

Beyond the Diagnosis Module 4: Clinical Companion Resources

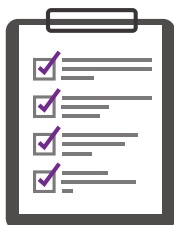
Emotional, Social, and Systemic Challenges Within the Rare Disease Community

This companion document was developed to support mental health providers participating in Module 4 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

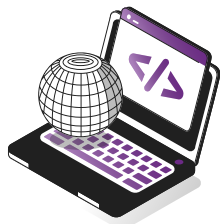
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Contents Include:

Family System Mapping Tool
Structured Connection Planning Tool
Sibling Support Guide

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Usage

This document is designed for use alongside the Module 3 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, & Parent Coach and Ronda Thorington, Licensed Professional Counselor, Mental Health Consultant, and Rare Parent

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FAMILY SYSTEM MAPPING TOOL

Understanding Relationship Strain in Rare Disease



Purpose

This tool helps you and your client:

- See how responsibilities are distributed across the family
- Identify where strain or imbalance may be building
- Explore where additional support or communication may be needed

Who Is Carrying What? (Role Mapping)

Instructions: List each person in the household.

For each area, note who primarily handles it.

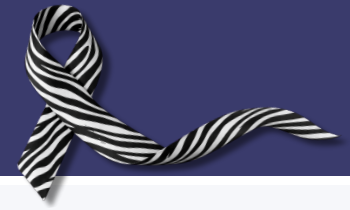
Area of Responsibility	Who Handles This?	How Heavy Does It Feel? (Low / Medium / High)
Medical care (appointments, meds, decisions)		
Emotional support (checking in, holding space)		
Finances / work / insurance		
Coordination (scheduling, communication, logistics)		
Household tasks (meals, cleaning, daily needs)		

Reflection Prompt:

Does one person appear to be carrying multiple “high” areas?

FAMILY SYSTEM MAPPING TOOL

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How Do We Each Cope?

Instructions:

When things feel overwhelming, which of these feel most like you?

Check all that apply:

- I focus on fixing problems or taking action
- I try to stay strong and keep things together
- I withdraw or shut down
- I seek connection or want to talk it through
- I stay busy or distract myself
- I avoid or put things off
- I become more irritable, reactive, or easily overwhelmed
- I try to control situations or plan ahead to reduce uncertainty
- I minimize what I'm feeling or tell myself "it's not a big deal"
- I take care of others instead of focusing on myself
- I become overly independent or handle things on my own
- I rely on routines or structure to feel stable
- I use substances (e.g., alcohol, medication, etc.) to cope
- I experience anxiety, worry, or constant "what if" thinking
- I feel emotionally numb or disconnected



Which of these help you feel better in the moment?

Which might create more stress over time?

Where Is the Strain Showing Up?

Instructions:

Mark where tension, stress, or disconnection is showing up most right now.

- Couple relationship
- Parent-child relationship
- Sibling relationships
- Extended family
- Friendships / social connections
- Work / professional relationships

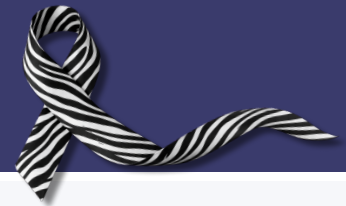


Where does stress show up most often?

Are there areas where strain is building but not being discussed?

FAMILY SYSTEM MAPPING TOOL

Understanding Relationship Strain in Rare Disease



What's Not Being Said?

Guiding Questions:

- Where does it feel like too much is being carried by one person?
- Where are needs going unspoken?
- What feels hardest to say out loud right now?
- What would feel most supportive, but hasn't been asked for?

Deepening Understanding:

Where might someone be saying "I'm fine" but not actually feeling fine?

What assumptions are being made about each other that haven't been checked?

Where might effort be happening, but not being seen or felt by others?

What feels unfair, but hasn't been named?

Where is there resentment building quietly?

What are you each protecting each other from by not saying certain things?

What are you most afraid might happen if you were fully honest?

Where has the relationship shifted, but hasn't been acknowledged?

What has been lost or changed that hasn't been grieved?

What do you wish someone understood about your experience, but haven't said?



If things could feel even 10% better, what would need to change?

What to Listen for:

- One person carrying multiple "high" roles
- Mismatched coping styles (e.g., fixer vs. withdrawer)
- Strain showing up in "secondary" areas (siblings, extended family)
- Unspoken needs or avoided conversations

How to Frame It:

Use language like:

- "This isn't about who's doing it right or wrong"
- "We're just trying to understand what the system is carrying"
- "This helps us see where support might be needed"

Structured Connection Planning Tool

Creating Space for Connection in High-Stress Systems

When life feels overwhelming, connection often gets pushed aside, not because it's unimportant, but because there isn't space for it.

This tool helps you intentionally create small, realistic moments of connection, even during high stress.

"You can't change a tire while you're driving a car."
Sometimes, you have to pause to take care of the relationship.

Reality Check

Before planning, take a moment to be realistic about your current life:

- When do we actually have time available?
- What usually gets in the way? (fatigue, schedules, caregiving demands, stress)
- What feels realistic right now, not ideal, but **doable?**

Prompt:

- If we're being honest, what could work this week?

Plan a Micro-Connection

Keep it small. Keep it consistent.



Fill in together:

- Time: _____
- Frequency: Weekly Biweekly Other: _____
- Length: 10 min 15 min 30 min
- Format:
 - Walk
 - Coffee / meal
 - Sitting together at home
 - In the car
 - Other: _____



Reminder:

It doesn't have to be perfect, it just has to happen.

Structured Connection Planning Tool

Creating Space for Connection in High-Stress Systems

What Helps Me Feel Connected

I feel most connected when...

(choose or add your own)

- You listen without trying to fix things
- You check in with me or ask how I'm doing
- We spend time together without distractions
- You acknowledge what I'm carrying
- You offer help without me having to ask
- We laugh or have a moment of lightness
- You express appreciation or affection
- You are physically present (sitting together, being close)
- You follow through on something we planned
- Other: _____

Conversation Prompts (If You Get Stuck)

You don't need a perfect conversation, just a place to start.

- What has been hardest for you this week?
- What do you wish I understood better?
- When did you feel most overwhelmed?
- What has helped you feel supported, even a little?
- What do you need more of right now?
- What's one thing you're carrying that I might not see?

Tip:

Listen to understand—not to fix.



“You’re not trying to fix everything, just creating space to stay connected.”

“This is about small, consistent moments, not big conversations.”

Reflection (Afterward)

After your time together, take a minute to reflect:

- What felt good about that time?
- What felt difficult or awkward?
- What made it easier to connect?
- What would we keep the same next time?
- What might we change?

Supporting Siblings in Families Living with Rare Disease

A Guide for Parents & Caregivers



Siblings often see and feel more than they say. They may try to stay strong, be helpful, or not add to the stress, but they still need support, attention, and space to be themselves.



What Siblings May Be Experiencing

Your child may be:

- Trying to be independent so they don't add to your load
- Feeling left out, overlooked, or less important at times
- Holding worry, fear, or sadness about their sibling
- Holding in their feelings so they don't add to parental burden
- Feeling guilty for being healthy or wanting attention
- Feeling frustrated or resentful, and then guilty for feeling that way

These feelings can exist all at once, and they are all valid.



Create Small Moments of Connection

It doesn't have to be big, it just has to be intentional.

Try:

- A quick errand together
- A short walk
- A car ride or coffee stop



The key is to name it:

"Come with me—I want to spend some time with just you."

When you name it, it becomes meaningful.

When you don't, it can get lost.

WHAT THEY NEED TO HEAR:

"It's okay to feel frustrated sometimes."

This isn't your fault."

"I see you, and you matter just as much."

"This disease really sucks. It's okay to feel mad about it."

"You're not responsible for your sibling's care."

Simple Check-In Questions

- "What's been hardest for you lately?"
- "Is there anything you wish we did differently?"
- "Do you ever feel like things aren't fair?"
- "What do you need more of right now?"

Ask and Listen: *Being heard matters more than having the "right" response.*