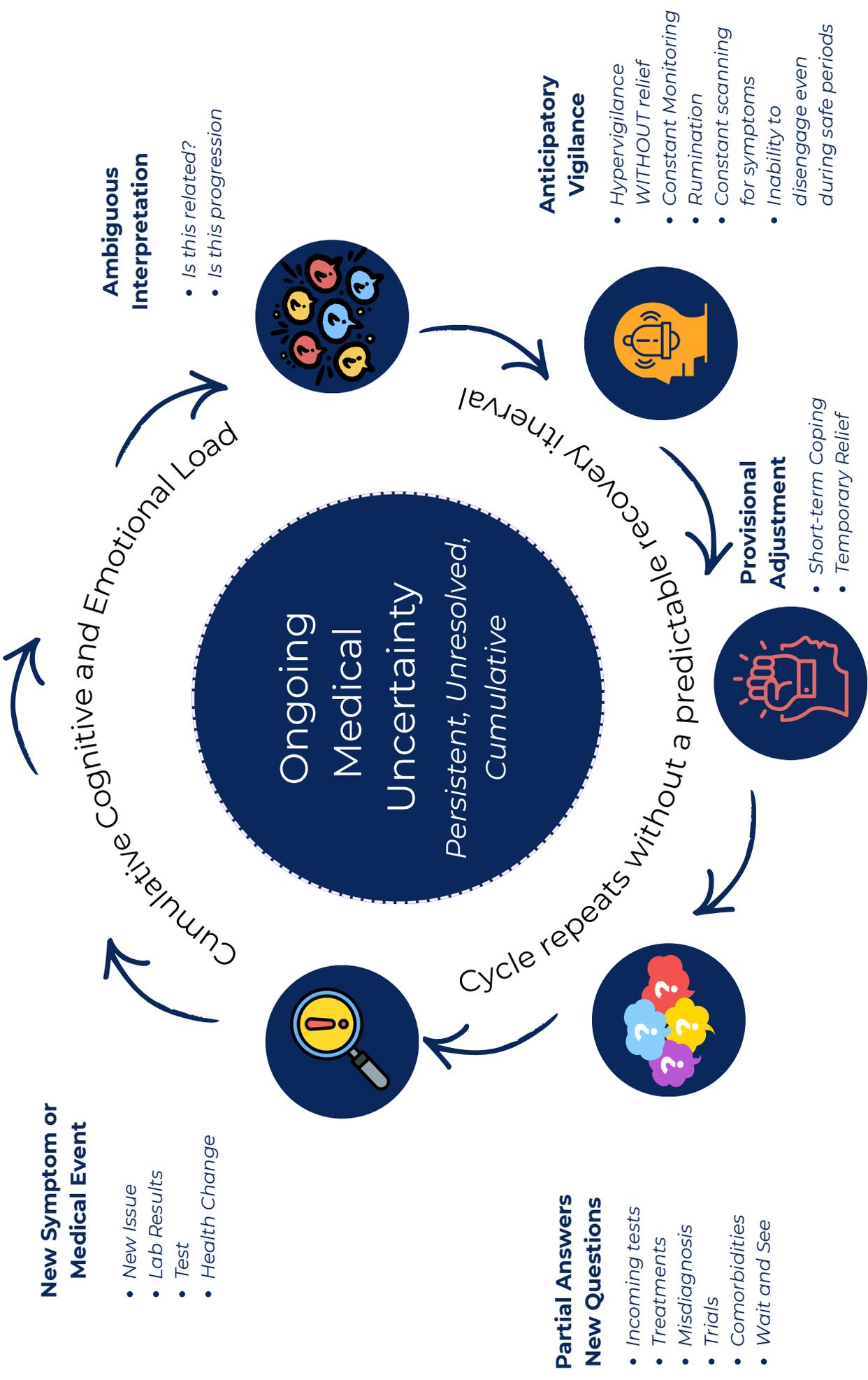
### Clinical Reminder

Hope is essential, but it must be balanced with realism.

Therapists and clinicians must navigate the fine line between offering hope and managing expectations. The goal is not to minimize grief or uncertainty but to allow hope to coexist with it in a compassionate and patient-centered manner.

In the rare disease space, hope is about possibilities, not guarantees.

Stay present with the patient's emotional needs, acknowledging both the trauma of uncertainty and the strength found in navigating it.



Model adapted from (Pearce et al., 2024)