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TRADITIO ET EXCELLENTIA



Different faces of grief in the context of rare diseases

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What comes to your mind when you think about grief and loss?

0 responses

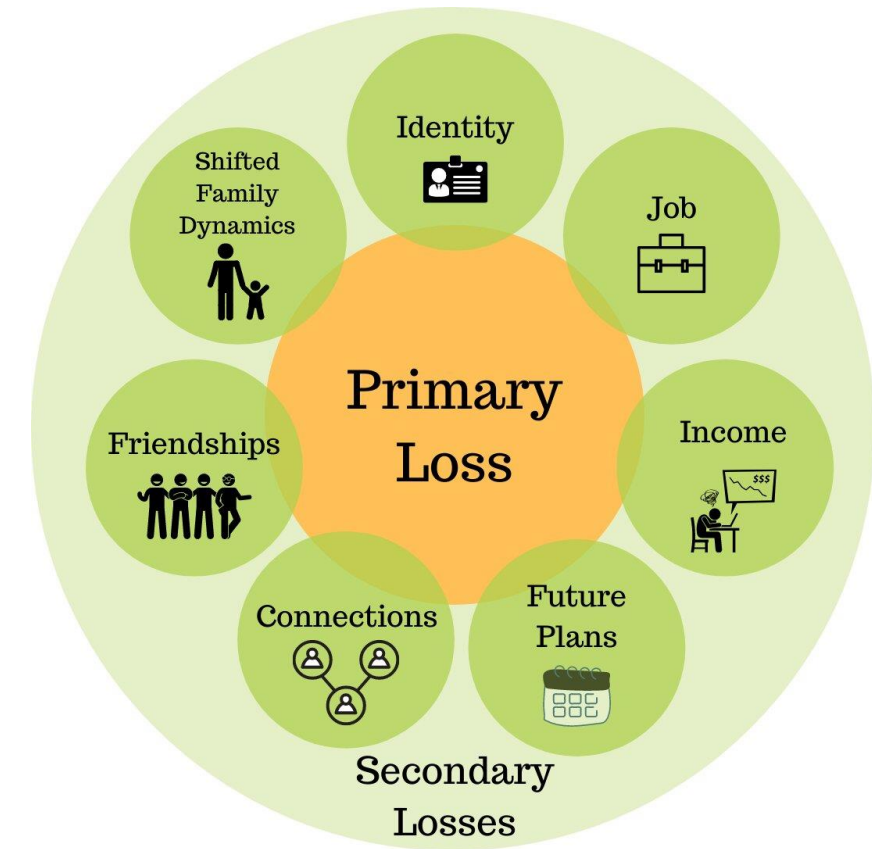


Overview

- How does grief and loss look from a psychological perspective
- What is grief and loss in the context of rare diseases
- How does effective psychological support look like

Grief and Loss

- **What is Grief and Loss?**
 - **Grief:** A natural response to loss, encompassing emotional, physical, and social reactions
 - **Loss:** Not just death but also loss of abilities, dreams, or life trajectory
- Each person's experience of grief and loss is different, although there are some universal reactions (*attachment theory*)



Impact (Psychological and Emotional)

Feelings

- Sadness, anger, blame, guilt, anxiety, loneliness, numbness

Physical sensations

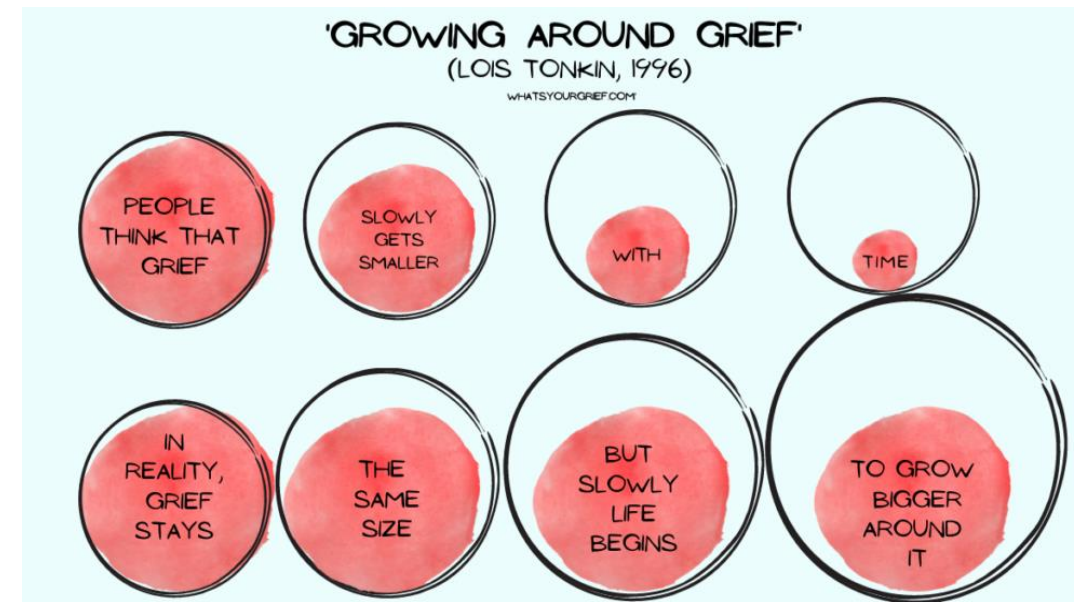
- fatigue, similar reaction to panic (chest pain, breathlessness, muscle weakness etc)

Thoughts

- Disbelief, confusion, preoccupation, sense of presence

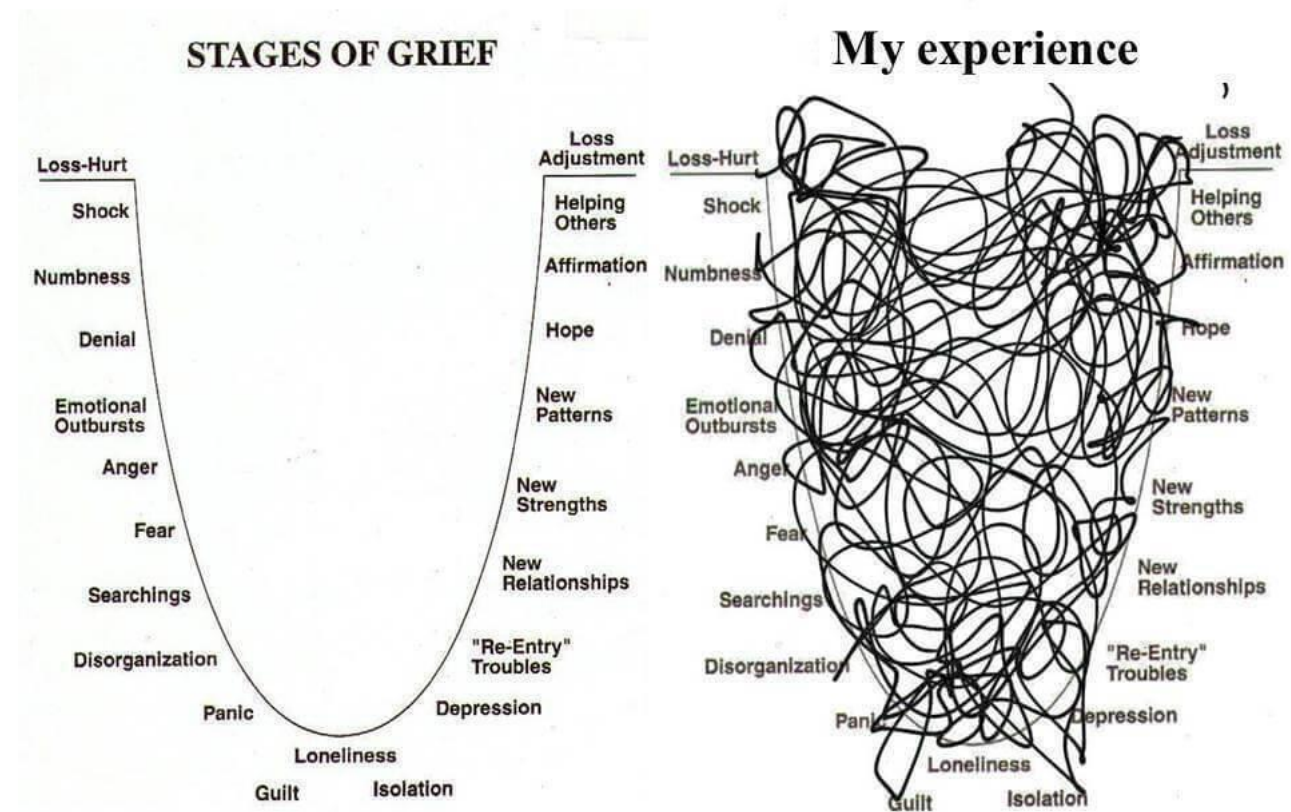
Behaviours

- Sleeping problems, eating problems, absent mind, social withdrawal, avoiding reminders, hyperactivity, revisiting places



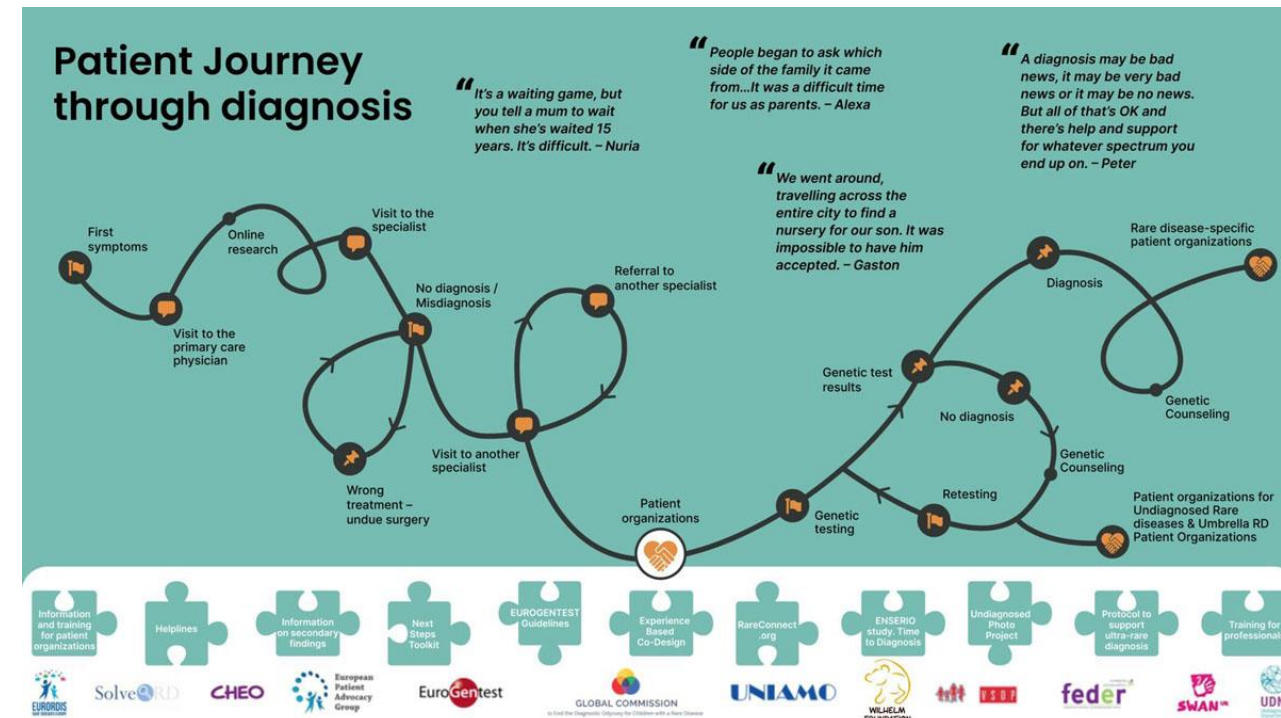
Grief Process is Not Linear

- There are different psychological **models and theories** on the stages of grief
- They provide help in **understanding** how we can best support the individual
- Grief can be cyclical, often reignited by new challenges
- Individuals experience grief differently; there is no "normal" timeline



Grief and Loss in the Context of Rare Diseases

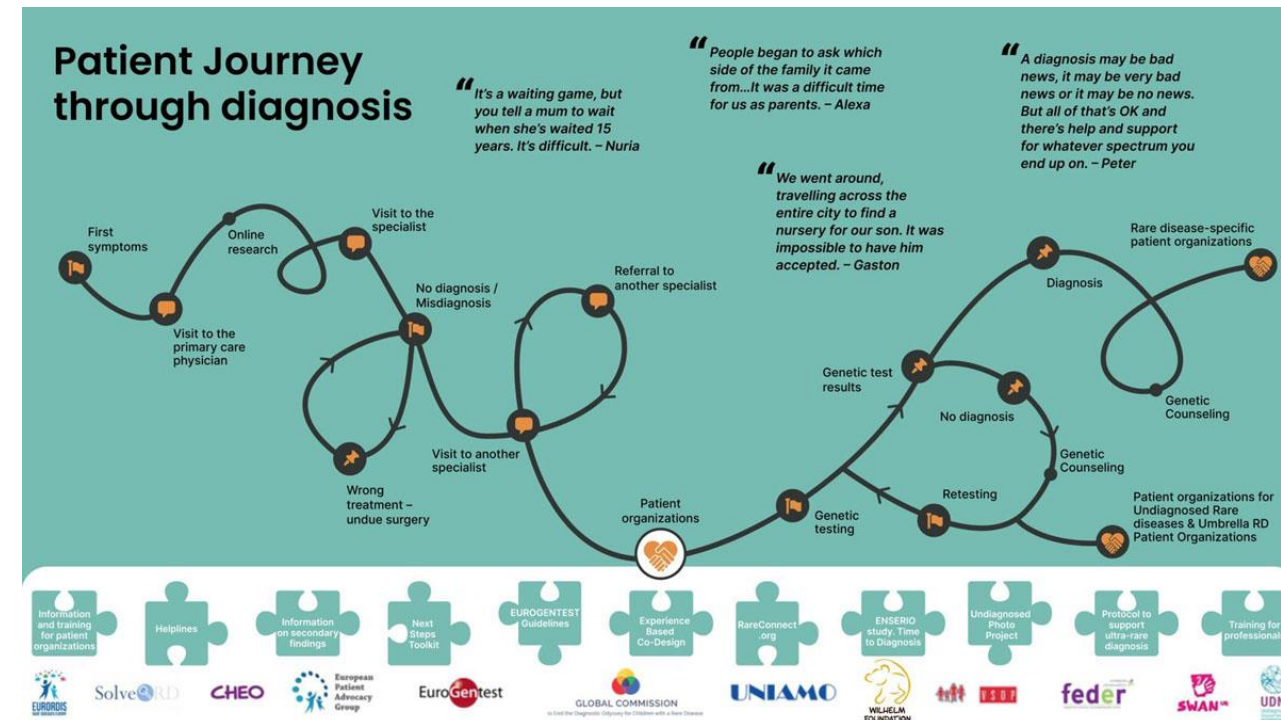
- Ongoing, **ambiguous losses** (e.g., loss of certainty, health, identity)
- **Family-wide** impact: caregivers and loved ones also experience grief
- The **rarity factor**: limited understanding and isolation amplify feelings
 - Unpredictable disease progression
 - Lack of clear prognosis or milestones
 - Social isolation due to the rarity of the disease
 - Misunderstanding from others who may not grasp the depth of loss



Grief and Loss in the Context of Rare Diseases

Different types of losses:

- Sudden Death/Violent Deaths
- Sudden Infant Death Syndrome (SIDS)
- Miscarriages/ Stillbirths/ Abortion
- Suicide
- Anticipatory Grief
- Grieving others losses in RD – it's not only about death (infertility, 'normal' trajectory or achievements, disability)



Effective Support – What Works?

Goal of grief counselling is to adapt to the loss of a loved one and to adjust to a new reality without them

1. Help the Individual Actualize the Loss
2. Help the Individual to Identify and Experience Feelings
3. Assist Living Without the Loved One
4. Help Find Meaning in the Loss
5. Help Find Ways to Remember the Loved One
6. Provide Time to Grieve
7. Interpret Normal Behaviour
8. Allow for Individual Differences
9. Examine Defences and Coping Styles
10. Identify Pathology and Refer Forward



Effective Support – What Works?

Useful Psychotherapeutic Techniques and Tools

- Evocative Language (to highlight emotions)
- Use of Symbols (pictures, letters, videos)
- Writing (journal, letters)
- Drawing (art therapy, suited for children)
- Role-Playing (to address practical situations)
- Cognitive Restructuring (to address challenging thoughts)
- Memory Books (activity to include the whole family)
- Directed Imagery (to address challenging feelings)
- Metaphors (for symbolic representation of the process)



Build Resilience and Going Forward

- Focusing on what can be controlled (e.g., lifestyle, connections)
 - Developing coping strategies and seeking joy in daily life
 - Advocacy and finding purpose in raising awareness or supporting others
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- Grief is a normal, natural, and evolving process
 - Effective support exists but must be personalized
 - Community, support, and care can build resilience



Thank you!

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