

Loss and Grief while Living with Primary Sclerosing Cholangitis: Who, Why, What, When and How



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Who might experience grief and loss?

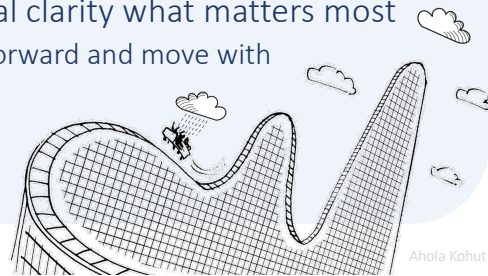
Everyone

- Signs and symptoms of grief, depression, sadness, and symptomatic PSC overlap
- Living with PSC, you may not realize part of this is a common process
 - Loss of rose coloured glasses, even if asymptomatic
 - Loss of what you imagined your life would look like
 - There are also instances where it is traumatic loss or complicated grief



Why spend time talking about grief and loss?

- Grief is not just about death, it is about loss and is a natural part of life
 - There are many forms of grief
- Acknowledging and integrating feelings allows you to better choose
 - Allow yourself to grieve without guilt
 - Naming an emotion or process allows it to naturally settle
- Grief has a way of highlighting with crystal clarity what matters most
 - Helps answer how you would like to move forward and move with



Boss, 2004; 2006

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What is grief?

Sadness

- Emotion
- Temporary
- Able to function
- Resolves on its own
- Few or mild physical symptoms
- Unhappiness, disappointment



Grief

- Process
- Life long
- May affect daily life
- Benefits from support and s/t therapy
- Some physical symptoms
- Sadness, longing, anger, guilt



Depression

- Mental health disorder
- Relapsing and remitting
- Impacts daily life
- Requires multidisciplinary treatment
- Many physical symptoms: appetite, sleep, pain
- Emptiness, hopelessness, numbness, anger, guilt

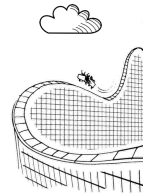
Fatigue and brain fog are common in all

Boss, 2006, DSM 5TR

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What is ambiguous loss?

- Grief that is unclear or uncertain, with no clear 'end', incomplete
 - Not often acknowledged in society, disenfranchised
 - Grieve all the versions of your life that you might not live
- Ambiguous loss can lead to feeling stuck or frozen
 - Common feelings of anger, disconnection, loneliness, uselessness, increased emotional stress



If you saw your struggles as grief, how might you treat yourself differently?

Boss, 2004; Boss & Couden, 2002

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What are common signs in PSC?

- Difficulty following or related to:
 - A change in ability, role, identity, purpose, future plans
 - Uncertainty in treatment plan or disease trajectory
 - Disease progression
- Often people question, invalidate, or ignore emotions
 - I 'should' be over this, I 'should' move on
 - I don't want to be a burden
 - Don't give yourself credit



"You are not a burden. You have a burden, which by definition is too heavy to carry on your own."

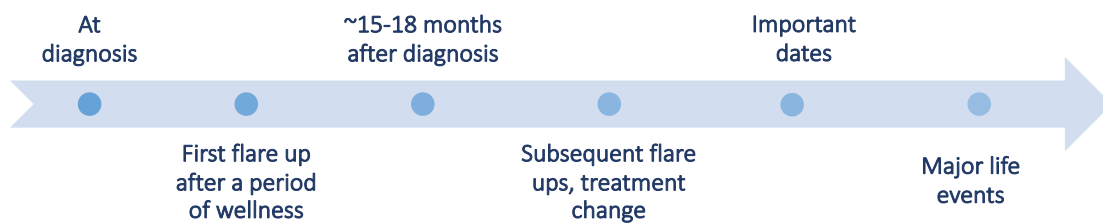
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Arndtz et al., 2025; Boss & Couden, 2002; Loesken et al., 2023; Tan et al., 2025

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When might this arise?

- At vulnerable stages throughout PSC process and life events
 - For yourself or other members of PSC community
- Anticipatory grief is also common



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...or it can be random!



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How to Cope with Loss

Movement

- Bodies in motion stay in motion
- Pacing your day
- Schedule time to do nothing and to rest
- You cannot wait for motivation to arrive, you start then it may build

Mind

- What has not been cancelled?
- Control the controllables
- What is going right?
- Feeling like you **should** do something?
 - Ask yourself - Do I have to? Do I want to?



Ahola Kohut et al, 2017; 2021; Ahola Kohut & Keefer, 2023; Ford et al., 2024; Hayes, Strosahl & Wilson, 2012 Ahola Kohut 2025

How to Cope with Loss



Emotions

- **Name them**, say hello to them
- Mindfulness
- Emotions are sensations
 - Find them in the body, notice their qualities
- Watch a sad/scary/thrilling movie to help process emotions physically

Purpose & Social

- Take the time to know your why
- Have workable boundaries
- Better out than in!
- Bring a friend or loved one, join a group



This is hard because it is hard, not because you did or are doing something wrong

YOU CAN'T CONTROL
THE WIND, BUT YOU CAN
ADJUST THE SAILS



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SickKids
Inflammatory Bowel
Disease Centre



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