

Loss and Grief for All of Us

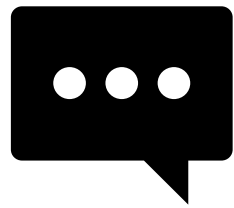
IL ARC QIPD Conference

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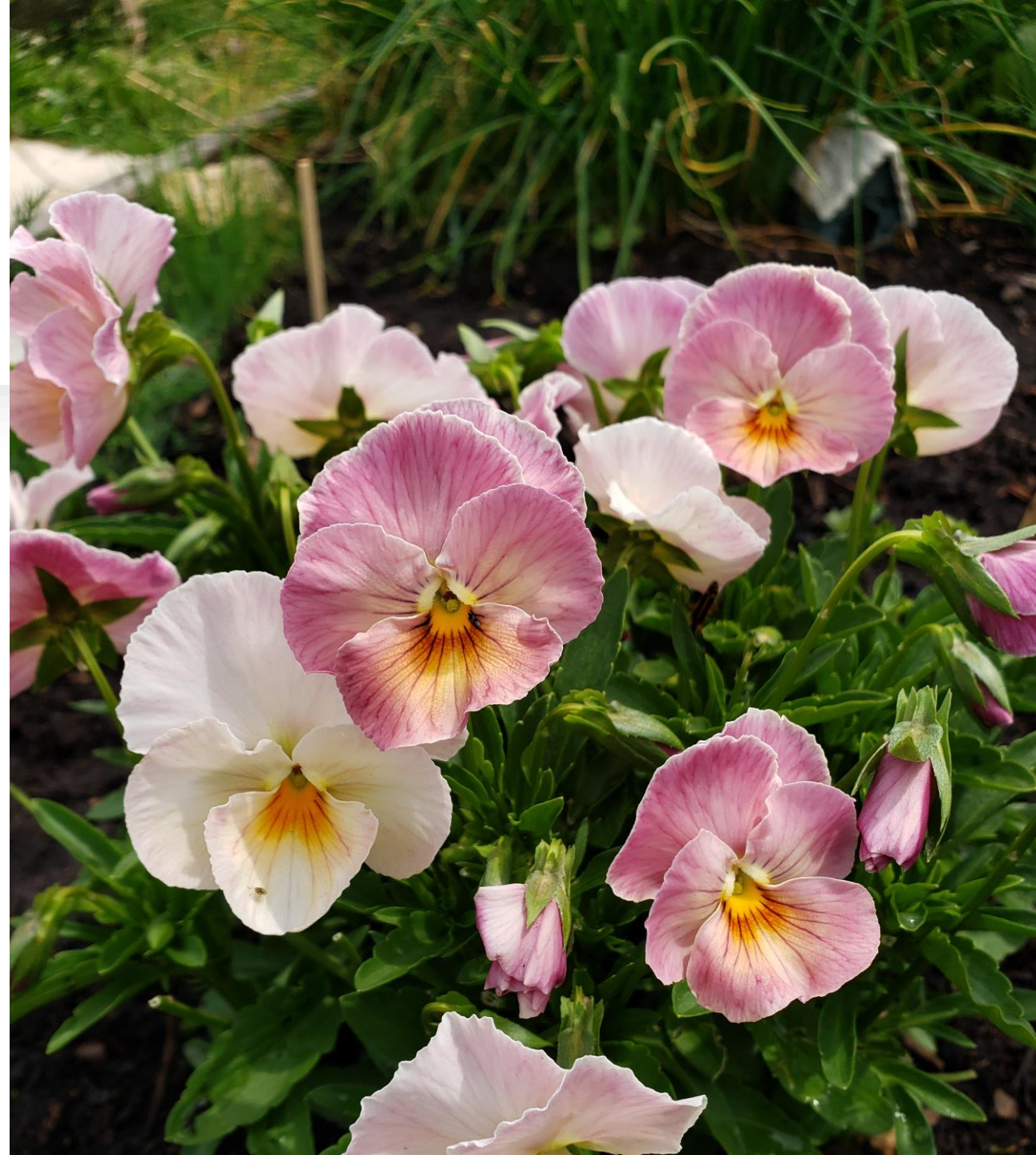
What is loss?

Loss can be...

- Death
- End of a friendship
- Divorce
- Leaving a job
- Loss of status
- Loss of role
- Moving/loss of home
- Changes in health / functioning

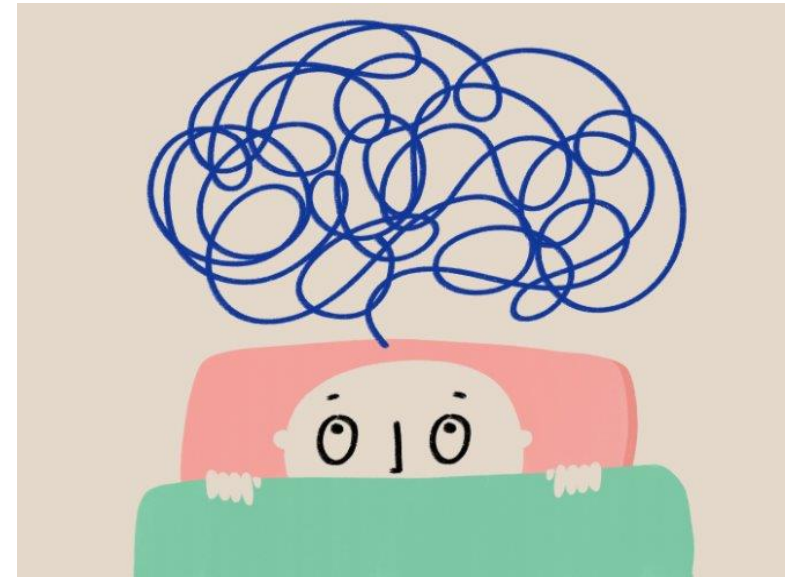
Grief is a healthy and
adaptive response to
loss, not a disorder.

Harris, 2023

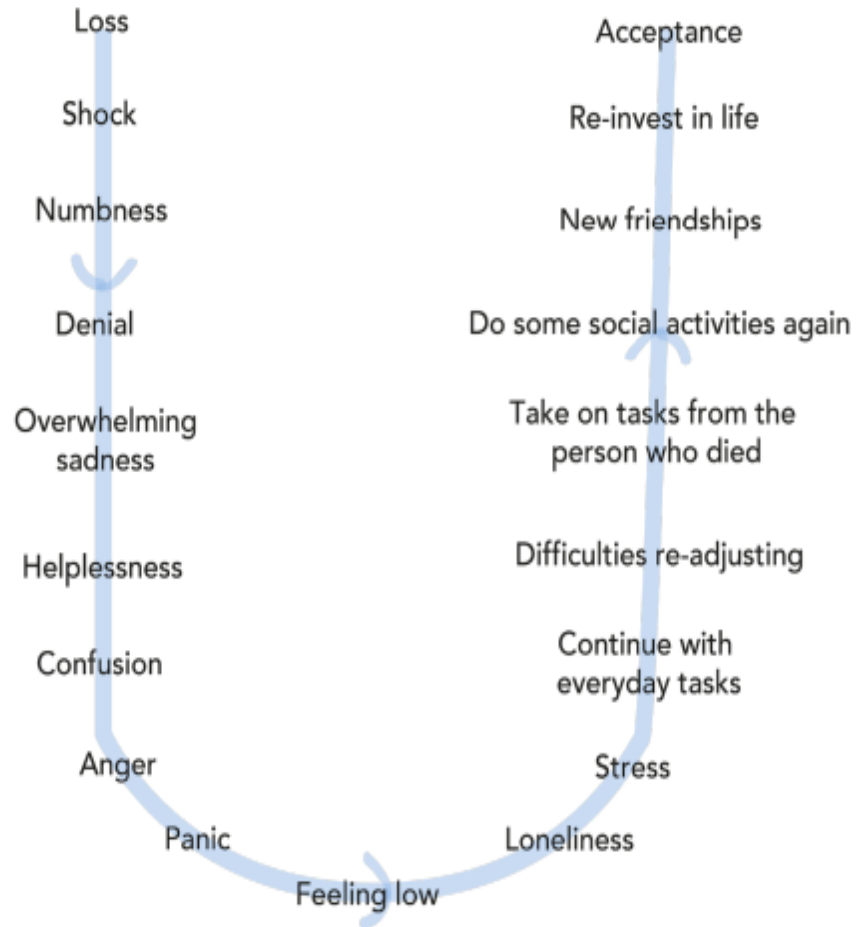


What is grief?

- Normal, natural process that occurs in response to loss
- Helps us to adapt to and integrate loss
- There is no timeline for grief
- There is no right or wrong way to grieve
- Universal and individually unique



Early theories of grief



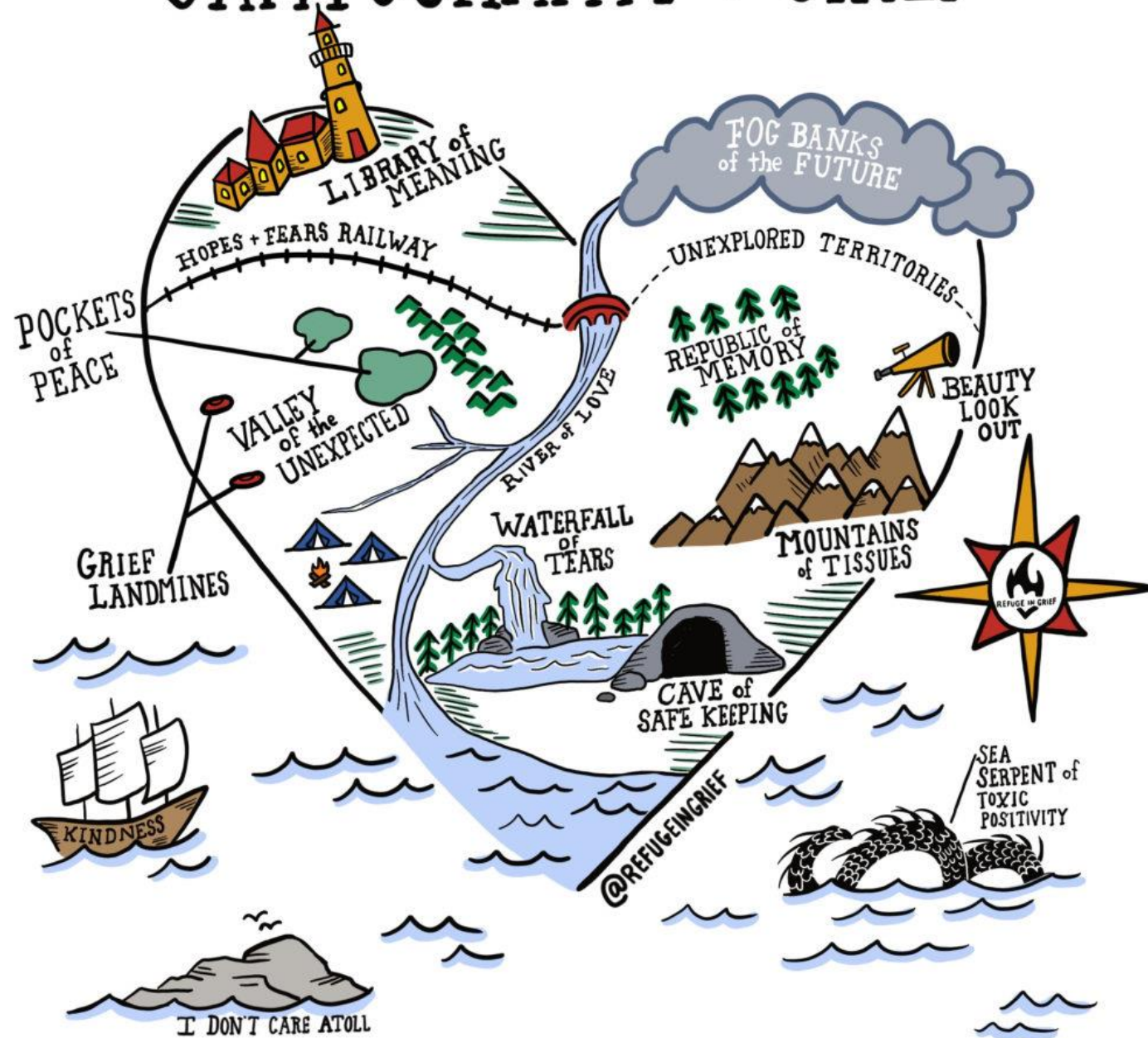
The reality



Grief can be.....

- Overwhelming Sadness
- Shock
- Numbness
- Anger
- Denial/Disbelief
- Guilt
- Relief
- Anxiety/Fear
- Low Energy
- Memory/Concentration changes
- Changes in sleeping and eating
- Keeping busy
- Decreased Resilience

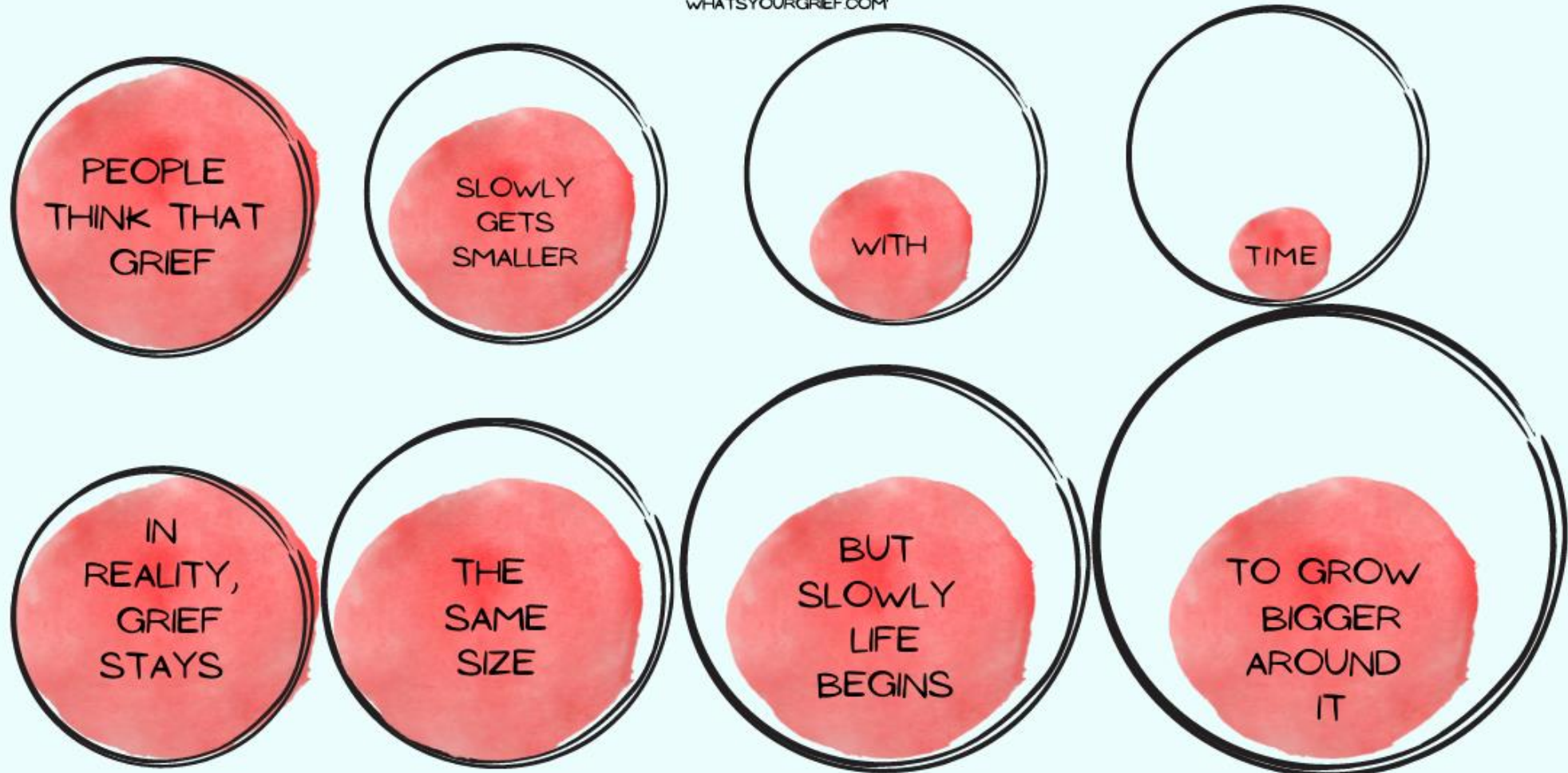
CARTOGRAPHY of GRIEF



'GROWING AROUND GRIEF'

(LOIS TONKIN, 1996)

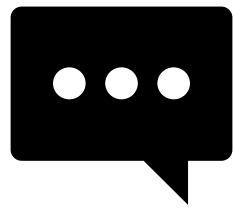
WHATSYOURGRIEF.COM



Avoid saying...

- You'll get through this
- Just don't think about it
- They're in a better place
- Everything happens for a reason
- Be strong
- I know exactly how you feel

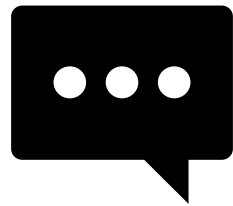




What do you say?
What do you do?

What to say and do...

- I'm so sorry for your loss
- Acknowledge that words don't feel like they're enough
- Validate feelings
- Actively listen
- Offer practical help
- Share memories, ask to hear theirs



What are some of the myths
about people with IDD and
grief/loss?

Grief and loss for people with IDD

- Cultural discomfort with grief and loss often leads to avoidance and minimizing
- Grief denied is grief delayed
- Belief that people with IDD need to be "protected" from grief
- Disenfranchised grief
- Diagnostic Overshadowing
- Communication differences

Grieving together

- Shared loss, different magnitudes
- Supporting staff = Supporting individuals with disabilities
- Self-awareness
- Boundaries
- Community Care & Rituals



Supporting grief

- Asking about memories
- Art, writing, music
- Creating memory books
- Creating spaces of remembrance
- Cultural, spiritual, religious rituals



Grief

- Specific Loss
- Fluctuating ability to
- feel pleasure
- self-esteem usually intact
- ebbs & flows

- low mood
- sadness
- low energy
- sleep disruption
- Appetite/weight change
- trouble focusing
- guilt
- apathy

Depression

- Inability to feel pleasure
- Feelings of worthlessness & self-loathing
- Isolation
- consistent

When to seek additional help...

- Check in with staff
- New psychotic symptoms
- Suicidality, self-injurious behavior
- Overwhelming / worsening grief 6 months after loss

Resources

Autism and Grief Project

<https://www.autismandgrief.org/>

Helping, Responding, Rituals

<https://boggscenter.rwjms.rutgers.edu/resources/publications/resources-about-grief-and-loss>

Books Beyond Words – When Somebody Dies

<https://booksbeyondwords.co.uk/bookshop/paperbacks/when-somebody-dies>

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