Beyond the Diagnosis Module 8: 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 8 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

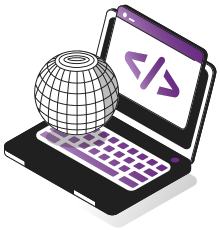
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Contents Include:

- Guilt in the Rare Disease Experience
- A Guided Reflection for Guilt, Responsibility & Decision Regret

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Usage

This document is designed for use alongside the Module 8 slide presentation and facilitator guide. It may be distributed to CE participants, clinical trainees, or supervisors seeking to implement trauma-informed support for rare disease patients.

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Contributor Note

These materials were developed in collaboration with Al Freedman, PhD., Psychologist, Educator, & Nancy Cincotta, LCSW, MPhil, is OCRA's Senior Director of Social Work Education and Research (Consultant)

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GUILT IN THE RARE DISEASE EXPERIENCE

Understanding guilt when decisions, outcomes, and uncertainty carry extraordinary weight



Why guilt can become so powerful

Rare disease often asks patients and families to make consequential decisions with incomplete information, limited options, uncertain outcomes, and significant emotional pressure. When outcomes are painful, people may look backward with knowledge they did not have when the decision was made.

Guilt may sound like:

Experience	Internal narrative
Diagnostic guilt	“Should I have noticed sooner?”
Decision guilt	“Did I make the wrong choice?”
Caregiver guilt	“Did I do enough?”
Access guilt	“Why did we get this opportunity when others didn't?”
Response / survivor guilt	“Why did this work for me?”
Family guilt	“Did my other children get what they needed?”
Bereavement guilt	“What if I had chosen differently?”
Scientific progress	“What if this had existed then?”

WHY HINDSIGHT CAN INTENSIFY GUILT



What is known now is not the same as what was knowable then.

New treatments, research findings, diagnostic tools, or changing standards of care can make earlier decisions look different in retrospect. But patients and families make these decisions within the information, resources, access, and uncertainty that existed at that time.



When Guilt Shows Up

Explore before reassuring:

Ask, “What do I feel responsible for?” Understanding the guilt can be more helpful than immediately trying to dismiss it.

Separate outcome from responsibility:

A painful outcome does not necessarily mean someone made a poor decision or could have prevented what happened. Return to what was known at the time. What information was available? What remained uncertain?

Recognize hindsight:

What is known now may be very different from what could have been known then. Allow mixed emotions. Guilt can exist alongside grief, relief, anger, love, hope, resentment, gratitude, and even joy.

Resist the urge to erase guilt too quickly:

“You shouldn't feel guilty” may be well intentioned, but guilt often needs to be understood before it can be processed.

You can only make a decision with the information, options, resources, and uncertainty available to you at the time.

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A Guided Reflection for Guilt, Responsibility & Decision Regret

When an outcome is painful, it can be easy to revisit a past decision using information you have today. This exercise helps reconstruct the decision as it actually existed at the time, including what was known, what remained uncertain, what options were available, and what mattered most.

Looking backward with today's knowledge can make yesterday's uncertainty disappear. You did not have today's knowledge then.

WHAT I KNOW NOW

What do you know today that you did not know when the decision was made?

Consider:

- The eventual outcome
- How a treatment or intervention worked
- New research or medical information
- How the disease progressed
- Information you learned later
- Treatments or options that became available afterward

What feels obvious now that was not obvious then?

_____

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_____

WHAT I KNEW THEN

Return to the moment when the decision actually had to be made.

- What information had you been given?
- What did you understand about the possible benefits and risks?
- What were you being told by the medical team?
- What did you understand about the disease or prognosis?
- What previous experiences were influencing you?

At that moment, what did you reasonably believe to be true?

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WHAT WAS STILL UNKNOWN

What could no one tell you with certainty?

Think about:

- Whether treatment would work
- How you or your loved one would respond
- Side effects or complications
- Disease progression
- Long-term outcomes
- Whether another treatment would become available
- What might happen if you waited

Which parts of the outcome were outside anyone's ability to predict?

WHAT OPTIONS DID I ACTUALLY HAVE?

Separate the options that seem possible in hindsight from those that were realistically available at the time.

Consider:

- Eligibility
- Geography
- Cost or insurance
- Clinical trial availability
- Timing
- Medical condition
- Caregiving responsibilities
- Transportation or time away from work
- Information and specialist access
- Your own physical and emotional capacity

What choices were genuinely available to me then?

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WHAT MATTERED TO ME?

Decisions are rarely made from information alone.

What were you trying to protect, preserve, or prioritize?

- ☐ Quality of life
- ☐ More time
- ☐ Comfort
- ☐ Safety
- ☐ Independence
- ☐ Family stability
- ☐ Hope
- ☐ Avoiding suffering
- ☐ Your loved one's wishes
- ☐ Your own values or wishes
- ☐ Other: _____

What were you hoping this decision would make possible?

_____

_____

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GUILT vs. RESPONSIBILITY

GUILT MAY SAY	ASK INSTEAD
“I should have known.”	**Could I reasonably have known?**
“I should have prevented this.”	**What was actually within my control?**
“I made the wrong decision.”	**Was there a clearly right decision available?**
“If I had chosen differently…”	**Could I have known what the other choice would lead to?**
“I should have done more.”	**What was realistically possible for me at the time?**

FINAL REFLECTION

Given what I knew, what remained uncertain, what I actually had access to, and what mattered most at the time, what was I trying to do or protect when I made this decision?