



International Association of
Hidradenitis Suppurativa Network, Inc.

eBook

Supporting Grieving Children with Hidradenitis Suppurativa (HS): A Therapist's Guide

"Working together, therapist and teen, we build a space of trust and understanding—where challenges are met with empathy, growth is celebrated, and the journey forward is guided by the teen's unique strengths and resilience."

Dr. Donna Atherton

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Introduction

Children with Hidradenitis Suppurativa (HS) face unique emotional and social challenges that can lead to feelings of grief. This grief may arise from the loss of normalcy, changes in friendships, or limitations in participating in activities their peers enjoy. As a therapist, recognizing and addressing these feelings is crucial to helping children process their experiences and build resilience.

This guide is designed to support therapists in understanding the specific grief that children with HS may experience and to offer practical approaches to help them navigate these emotions. By fostering a compassionate environment and providing targeted coping strategies, you can empower children with HS to embrace their strengths, feel supported, and find hope beyond their condition.

MODULE 1



Recognizing Grief in Children with HS

Children with HS may experience grief differently than those grieving a loved one. Look for these common grief indicators associated with chronic conditions:

- **Loss of Normalcy:** Children may express sadness or frustration over being unable to engage in typical activities, from physical play to social events.
- **Social Withdrawal:** They may avoid social activities due to pain, self-consciousness, or fear of judgment, leading to isolation and loss of friendships.

- **Emotional Sensitivity:** Heightened sensitivity and emotional reactions may stem from the ongoing stress of managing HS, impacting their self-esteem and mood.
- **Low Self-Worth:** Children may feel “different” from peers, leading to negative self-perception, feelings of inadequacy, and shame related to visible symptoms.

Tip: Encourage gentle, open-ended questions to help the child share experiences in their own words, such as, “What’s been the hardest part about HS for you?”

MODULE 2

Creating a Safe, Compassionate Environment for Emotional Expression



Therapy should provide a space where children feel safe to explore complex feelings around HS and its impact on their lives.

Creating a Safe, Compassionate Environment for Emotional Expression

- ✓ • **Acknowledge Their Losses:** Affirm that it's normal to feel grief over the changes HS has brought, such as limitations on activities or changes in friendships.
- ✓ • **Normalize Their Experience:** Help children understand that it's common to feel upset, frustrated, or sad, and they are not alone in feeling this way.
- **Use Creative Expression:** Art therapy, journaling, and storytelling can provide an outlet for children to express feelings they may find difficult to verbalize.



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Tip: Incorporate prompts like “Draw what a tough day with HS looks like” or “Write a story about a hero who faces challenges.”

MODULE 3



Helping Children Process Loss and Navigate Change

HS often means a loss of normal childhood experiences. Therapists can help children process these losses by:

- **Recognizing Loss of Routine:**
Validate the impact of missing out on sports, events, or activities. Emphasize their strength in adapting to these changes.
- **Reframing Challenges:** Help them understand that HS does not define them; instead, focus on their bravery and resilience in handling their unique situation.
- **Encouraging Emotional Exploration:** Use age-appropriate language to discuss emotions related to grief, like sadness, frustration, and even anger. Help them build vocabulary to express these feelings.

✓ **Tip:** Create a “Strengths Journal” where the child records personal qualities or moments of resilience, shifting focus from loss to capability.

MODULE 4



Building Resilience and Coping Skills

Teaching coping strategies empowers children to face challenges related to HS with confidence and resilience.

- **Mindfulness and Relaxation:** Simple relaxation techniques, like deep breathing or body scanning, can help children manage physical discomfort and reduce stress.
- **Positive Self-Talk:** Introduce affirmations and reframing techniques. For example, change “I can’t do what others do” to “I am learning to do things in my own way.”

- **Problem-Solving Skills:** Practice small steps in decision-making to build confidence. For example, help them plan strategies for communicating their needs to teachers or friends.

Tip: Develop a “Comfort Kit” together, filled with tools and techniques, like a small stress ball, affirmation cards, or a quick breathing exercise guide, they can use at school or home.

MODULE 5

Encouraging Social Connection and Support



Social isolation can heighten feelings of grief and loss. Encourage strategies that help children maintain connections and build a support network:

- **Building a Support Team:** Identify supportive friends, family members, or mentors who understand their needs and can provide a positive influence.
- **Support Groups and Peer Connections:** Recommend peer support groups (either in-person or online) where children can meet others with HS or similar conditions. Shared experiences can foster camaraderie and reduce feelings of isolation.
- **Practicing Social Confidence:** Role-play situations with the child to help them feel comfortable explaining HS to friends or setting boundaries for comfort.

Tip: Suggest simple conversation starters like, “I sometimes need extra breaks because of my skin condition” to boost their confidence in social settings.

MODULE 6



Working with Parents and Caregivers

Engaging parents in therapy ensures a supportive environment continues outside the therapy room.

- **Educate Parents on Grief in Chronic Illness:** Explain that children may grieve losses related to normalcy, social roles, or physical comfort and that this grief is a natural part of their journey.
- **Encourage Open Communication at Home:** Suggest that parents create regular check-ins to encourage their child to share thoughts and emotions about HS.
- **Empower Parents to Build Resilience:** Provide parents with tools, like mindfulness techniques or positive reinforcement practices, that they can use to support their child's growth.

✓ **Tip:** Offer parents resources, such as articles or support groups for caregivers of children with chronic illnesses, to build their understanding and support network.

MODULE 7



Grief Resources for Children with Chronic Illnesses

- **Books on Coping with Chronic Illness and Resilience:** Recommend age-appropriate books or stories about resilience, self-acceptance, and coping with chronic conditions.
- **Activity Sheets for Home Use:** Provide creative prompts, gratitude journals, or coping strategy worksheets that children can use between sessions to reflect and build skills.
- **Mindfulness Apps for Kids:** Suggest kid-friendly apps with guided mindfulness exercises to help manage anxiety and stress related to HS.

✓ Therapists play a crucial role in helping children with HS process grief, build resilience, and foster self-confidence. By providing a compassionate space, practical coping tools, and resources to nurture their strengths, you empower children to navigate the challenges of HS with hope and resilience.

"By offering empathy,
guidance, and a safe space,
you empower children to
find resilience and hope
beyond their challenges.
Your support helps them
see that they are defined
not by their condition, but
by their strength and
courage."

Conclusion and Next Steps

Supporting children with Hidradenitis Suppurativa (HS) requires a compassionate approach that acknowledges their unique experiences of grief and loss. By creating a safe space for them to express their feelings, fostering resilience through practical coping strategies, and encouraging positive social connections, you help them develop the emotional tools needed to navigate life with confidence and hope.

Thank you!



Dr. Donna,



LEARN MORE



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