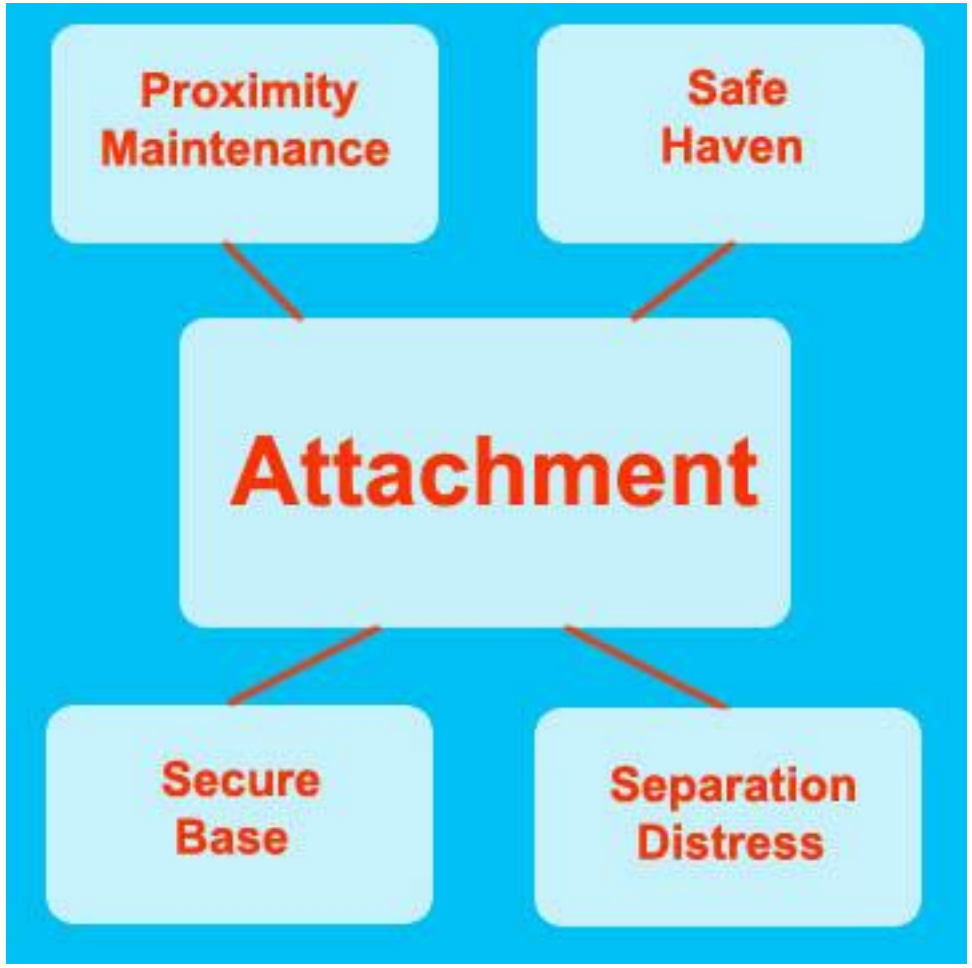
Prolonged Grief Disorder/Complicated Grief :

What is it and how can we help?

Dr Susan Delaney

To understand grief we have to understand attachment

Bowlby was right!



We are hard-wired to attach to others. We first attach for our very survival, but we continue to attach to people throughout our lives. We have our “go-to” people. Bereavement by its nature, disrupts the grieving person’s attachment to their person. The yearning and preoccupation we experience compels us to try to find ways to restore our connection to them

So if we are hard wired to attach, how do we ever cope with the death of someone close to us?

Excellent question, so glad you asked…..

LOSS TRIGGERS AN INSTINCTIVE HEALING PROCESS

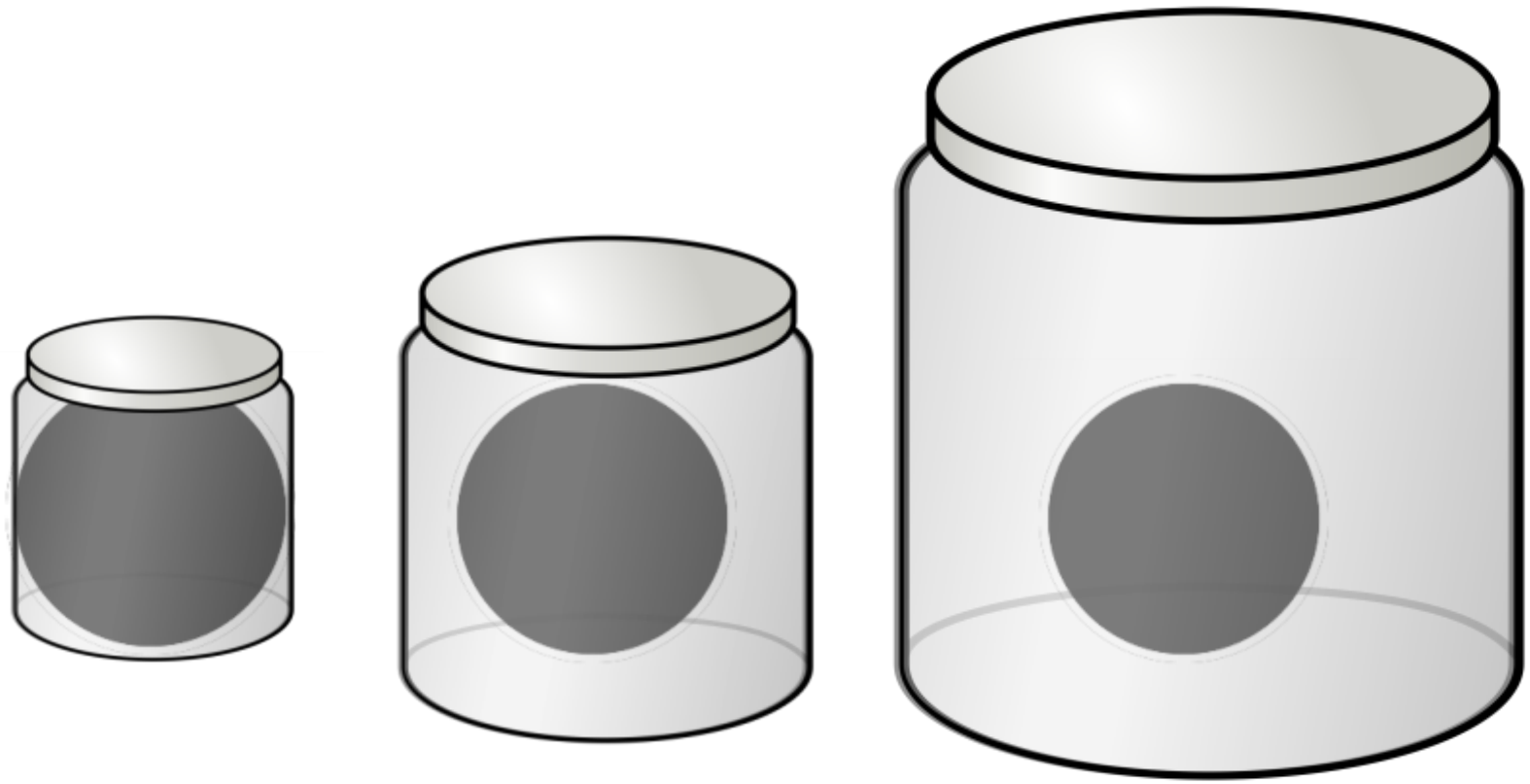
- Information about the death is assimilated;
- Emotional pain and positive feelings are gradually integrated resulting in bittersweet acceptance of the loss
- Grief is not "completed" but it is transformed

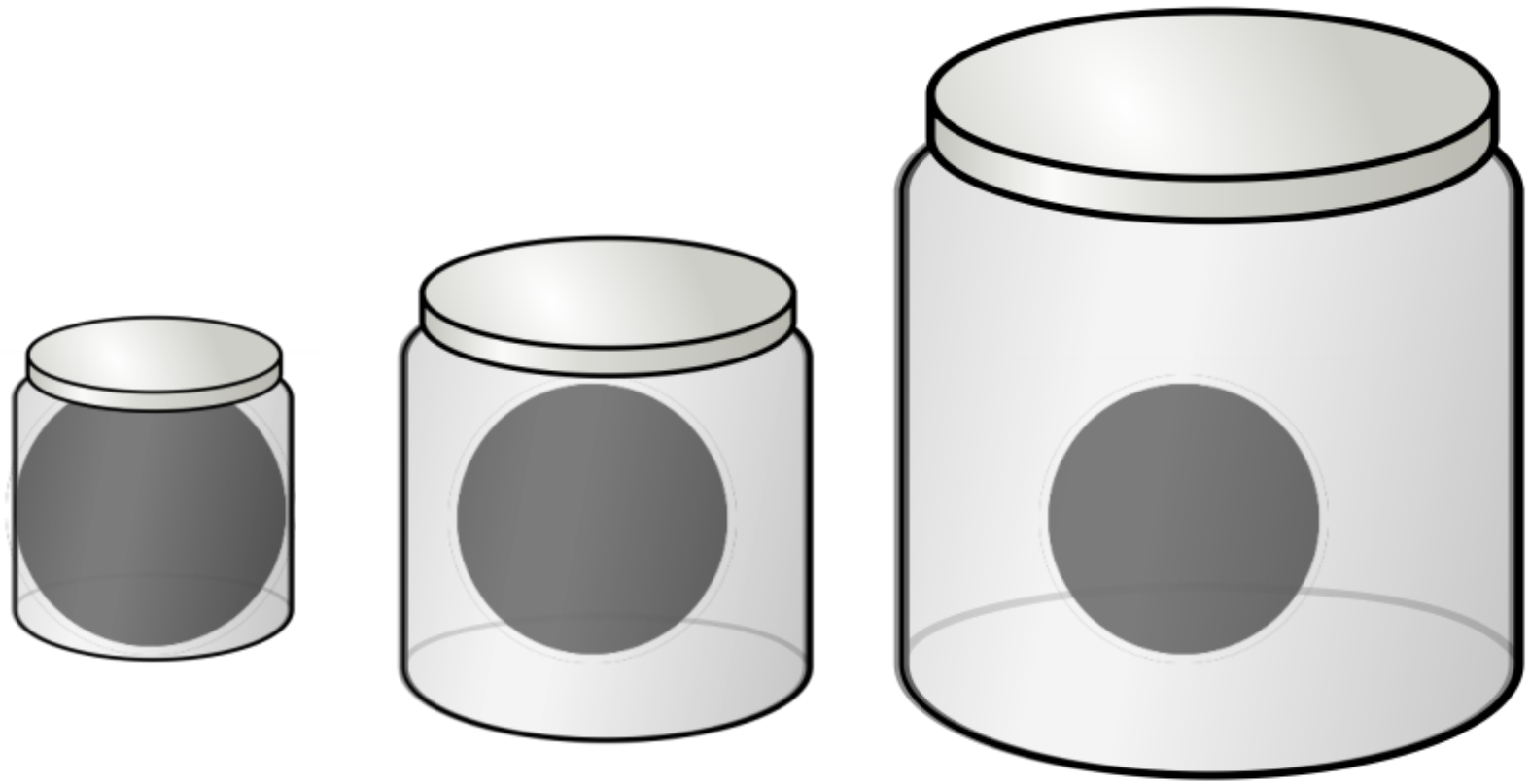
INTEGRATED GRIEF

Acceptance of the painful reality, including

1. Finality and consequences of the death (all that it means to the bereaved person)
2. A way to stay connected to the deceased
3. A way to go on with life that seems purposeful, and that includes experiences of joy and satisfaction

Growing around grief; Lois Tonkin





RECOGNISING OBSTACLES – when grief gets stuck

THE TERM "COMPLICATED" is used in the medical sense of a superimposed problem that interferes with healing

BEREAVEMENT

↓

ACUTE GRIEF, COMPLICATED BY

1. Rumination, e.g. counterfactual "if only" thinking
2. Excessive avoidance
3. Ineffective emotion regulation
4. Inadequate companionship

→

Intrusive troubling rumination about the circumstances or consequences of the death

Intense reactivity to reminders of the loss and/or excessive avoidance of reminders

Unrelenting yearning, longing; despairing sadness

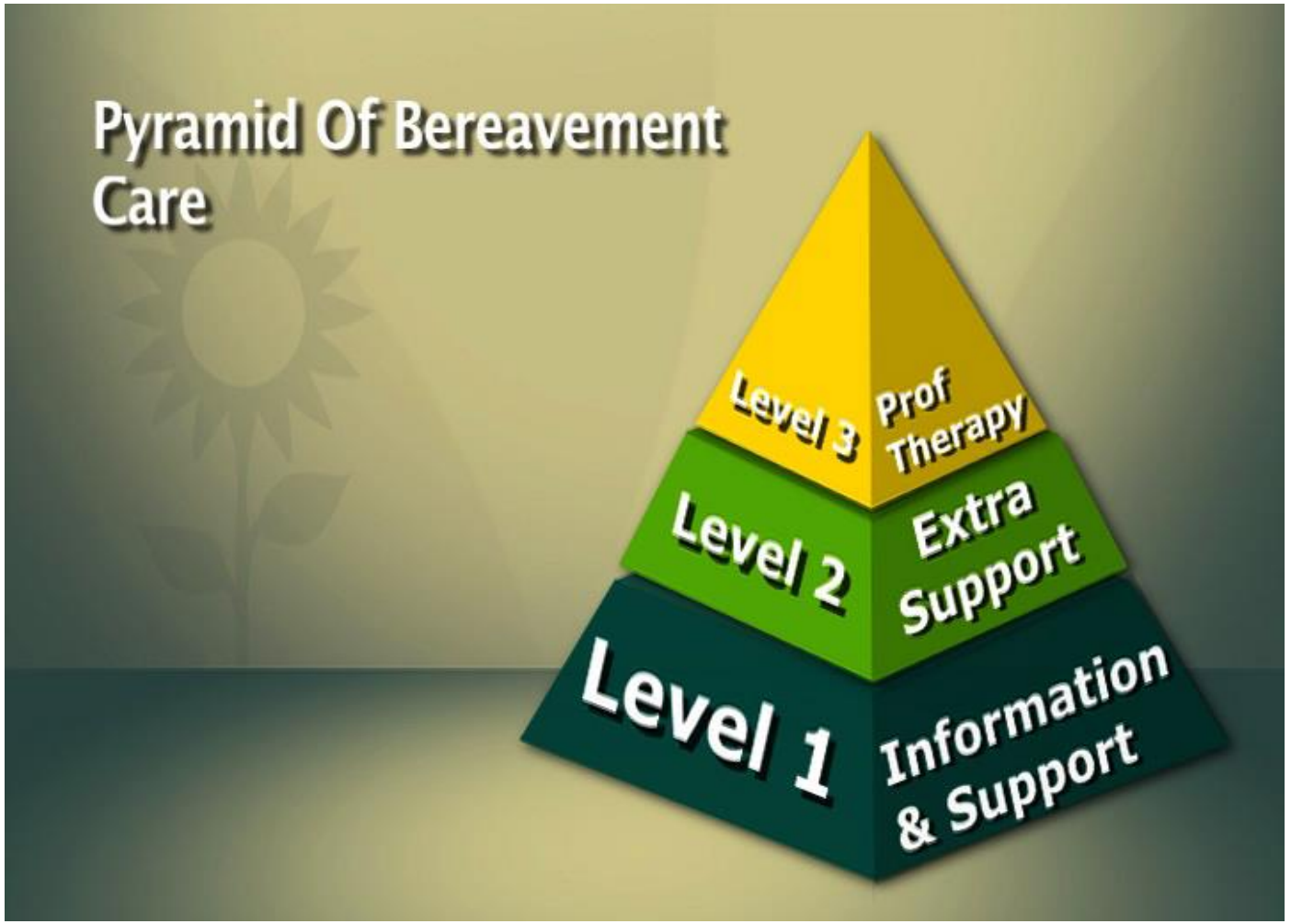
Preoccupation with thoughts and memories of the deceased, or compulsive proximity seeking

Feeling life has no purpose or joy

ICD-11 Guidelines

Prolonged grief disorder is a disturbance in which, following the death of a partner, parent, child, or other person close to the bereaved, there is persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities)..

The grief response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis. The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning



Graphic from Irish Hospice Foundation

Grief and depression are not the same thing

MDD

- Pervasive loss of interest or pleasure
- Pervasive dysphoric mood across situations
- General sense of guilt or shame

PGD

- Loss of interest or pleasure related to missing loved one
- Pangs of emotion triggered by reminders of loss
- Preoccupation with the deceased; guilt and self blame focused on death

DIFFERENCES BETWEEN PTSD AND PGD

- Triggering event: threat
- Primary emotion: fear
- Intrusive thoughts of event
- Avoidance: fear-based
- Nightmares prominent
- Reminders linked to event (not pervasive), evocative of fear or anger
- No proximity seeking

- Triggering event: loss
- Primary emotion: sadness
- Intrusive thoughts of person
- Avoidance: loss-based
- Nightmares rare
- Reminders linked to the person (pervasive) bittersweet,
- Proximity seeking is prominent and associated with yearning

Risk Factors

Predisposing risk factors

- Close kinship to the deceased
- History of Insecure attachment

(People with secure attachments can down regulate more easily – “survival of the nurtured”)

- Caregiver burden

Death-related Risk factors

- Bereavement over-load
- Low acceptance of imminent death
- Violent death
- Finding or viewing the body following violent death
- Dissatisfaction with death notification
- COVID???

Treatment related Risk factors

- Aggressive medical intervention
- Ambivalence regarding treatment
- Family conflict regarding EOL treatment

Post-loss risk factors

- Quality of available social support
- Impact of COVID??
- Beliefs about whether the death was preventable
- Meaning-making ability

Prof Holly Prigerson
Cornell University

http://endoflife.weill.cornell.edu/research/assessments_and_tools

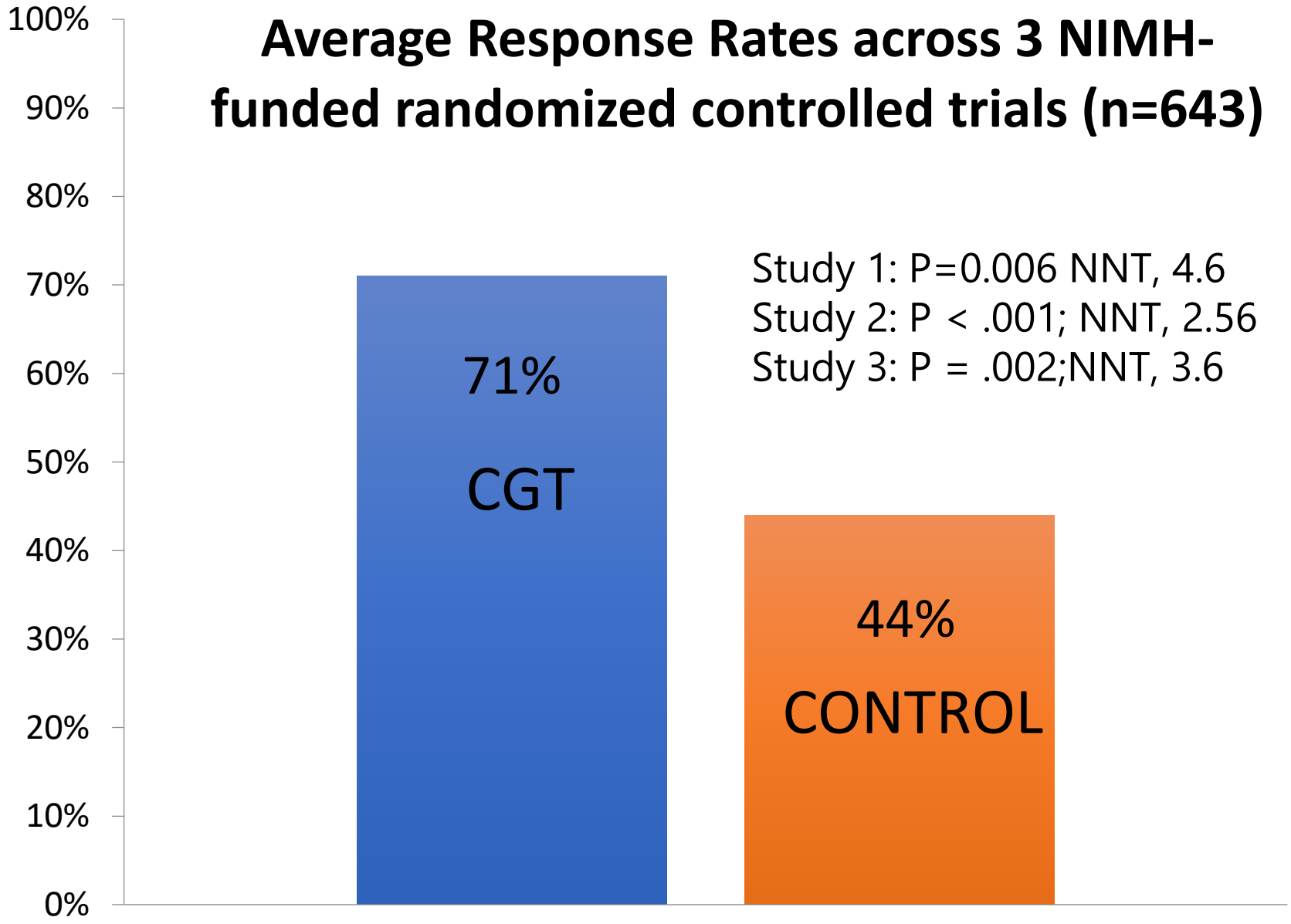
Center for Complicated Grief, Columbia University

www.complicatedgrief.org

CGT

CGT is the first evidence-based treatment protocol for treating CG. It was developed by Dr Kathy Shear at Columbia University. CGT is based on Attachment Theory and draws on the Dual Process model of Bereavement.

It integrates strategies derived from Interpersonal Psychotherapy (IPT), Cognitive Behavioural Therapy for PTSD (CBT) and Motivational Interviewing (MI).


Average Response Rates across 3 NIMH-funded randomized controlled trials (n=643)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
71%
CGT
44%
CONTROL
Study 1: P=0.006 NNT, 4.6
Study 2: P < .001; NNT, 2.56
Study 3: P = .002;NNT, 3.6

Dysfunctional beliefs that hinder grief integration

- Grief is my main tie to the person that died
- Grieving less would mean I am uncaring, or that I am betraying that person
- The only thing that would help me is to have this person back
- I need to guard against forgetting the person who died

Grief Avoidance

Do you avoid:

- Visiting the final resting place
- Looking at photos
- Contact with person’s personal belongings
- Places associated with the person who died
- Activities associated with person who died

Core themes of CGT

- Psycho – education
- Encouraging self-observation and reflection
- Rebuilding and strengthening personal/social connections
- Focusing on loss and restoration- related activities in tandem
- Fostering emotion regulation
- Imagining possibilities

How can we help?

Be willing to work in a different way. Many of us trained in more traditional ways of working with grief, it turns out that a more structured approach and careful sequencing can be more impactful. This doesn’t mean that compassionate listening and positive regard aren’t important, having grief witnessed is always important. It means it simply isn’t enough when grief is stuck

Use a dual process approach in your sessions. Very specifically, engage in grief work and restoration/renewal work in each session. Both matter, both are equally part of grief work

Teach clients about self Compassion

Bereaved people are often in a fear state – (fight or flight) and find it difficult to make good choices in their lives or to imagine a time when things might be different for them.

Ask clients to engage in simple self care, whether or not they want to

(or feel they deserve it).

Many of these clients are very hard on themselves. They berate themselves for not having done more. The person who died was often the only person who took care of them.

Get clients curious about their grief: Grief Monitoring

Encourage clients to make notes about their grief. This can help:

- Learn to move towards and away from their grief
- Notice that grief changes – it doesn't stay the same
- Notice that internal and external factors impact on their grief experience; sad songs, a thoughtful note…
- Become aware that they are already using strategies to manage their grief

(see GriefSteps App)

SAMPLE GRIEF MONITORING DIARY

Using a scale where 1=the least intense, and 10=the most intense grief you can imagine, please record the minimum and the maximum intensity of your grief each day and tell us when these **lowest** and **highest** points occurred. Then, at the end of the day, rate the average intensity for that day.

DAY	HIGHEST GRIEF	NOTES	LOWEST GRIEF	NOTES	AVERAGE GRIEF
Thurs	8	Had dinner with friends I haven's seen since I died	3	Spent time with 4 year old grand niece. She is very cute and funny	6
Fri	9	Before I went to bed. Missing I so much	7	Trying to watch tv (this was a bad day. home alone all day. no one called)	8

*****Griefsteps

Encourage clients to engage in small, rewarding activities, and encourage them to imagine what they would be doing if their grief was not so overwhelming?

Aspirational goals

Activities or projects that tap into intrinsic motivation:
Ask: What would you be doing if your grief wasn’t so overwhelming?

In summary

- Psychoeducation: Explain what PGD is and let clients know that working in a more structured way seems to help.
- Offer realistic hope that life can again be meaningful and even joyful
- Ask clients to write down what they are going to do for themselves between meetings
- Encourage clients to be curious about their grief and engage in guided discovery
- Encourage them to bring someone else into a meeting
- Mind yourself and your grief

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TEDX https://www.youtube.com/watch?v=4GDTbtePHUU

Acknowledgements

The “Balls and Jars” concept has been used by Jerusha McCormick and Barbara Monroe and was informed by the work of Tonkin:
Tonkin, L .(1996): Growing around grief—another way of looking at grief and recovery, *Bereavement Care*, 15:1

Complicated grief concepts and treatment were informed by the work of Prof Kathy Shear, Center for Complicated grief, Columbia University, NY. www.complicatedgrief.org