



DR. ABIGAIL NATHANSON

THERAPY AND CONSULTING FOR ILLNESS, CAREGIVING, AND LOSS

# Grieving the Losses of Prion Diseases

CJD Foundation Family Conference

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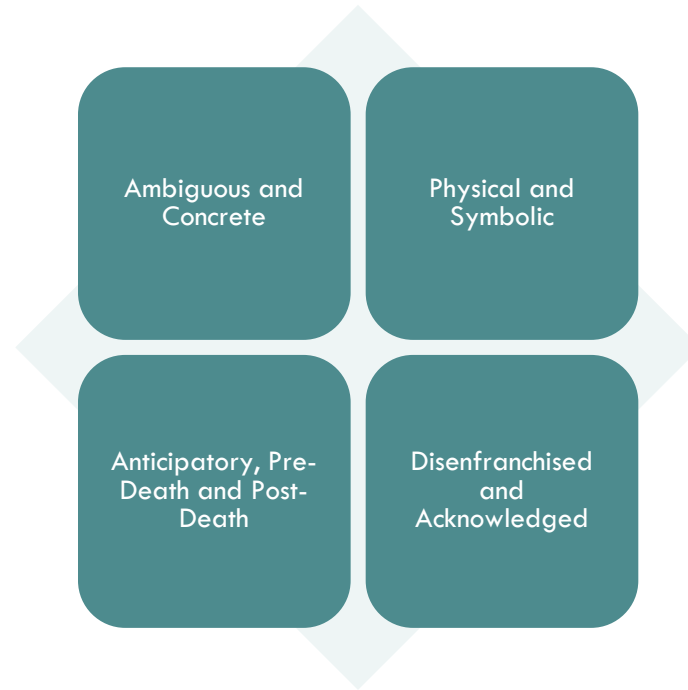
Everybody dies in the middle of  
someone else's story.

-A.H., 83 years old

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# Ways To Understand Grief



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Ask yourself:

How do I feel about my grief?  
How do I feel right now?

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## Dual Process Model of Grief

Schut & Stroebe

Make it normal to go between feeling the loss, and focusing on how to live your life without- neither is a step backwards.

*Periodic* avoidance is useful.

*Permanent* avoidance is worth tweaking.

## Window of Tolerance

Dan Siegel

*Am I **present***, is my world tolerable right now to both think and feel, even if it's very painful?

*Am I in **hyperarousal***, and trying to run and fix and spin and do?

*Am I in **hypoarousal***, and numb and not feeling much?

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Ask yourself:

When did my grief start?

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# Some Typical Losses with CJD

- Roles & other milestones, life you thought you were going to have
- Out of life cycle
- Person as you knew them before
- Having role of expert in healthcare/advocate
- Control, predictability, security, connection
- Existing connections as they may not understand or get fatigued
- Relationship to higher power
- Faith in healthcare
- Income, career
- Time to grieve losses

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Ask yourself:

Where do I hold my grief  
in my body?

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# STRUGGLES OF CJD GRIEF

Finding others who get it

Trauma of diagnosis

Watching a person  
become unrecognizable,  
so quickly

Coming out of “survival  
mode”

Integrating the  
ambiguous losses

Grief of changed  
relationships

Missed milestones  
throughout life of  
survivors

Often unable to have  
“closure”/unfinished  
narratives

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Ask yourself:

What can I do less of,  
in my grief?

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# Coping with CJD Grief

- NAME what you've lost, and hold it lovingly.
- *BE KIND to yourself about how you're coping- it's probably okay.*
- BE KIND to others who may not show up how you need them, or to people who cope differently than you do. Look for opportunities for imperfect connections.
- RECOGNIZE that while nothing will fill the hole, you can create a life worth living, even if it's not how you expected it to be- *and let yourself grieve that, too.*
- DON'T COMPARE your INSIDES to other people's OUTSIDES.
- *DON'T hold yourself to timelines and expectations for where you "should" be at a certain point in your grief.*
- LET YOURSELF have your feelings without the pressure of action or being "over it." (Listen with compassion for the self-judgy voices!)

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Ask yourself:

In my hardest moments,  
what do I most need to hear,  
know & remember?

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# When Considering More Care...

## Individual Considerations

- Reflect on baseline traumas, family dynamics, temperament, impacts on other relationships
- When hearing other people's experiences is mostly more flooding than comforting
- *Always, when:* Risk of destabilization, Prolonged Grief Disorder, PTSD, active substance use or impairing mental disorder
- *Ask:* How does provider treat grief differently from depression?
- *Ask:* How does provider see goals, change in grief? (Not "less/fix grief"!)

## Group Considerations

- Run by peer or professional
- Open or closed
- Short or long term
- Relationship, illness or mixed
- Orientation (structured vs emerging themes)
- Caregivers and/or bereaved
- Often free or very accessible

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# Additional Grief Resources

- Book, Social Media and Website:

*What's Your Grief*, by Haley & Williams

- Chimamanda Ngzoi Adichie, *Notes on Grief*
- Rebecca Solnit, *A Field Guide to Getting Lost (uncertainty)*
- George Bonnano, *The Other Side of Sadness (resilient mourning)*
- Bessel Van Der Kolk, *The Body Keeps The Score (trauma)*

- Local hospices (even if not a patient there)
- CJD Foundation Support Groups
- [www.good-grief.org](http://www.good-grief.org)
- [www.dougy.org](http://www.dougy.org)

## **For Kids (and the kids in all of us):**

Ida, Always (Levis – illness, caregiving and death)

Invisible String (Karst – continued connection)

When Dinosaurs Die (Brown – asks all of the questions)

The Dead Bird (Brown – normalizes kids' approach to death)

The Rabbit Listened (Doerrfeld- about feelings and listening)

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# Contact

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