

Beyond the Diagnosis Module 6: 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 6 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

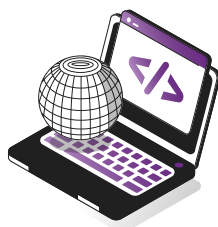
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Contents Include:

- Rare-Disease-Informed Clinical Check-In
- Micro-Reset Techniques & Closure Scripts for emotional regulation
- Resource and Referral Pathways

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Usage

This document is designed for use alongside the Module 6 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, & Lara Govendo, LCPC

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RARE-DISEASE-INFORMED CLINICAL CHECK-IN

A practical tool for understanding what the client needs today,
what may be driving distress, and where to go next.



PAGE 1 OF 2

1 START WITH TODAY

What does this session need to hold?

What feels most important to use
our time for today?

Is there anything happening medically
that I need to understand before we
go further?

What would feel most helpful from me today?

- ☐ Listen – I need someone to say what I am carrying.
- ☐ Regulate – I feel overwhelmed, activated, shut down, or stuck.
- ☐ Clarify – I need help making sense of what is happening.
- ☐ Problem-solve – There is something specific I need to work through.
- ☐ Prepare – I need help getting ready for a conversation, appointment, or decision.
- ☐ Connect – I need help identifying support, resources, or people who can help.
- ☐ Clinical treatment – There is a mental health concern we need to address directly.
- ☐ I don't know yet.

2 WHAT'S HAPPENING?

Look beyond the diagnosis.

Which areas are taking up space right now?

AREA	What's happening?	Impact today
☐ Medical / symptoms		Low Med High
☐ Emotional / psychological		Low Med High
☐ Relationships / family		Low Med High
☐ Caregiving / receiving care		Low Med High
☐ Work / school		Low Med High
☐ Financial / insurance		Low Med High
☐ Healthcare navigation		Low Med High
☐ Identity / independence		Low Med High
☐ Disability / accessibility		Low Med High
☐ Grief / loss / uncertainty		Low Med High
☐ Community / belonging		Low Med High
☐ Other		Low Med High



Which of these feels heaviest today?



Which feels most changeable or actionable?



Is there something important that isn't on this list?

4 BEFORE • AFTER • INTERACTION

Build the formulation without making rare disease explain everything.

BEFORE

What was already part
of the person's story?

What was present before
the rare-disease experience?

AFTER

What emerged or significantly
changed?

What emerged after diagnosis,
symptom onset, or medical
escalation?

INTERACTION

What changes when
medical stress increases?

What gets louder when
symptoms, appointments,
procedures, uncertainty, or
healthcare-system stress
increase?

CURRENT WORKING PICTURE

(Choose one)

- ☐ Primarily understandable illness-related distress
- ☐ Pre-existing concern being amplified by medical stress
- ☐ Independent / co-occurring mental health condition
- ☐ Multiple interacting concerns
- ☐ Further assessment needed



Remember: Not everything is caused by rare disease, and not everything is separate from it.
Hold the whole picture.

3 HIGH + LOW

Track the range, not just the moment.

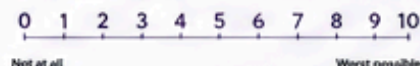


LOW

What has been your lowest point since
we last met?

What was happening?

How low did things get?



What made that moment particularly difficult?

How long did it last?

What helped you move through it, even a little?



HIGH

What has been your highest point since
we last met?

What was happening?

What felt different?

What was available to you in that moment?

- ☐ More energy ☐ Less pain / symptoms
- ☐ Connection ☐ Support ☐ Hope
- ☐ Agency/control ☐ Effective coping
- ☐ Meaning/purpose ☐ Enjoyment
- ☐ Something else:

RAISING THE FLOOR

Compared with earlier in treatment:

- ☐ Lowest points are less severe
- ☐ Lowest points don't last as long
- ☐ Recovery happens sooner
- ☐ Coping strategies are accessed earlier
- ☐ Client asks for help sooner
- ☐ More good/neutral moments are occurring
- ☐ Functioning has improved
- ☐ Client feels more able to tolerate uncertainty
- ☐ No meaningful change yet
- ☐ Things have become more difficult

What seems to be changing?

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Rare-Disease-Informed Clinical Check-In

A practical tool for understanding what the client needs today, what may be driving distress, and where to go next

Rare disease rarely arrives in the therapy room as a single, neatly defined concern. Clients may be navigating symptoms, medical uncertainty, trauma, relationships, caregiving, disability, identity, work, finances, healthcare systems, and mental health concerns at the same time. The challenge for clinicians is often not identifying whether distress exists, but understanding what is happening, what matters most today, and what kind of support is needed next. The Rare-Disease-Informed Clinical Check-In is a flexible clinical guide designed to support that process. It provides a structured way to listen broadly, identify intersecting stressors, distinguish illness-related distress from co-occurring concerns, recognize meaningful change over time, and collaboratively determine the next right step.

This tool can be used at intake, periodically throughout treatment, or during sessions when the clinical picture feels particularly complex or overwhelming. It does not need to be completed from beginning to end in every session. Instead, clinicians can use the sections that are most relevant to the person and the moment.

START WITH TODAY

What feels most important to use our time for today?
Is there anything happening medically that I need to understand before we go further?

What would feel most helpful from me today?

- ☐ **Listen** — I need somewhere to say what I am carrying.
- ☐ **Regulate** — I feel overwhelmed, activated, shut down, or stuck.
- ☐ **Clarify** — I need help making sense of what is happening.
- ☐ **Problem-solve** — There is something specific I need to work through.
- ☐ **Prepare** — I need help getting ready for a conversation, appointment, or decision.
- ☐ **Connect** — I need help identifying support, resources, or people who can help.
- ☐ **Clinical treatment** — There is a mental health concern we need to address directly.
- ☐ **I don't know yet.**

HIGH + LOW

Track the range, not just the moment.

LOW

What has been your lowest point since we last met?
What was happening?

How low did things get?
0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10
What made that moment particularly difficult

Rare-Disease-Informed Clinical Check-In

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How long did it last?

What helped you move through it, even a little?

HIGH

What has been your highest point since we last met?

What was happening?

What felt different?

0 ——— 1 ——— 2 ——— 3 ——— 4 ——— 5 ——— 6 ——— 7 ——— 8 ——— 9 ——— 10
How low high did things get?
What made that moment particularly encouraging?

What was available to you in that moment?

- ☐ More energy
- ☐ Less pain / fewer symptoms
- ☐ Connection
- ☐ Support
- ☐ Hope
- ☐ Agency/control
- ☐ Effective coping
- ☐ Meaning/purpose
- ☐ Enjoyment
- ☐ Something else: _____

RAISING THE FLOOR

Then instead of simply asking, “Are you feeling better?”, look for movement:

Compared with earlier in treatment:

- ☐ Lowest points are less severe
- ☐ Lowest points don't last as long
- ☐ Recovery happens sooner
- ☐ Coping strategies are accessed earlier
- ☐ Client asks for help sooner
- ☐ More good/neutral moments are occurring
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What seems to be changing?

Rare-Disease-Informed Clinical Check-In

A practical tool for understanding what the client needs today, what may be driving distress, and where to go next

BEFORE • AFTER • INTERACTION

Build the formulation without making rare disease explain everything.
I'd actually make this a little visual, maybe three overlapping circles.

BEFORE

What was already part of the person's story?

Consider:

- Mental health history
- Trauma
- Loss
- Family patterns
- Relationships
- Substance use
- Neurodevelopmental factors
- Previous stressors or vulnerabilities
- Existing strengths and coping

What was present before the rare-disease experience?

AFTER

What emerged or significantly changed?

Consider:

- Medical trauma
- Anxiety or hypervigilance
- Grief
- Disability-related changes
- Identity disruption
- Isolation
- Caregiver/family strain
- Financial or employment stress
- Healthcare-system distress

What emerged after diagnosis, symptom onset, or medical escalation?

INTERACTION

What changes when medical stress increases?

What gets louder when symptoms, appointments, procedures, uncertainty, or healthcare-system stress increase?

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WHAT IS SUSTAINING THEM?

What currently helps this person feel most like themselves?

- ☐ Relationships
- ☐ Family/chosen family
- ☐ Peer community
- ☐ Advocacy/community involvement
- ☐ Work/school
- ☐ Creativity
- ☐ Spirituality/meaning
- ☐ Humor
- ☐ Routine
- ☐ Movement/activity
- ☐ Interests/hobbies
- ☐ Therapy
- ☐ Medical team
- ☐ Other: _____

What brings relief, connection, meaning, or joy?

What strength is this person already using that we can build on?

THE NEXT RIGHT STEP

- What needs attention NOW?
- What can WAIT?
- What is OUTSIDE my role or scope and may need another resource?

Before we meet again, the next right step is:

Who owns the next step?

- ☐ Client
- ☐ Clinician
- ☐ Together
- ☐ Caregiver/support person
- ☐ Medical provider/team
- ☐ Another resource: _____

When will we revisit it?

MICRO-RESET TECHNIQUES & CLOSURE SCRIPTS FOR EMOTIONAL REGULATION



Purpose

Provide fast, body-based regulation tools (“micro-resets”) and brief closing rituals to help both victims, mental health professionals, and peer facilitators maintain safety and containment in group or session work. Each technique can be done in 30–90 seconds—ideal between clients, after difficult disclosures, or as a group transition.



What Is a Micro-Reset?

“The brain needs physical evidence that you’re safe again.” — Dr. Jennifer Lawrence

Micro-resets are short, sensory-based actions that signal “the threat is over.”

They:

- lower heart rate and cortisol,
- restore orientation to time and place,
- model co-regulation when done collectively.

Use them:

- at the start of sessions (to settle),
- between heavy topics,
- and at closure (to re-ground).



Box Breathing (4-4-4-4)

- Inhale 4 – Hold 4 – Exhale 4 – Hold 4 × 3 rounds.
- Use anytime anxiety or pacing increases.



Feet to Floor

- Press soles down, feel weight shift, notice texture and temperature; exhale slowly.
- After triggering material or emotional flooding.



5-4-3-2-1 Grounding

- Name 5 things you see, 4 touch, 3 hear, 2 smell, 1 taste.
- When dissociation or rumination appears.



Shoulder Roll + Sentence Anchor

- Roll shoulders × 3 and say silently, “I’m here / It’s now / I’m okay.”
- Quick reset during long group or telehealth sessions.



Temperature Shift

- Drink a cold drink, run wrists under cold water, or put a cold compress on the neck.
- To interrupt panic or emotional overheating.

INTEGRATING MEANING



Pair each reset with why it matters:

- “This breath teaches my body the difference between danger and discomfort.”
- “This pause tells my nervous system the story is over for now.”
- Purposeful language transforms coping into neurobiological re-training.



Co-Regulation Rituals

Opening (Settle)

“Let’s all take one slow breath together and notice our feet on the floor.”

Mid-Session (Containment)

“Let’s pause for a moment. Everyone take a sip of water, stretch, and look around the room.”

Closing (Release)

“Before we end, take one deep breath in, one long breath out. Feel your seat, feel the ground. The work stays here; you take your calm with you.”

CLOSURE SCRIPTS FOR FACILITATORS

After Intense Sharing: “Let’s honor what was shared by taking a slow breath. The story has been witnessed; now let’s help our bodies return to the present.”

End of Group: “We’re closing for today. Notice one thing that feels steady right now—maybe your heartbeat, the chair, or a small sense of relief.”

Transition Between Clients: “I’m releasing the last session with this breath, clearing space for the next.”

Virtual Peer Support Debrief: “Before we log off, one word check-out: how’s your body feeling as we end?”

Resource and Referral Pathways

If a Client is Looking for...		Consider...	
	Disease education		Disease-specific advocacy organizations
	Practical advice from someone who's been there		Peer Mentor
	Emotional Support		Facilitated support groups
	Friendship and Belonging		Conference and community events
	Navigation across rare diseases		NORD , Global Genes
	Opportunities to give back		Advocacy or volunteer programs

Community isn't a single destination. It's an ecosystem of resources that can support people in different ways and at different points in their journey.

Clinical Pearls:

- ✓ Ask about the client's goals, preferences, and comfort level.
- ✓ Introduce one resource at a time.
- ✓ Needs and interests may change over time. Revisit regularly.
- ✓ Offer ongoing support before, during, and after engagement.

Connecting clients to the right type of community support, at the right time, can foster connection, belonging, hope, and empowerment throughout the rare disease journey.