Complex Bereavement

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SESSION AIMS

- What is Bereavement?
- Grief concepts – historic and contemporary
- Screening for risk and protective factors
- Grief support during the illness phase
- Bereavement support after the death
- Normal Grief vs Complex Bereavement
- Case Discussion
- Questions

BEREAVEMENT

Encompasses the ***anticipation***, ***death*** and subsequent ***adjustment following the death*** of a loved one

GRIEF

Most people experience normal grief - which although painful and disruptive can:

- Still function in their daily lives.
- Integrate the loss into their life with support from family, friends and their community.
- Cope with the pain of grief *without the need for professional help.*
- Over time begin to adjust to their loss and to feel better.

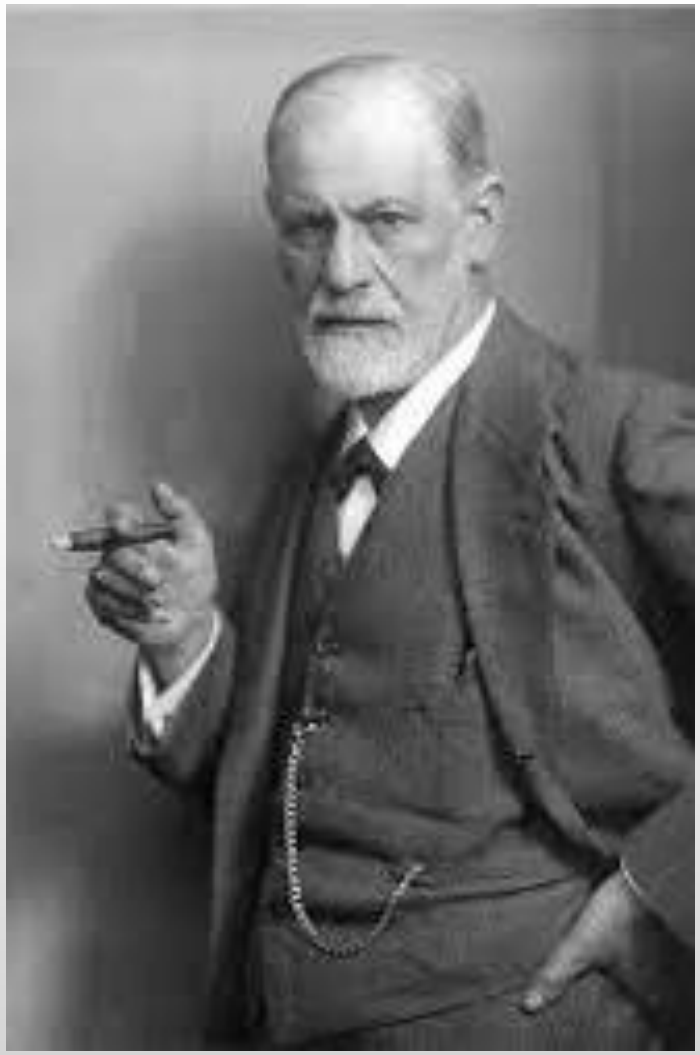
However some individuals may be at increased risk of experiencing problems in the lead up to and after the person's death

HISTORICAL CONCEPTS OF GRIEF

Freud Mourning and Melancholia (1917)

- Breaking ties with the deceased
- Energy directed at 'grief work' to acknowledge and express painful emotions
- Aim to return to normal functioning quickly
- Failure to complete grief work leads to grief complications and mental illness

(C. Hall, InPsych 2011 | Vol 33)



HISTORICAL CONCEPTS OF GRIEF

Kubler-Ross - Stages of Grief

- Transformed from ‘anticipatory grief’ with the dying – to widespread application to bereavement and other forms of change/grief.
- Implies grief involves an orderly progression through the stages and failure to complete any of these stages could be problematic.
- *Has been empirically rejected*, however has become deeply ingrained in our cultural and professional beliefs about loss.

(C. Hall, InPsych 2011 | Vol 33)

CONTEMPORARY GRIEF THEORY

- Multiple trajectories through grief (Bonanno et al., 2002, 2004)
- Phasal models of grief – Dual Process Model (Stoebe and Schut, 1999)
- Continuing Bonds (Klass, Silverman and Nickman, 1996)
- Meaning Reconstruction (Neimeyer, 2001)
- Range of Response to Loss Model (Machin, 2009, 2014)
- Growing around grief (Tonkin, 1996)
- Disenfranchised Grief (Doka, 2002)

DUAL PROCESS MODEL – Stroebe & Schut 1995

Dual Process Model of Coping with Bereavement

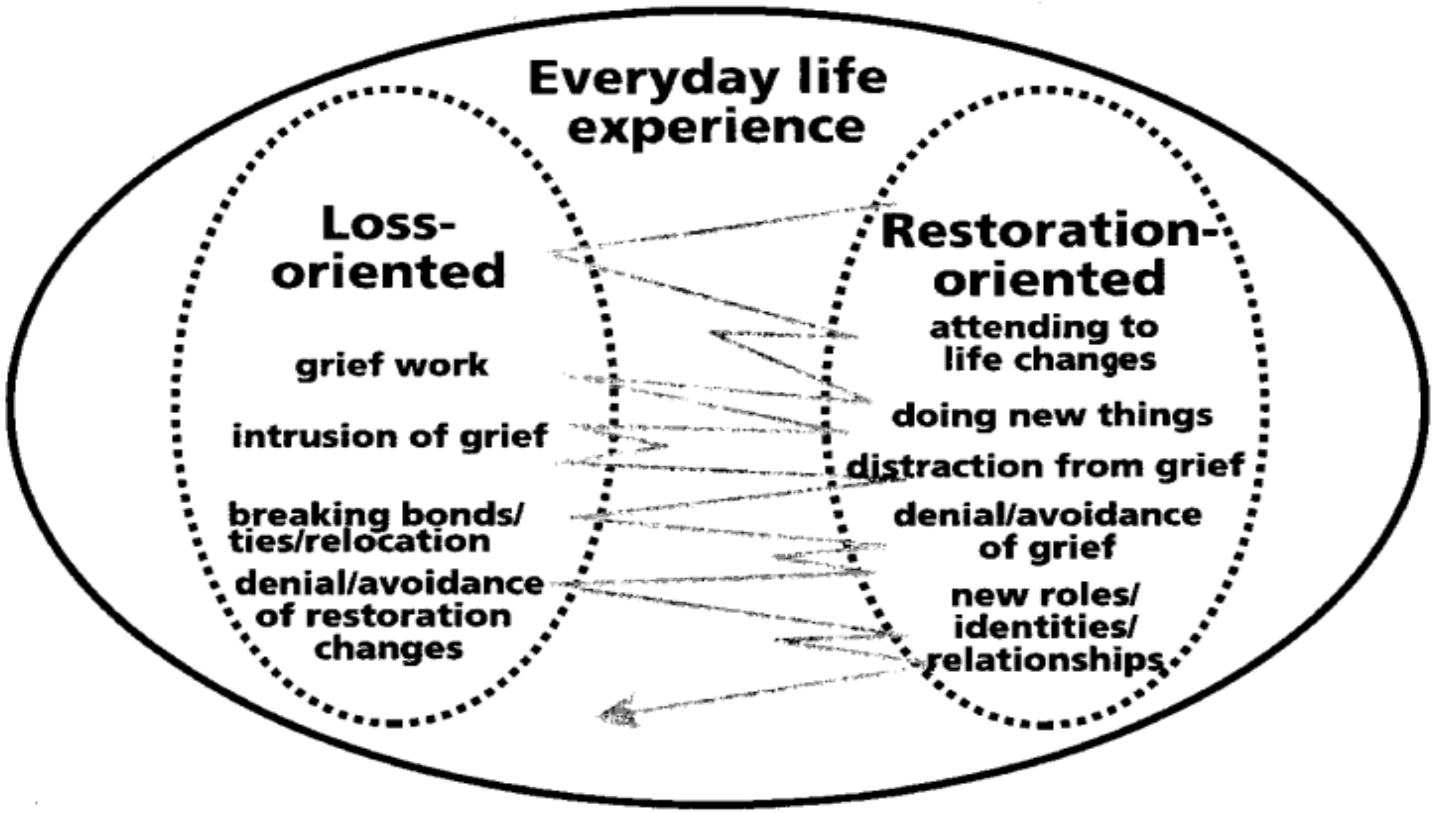
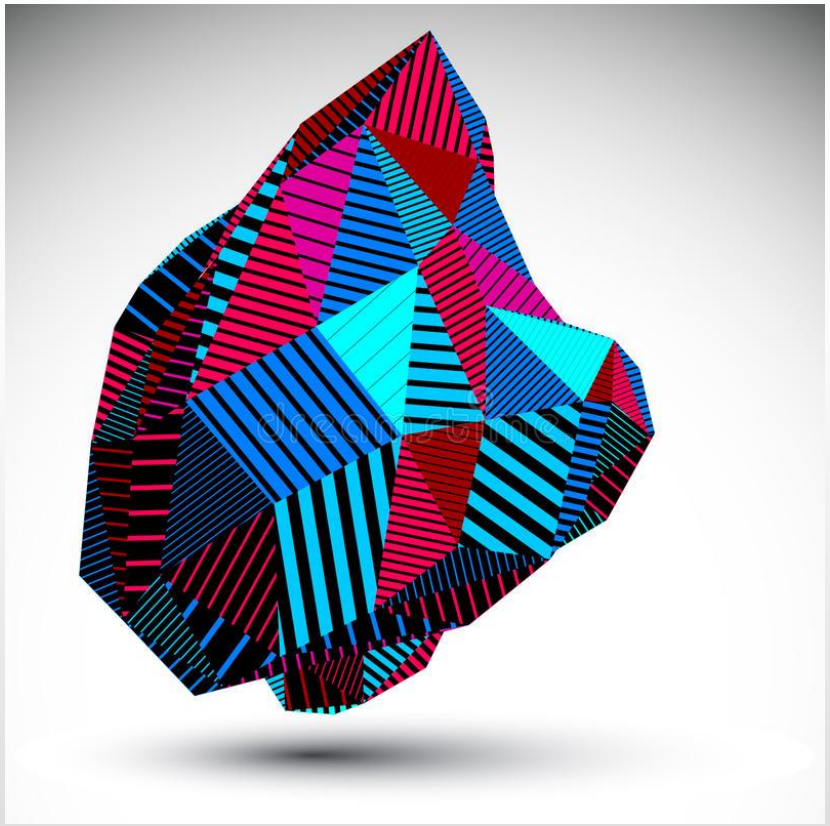


FIGURE 1 A dual process model of coping with bereavement.

GRIEF

Multifaceted response:

- Physical & Cognitive
- Emotional
- Behavioural
- Social
- Spiritual
- Practical



Grief is a normal response to loss, however the course and consequences of bereavement will vary for each individual

PHYSICAL EFFECTS

- Fatigue, restlessness
- Diarrhoea, constipation
- Change in appetite, nausea, weight loss or gain
- Dizziness
- Headache
- Back pain, abdominal pain
- Throat tightness, shortness of breath
- Chest pain, palpitations
- Trouble initiating or maintaining sleep

COGNITIVE EFFECTS

- Forgetfulness
- Difficulty concentrating
- Slowed thinking
- Can exacerbate existing cognitive decline

EMOTIONAL EFFECTS

- Sadness
- Longing
- Abandonment, vulnerability
- Disbelief, denial
- Apathy
- Anxiety, fear, panic
- Anger, irritability
- Loneliness, numbness
- Guilt, self-blame
- Meaningless
- Hopelessness
- Helplessness
- Relief

PRACTICAL DISTRESS

- Financial
- Life administration
- Housing
- Transport
- Work
- School or child care
- Managing family

RISK SCREENING: ILLNESS PHASE

Begins during the patient's illness and continues post death.

However….there is no well validated tool that screens for risk of complicated bereavement prior to the person's death.

DISTRESS SCREENING

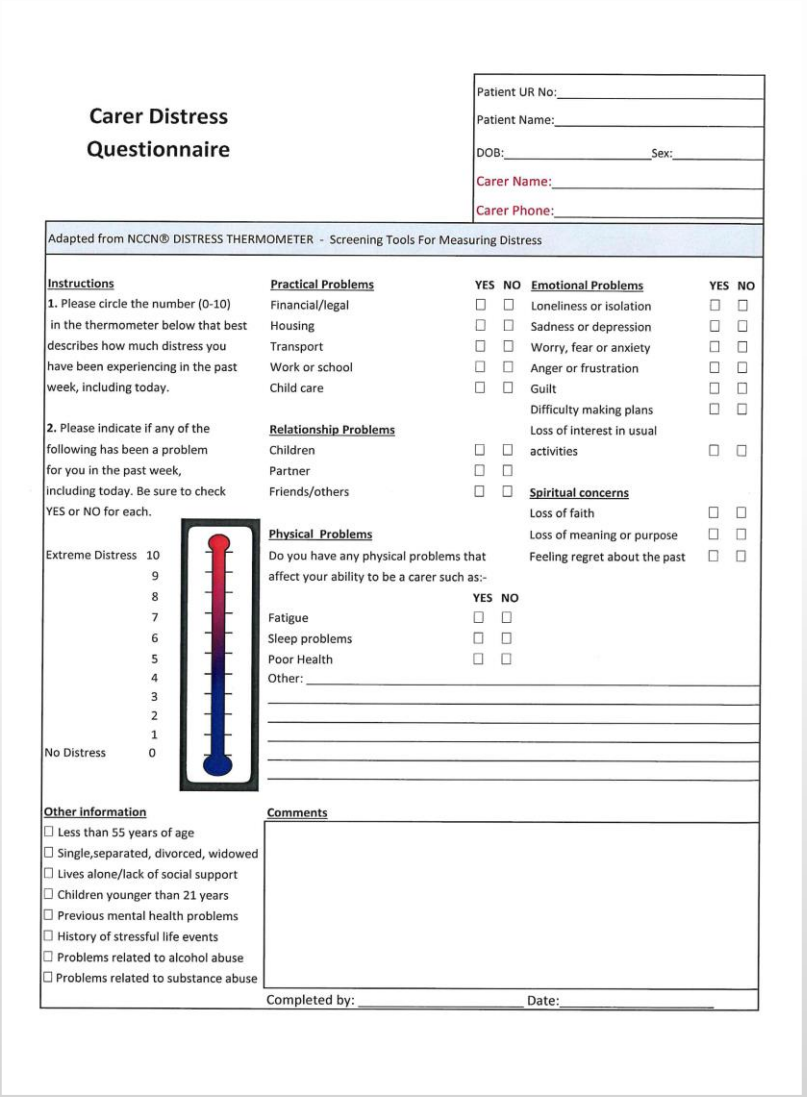
Distress thermometer

National Comprehensive Cancer Network 2012

One tool recommended for screening for psychosocial distress.

Ask about Caregiver distress.

- What concerns underlie the distress?
- Does the person want support for their distress?



Carer Distress Questionnaire

Patient UR No:
Patient Name:
DOB: Sex:
Carer Name:
Carer Phone:

Adapted from NCCN® DISTRESS THERMOMETER - Screening Tools For Measuring Distress

Instructions

1. Please circle the number (0-10) in the thermometer below that best describes how much distress you have been experiencing in the past week, including today.

2. Please indicate if any of the following has been a problem for you in the past week, including today. Be sure to check YES or NO for each.

Extreme Distress 10 9 8 7 6 5 4 3 2 1 No Distress 0

Practical Problems	YES	NO
Financial/legal	☐	☐
Housing	☐	☐
Transport	☐	☐
Work or school	☐	☐
Child care	☐	☐

Relationship Problems		
Children	☐	☐
Partner	☐	☐
Friends/others	☐	☐

Physical Problems

Do you have any physical problems that affect your ability to be a carer such as:-

	YES	NO
Fatigue	☐	☐
Sleep problems	☐	☐
Poor Health	☐	☐

Other: _____

Emotional Problems	YES	NO
Loneliness or isolation	☐	☐
Sadness or depression	☐	☐
Worry, fear or anxiety	☐	☐
Anger or frustration	☐	☐
Guilt	☐	☐
Difficulty making plans	☐	☐
Loss of interest in usual activities	☐	☐

Spiritual concerns

Loss of faith	☐	☐
Loss of meaning or purpose	☐	☐
Feeling regret about the past	☐	☐

Other information

- ☐ Less than 55 years of age
- ☐ Single,separated, divorced, widowed
- ☐ Lives alone/lack of social support
- ☐ Children younger than 21 years
- ☐ Previous mental health problems
- ☐ History of stressful life events
- ☐ Problems related to alcohol abuse
- ☐ Problems related to substance abuse

Comments

Completed by: _____ Date: _____

RISK FACTORS (Bereavement Standards Vic 2012)

Risk factors that may influence a grief response:

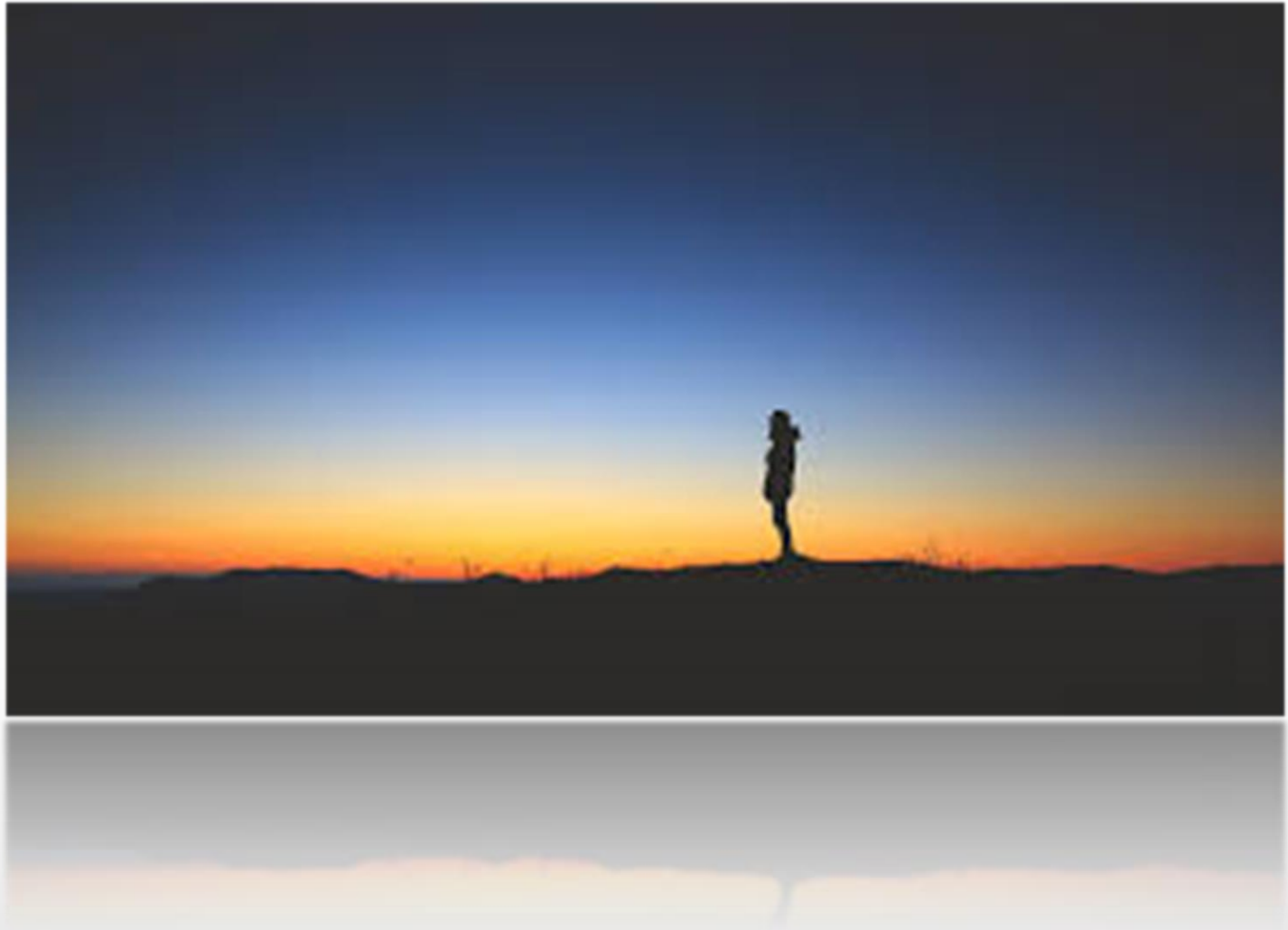
- Intrapersonal
- Interpersonal
  - Dependency
  - Centrality of deceased to person's life
  - Problematic relationship
  - Lack of social support
- Situational
  - Sudden, unexpected, traumatic death
  - Death of life partner or child

RESILIENCE (Bereavement Standards Vic 2012)

- Resulting from an individual's personal attributes
- Can also be impacted by a variety of community and cultural factors
- (Bonanno et al., 2002) – found *resilience* is the most common grief pattern and that delayed grief reactions are rare

RESILIENT INDIVIDUALS
(Bereavement Standards Vic 2012)

- Draw upon past experiences of loss survival.
- Connect with communities.
- Draw upon religious/spiritual beliefs.
- Identify internal/external strengths & resources.
- Reconstruct a world of meaning and personal identity.
- Draw upon support of other bereaved people.
- Have higher levels of practical support.
- Hold a belief in a just world and acceptance of death.
- May gain comfort from talking or thinking about the deceased.



WHAT CAN YOU DO?

ILLNESS PHASE SUPPORT

- Facilitated conversations or family meetings.
- Encouraging Goals of Care and Advanced Care Directive discussions.
- Accurate information about what happens when someone is dying in addition to providing best care.
- Options for site of care & realistic supports.
- Clear out-of-hours plan.

ILLNESS PHASE SUPPORT

- MDT referrals:

  - social work, OT, physio, rehab, art/legacy therapy, volunteers

- External referrals to address support needs:

  - financial, legal, accommodation, childcare, transport, work

- Early referral to mental health practitioners as indicated.
- Loss and Grief resources.

EARLY BEREAVEMENT SUPPORT

Early grief (first 12 months after the death)

- Acute grief is not a problem to be 'fixed'
- Focus is on facilitating normal grief:
  - 'Holding space' – multiple opportunities.
  - Coping skills and strategies (mindfulness, self compassion).
  - Psychoeducation – culturally appropriate.
  - Support close relationships and connect to available networks.

COMPLEX BEREAVEMENT

Some people will experience more intense and persistent symptoms of distress or adverse psychological outcomes.

- Prolonged Grief Disorder
- Anxiety, Depression and PTSD.
- Increased risk of self-harm or suicide.

Use of standardised, validated tools to diagnose prolonged grief in those who have persistent signs and symptoms can assist in appropriate referral for treatment.

Structured screening and assessment is both indicated and effective in these situations.

PROLONGED GRIEF DISORDER

- Death at least 12 months ago and
- Intense yearning/longing for deceased person and/or
- Preoccupation of thoughts/memories of the deceased person and

PROLONGED GRIEF DISORDER

- 3 of the following for > 1 month:

  - Identity disruption
  - Disbelief around death
  - Avoidance of reminders of death
  - Intense emotional pain (bitterness, anger, sorrow)
  - Difficulty with reintegration into life
  - Emotional numbness (stunned)
  - Feeling that life is meaningless
  - Intense loneliness

The disturbance causes clinically significant distress/impairment in social, occupational or other important function.

PROLONGED GRIEF

Prolonged Grief Disorder (12 months post-death)

- Often requires therapeutic interventions to shift problematic aspects of grief.
- Co-addresses trauma/depression/anxiety.
- Range of cognitive and behavioural interventions.
- Includes (not limited to):
    - Cognitive behavioural therapy
    - Acceptance-commitment therapy
    - Family therapy

GRIEF INTENSITY SCALE

DSM-5 Prolonged Grief Disorder

Diagnostic screening tool

https://endoflife.weill.cornell.edu/research/grief-intensity-scale

Q1. Have you lost someone significant to you? ◯ Yes ◯ No

Q2. How many months has it been since your significant other died? ☐ Months

For each item below, please indicate how you currently feel

Since the death, or as a result of the death...	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
Q3. Do you feel yourself longing or yearning for the person who died?	◯	◯	◯	◯	◯
Q4. Do you have trouble doing the things you normally do because you are thinking so much about the person who died?	◯	◯	◯	◯	◯
Q5. Do you feel confused about your role in life or feel like you don't know who you are any more (i.e., feeling like that a part of you has died)?	◯	◯	◯	◯	◯
Q6. Do you have trouble believing that the person who died is really gone?	◯	◯	◯	◯	◯
Q7. Do you avoid reminders that the person who died is really gone?	◯	◯	◯	◯	◯
Q8. Do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death?	◯	◯	◯	◯	◯
Q9. Do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	◯	◯	◯	◯	◯
Q10. Do you feel emotionally numb or detached from others?	◯	◯	◯	◯	◯
Q11. Do you feel that life is meaningless without the person who died?	◯	◯	◯	◯	◯
Q12. Do you feel alone or lonely without the deceased?	◯	◯	◯	◯	◯

Q13. Have the symptoms above caused significant impairment in social, occupational, or other important areas of functioning? ◯ Yes ◯ No

BEREAVEMENT SUPPORT: ACCESS INEQUALITY

- Palliative Care Services
- GP support
  - Short appointment times
  - Relationship dependent
- Private Psychologist or Accredited MHSW
  - DSM diagnosis – risk of pathologising grief
  - Cost
  - Location
  - Wait times

STATEWIDE BEREAVEMENT SERVICE

- COVID-19 pandemic
- Multiple impacts on bereaved
  - Visiting restrictions during the illness
  - State/international border restrictions
  - Grief rituals - including funerals
  - Access to social support networks
- Increased awareness of lack/limitations of existing bereavement support services
- Draft Palliative Care Strategic Framework 2021-2026

  Need for a comprehensive approach to grief and bereavement for SA

  PCCN Grief and Bereavement advisory sub-group and Health Services Programs and Funding, DHW

RESOURCES

- Online information and resources

- Bereavement Portal (SA Health)
  - For bereaved people
  - For those supporting bereaved individuals
  - For GP's and health professionals

https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/conditions/mental+health+and+mental+illness/bereavement

RESOURCES

- Grief Australia
- MyGrief app

THANK YOU

Case Presentation