

THE IMPACT OF RARE CONDITIONS ON SELF-IDENTITY

# Embracing Differences

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NOVEMBER 18, 2024

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# Overview

- 1 Living with Dwarfism (Achondroplasia)
- 2 The Emotional Journey
- 3 Societal Barriers
- 4 The Psychology of Activism
- 5 Finding Identity Beyond the Condition

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# Acknowledgement

My experiences with a rare condition are personal and may not reflect the journeys of everyone in the rare condition community. Each story is unique, and it's essential to acknowledge and respect the diverse challenges we all encounter.

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# Living with Dwarfism

- Brief Overview
- My Journey
- Significance of Sharing Personal Experiences

# The Emotional Journey

*Internal ID*

**IMPACT**

**GRIEF MAPPING**

**ACKNOWLEDGEMENT**

# Mapping the Grieving Process



*\*A technique for navigating complex emotions that has been beneficial for me.*

# Importance of Acknowledging Feelings & Experiences

**VALIDATION**

**ENCOURAGING  
OPENNESS**

**SUPPORT  
NETWORKS**

# Societal Barriers

*External ID*

- Stigma & Discrimination
- Examples of Societal Barriers
- The Impact on Self-Perception & Identity
- Strategies for Empowerment

# Stigma & Discrimination

**STEREOTYPING**

**STRUCTURAL  
INTERPERSONAL  
EXPERIENCED**

**RESISTANCE TO CHANGE**

# Societal Barriers

**PHYSICAL**

**SOCIAL**

**ECONOMIC**

# The Impact on Self-Perception & Identity

**INTERNALIZED  
STIGMA**

**ISOLATION  
&  
LONELINESS**

# Strategies for Empowerment

**EDUCATION &  
AWARENESS**

**ADVOCACY  
& SUPPORT**

**BUILDING  
COMMUNITY**

# The Psychology of Activism

- Activism in the Context of Rare Diseases & Conditions
- Healthy Vs Wounded
- The Role of curiosity in Activism
- Connection Between Activism & Self-ID

# Activism in the Context of Rare Diseases & Conditions

**WHAT IS  
ACTIVISM?**

**IMPORTANCE  
FOR RARE  
CONDITIONS**

# Healthy Activism vs. Wounded Activism

**HEALTHY**

**WOUNDED**

# The Role of Curiosity in Activism

**CURIOSITY AS A  
CATALYST**

# Connection Between Activism & Self-Identity

**IMPACT ON SELF-ID:  
INTERNAL FAMILY  
SYSTEMS  
FRAMEWORK**

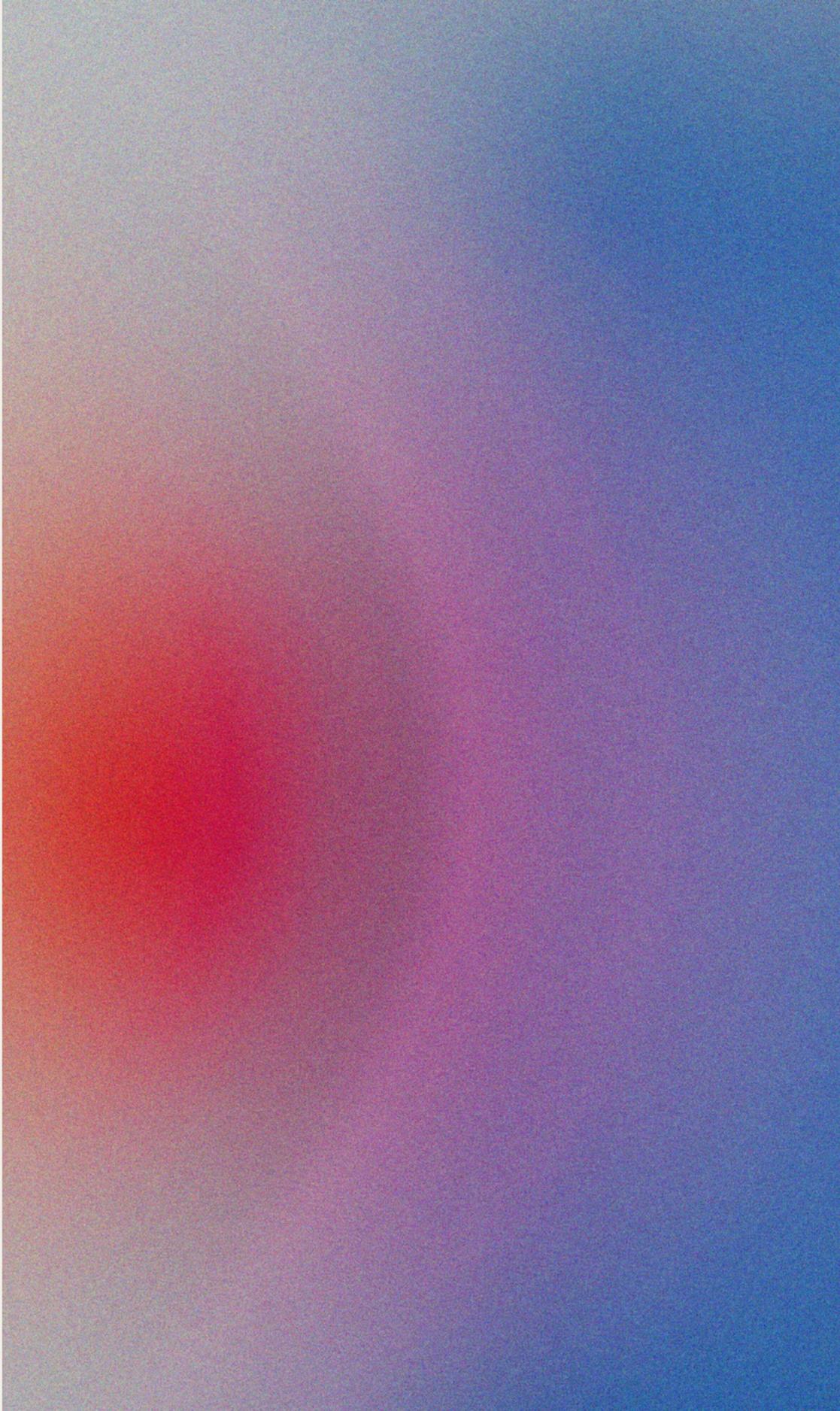
**COMMUNITY  
&  
BELONGING**

Why is this relevant ?

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# Finding Identity Beyond the Condition

- Self-Acceptance
  - Community Connections
  - My Story of Transformation
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# Self - Acceptance

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# Community Connections

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# My Story of Transformation

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# Thank you

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