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Supporting caregivers and families
Grief & Bereavement

Discussion Points

- What is Bereavement?
- Grief concepts – historic and contemporary
- Screening for risk and protective factors
- Factors that can influence the grief response
- Grief support in the illness phase
- Bereavement support after the death

Bereavement

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

Historical concepts of grief

- Freud Mourning and Melancholia (1917/1957)
 - 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 (and continues to be maintained) in our cultural and professional beliefs about loss

(C. Hall, InPsych 2011 | Vol 33)

Grief

Multifaceted response which can include the :

- Physical
- 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 signs

Fatigue or restlessness

Diarrhoea; Constipation

Change in appetite; Nausea; Weight change

Dizziness; Lightheaded

Headache

Back pain; Stomach pain;

Tightness in throat; Shortness of breath

Chest pain; Palpitations

Trouble initiating or maintaining Sleep

Cognitive signs

Forgetfulness

Difficulty concentrating

Slowed thinking

Can exacerbate existing cognitive decline

Emotional Signs

Sadness; Longing; Abandonment

Disbelief; Denial

Apathy

Fear; Helplessness; Anxiety; Panic ; Vulnerability

Anger; Irritability

Loneliness; Numbness; Emotionally labile

Guilt; Self Blame

Relief

Meaninglessness; Hopelessness

Practical distress

- Financial
- Housing
- Transport
- Work or school
- Child care

Is it Grief?

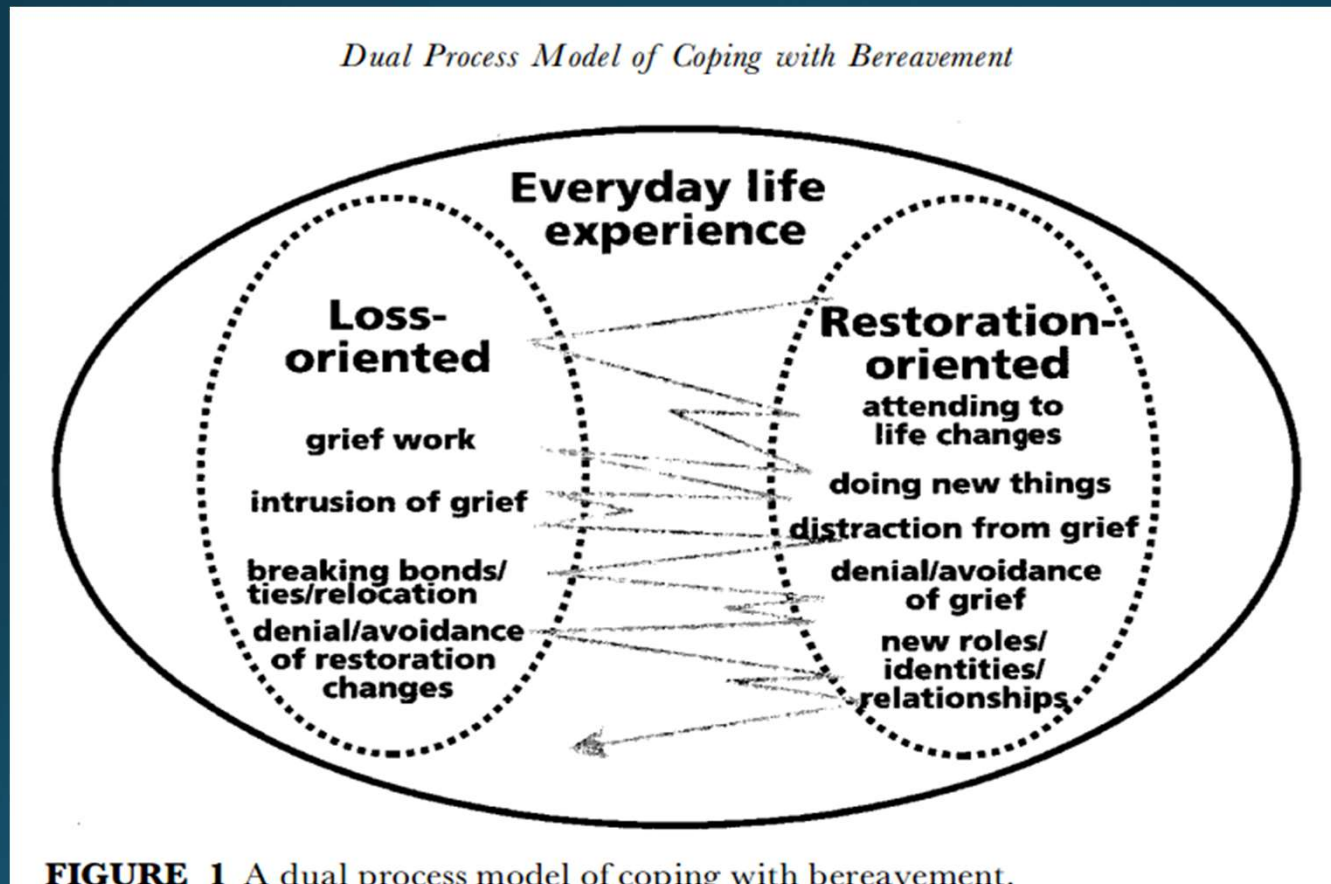
Signs and symptoms of grief can overlap with those of depression

	Bereavement reaction	Depression
Cognitive	Focus on the lost person	Focus on negative interpretation of self, world
Affects	Yearning for lost person; separation anxiety; anger (externalising); sadness	Despair; Anxiety re 'black' world; anger (internalising); depression
Arousal	Scanning for lost person	Decreased or agitated arousal
Sleep	Dreams, sleep disturbance	Bad or no dreams, changes in dream architecture

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)



Grief

Most people experience normal grief - which although painful and disruptive

- Are still able to function in their daily lives, and
- Are able to 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

Some individuals are at increased risk of experiencing problems in the lead up to and after person's death

Bereavement Risk

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

- Prolonged Grief Disorder
- Post-Traumatic Stress Disorder and
- 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

Risk Screening in the Illness Phase

(Bereavement Standards Vic 2012)

Begins during the patient's illness and continues post death, however....there is no particular tool that screens for risk of complicated bereavement prior to the person's death

Distress Screening

Distress Screening Thermometer

The distress thermometer (National Comprehensive Cancer Network 2012) is one of tools recommended for screening for psychosocial distress

Ask about Caregiver distress –

- What concerns underlie the distress?
- Does the person want support for the issue(s) causing distress?

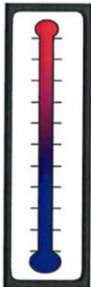
Patient UR No: _____
 Patient Name: _____
 DOB: _____ Sex: _____
 Carer Name: _____
 Carer Phone: _____

Carer Distress Questionnaire

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

<p>Instructions</p> <p>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.</p> <p>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.</p>	<p>Practical Problems</p> <p>Financial/legal <input type="checkbox"/> <input type="checkbox"/></p> <p>Housing <input type="checkbox"/> <input type="checkbox"/></p> <p>Transport <input type="checkbox"/> <input type="checkbox"/></p> <p>Work or school <input type="checkbox"/> <input type="checkbox"/></p> <p>Child care <input type="checkbox"/> <input type="checkbox"/></p> <p>Relationship Problems</p> <p>Children <input type="checkbox"/> <input type="checkbox"/></p> <p>Partner <input type="checkbox"/> <input type="checkbox"/></p> <p>Friends/others <input type="checkbox"/> <input type="checkbox"/></p> <p>Physical Problems</p> <p>Do you have any physical problems that affect your ability to be a carer such as:-</p> <p>Fatigue <input type="checkbox"/> <input type="checkbox"/></p> <p>Sleep problems <input type="checkbox"/> <input type="checkbox"/></p> <p>Poor Health <input type="checkbox"/> <input type="checkbox"/></p> <p>Other: _____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<table border="0" style="width: 100%;"> <tr> <td style="width: 50%;">Emotional Problems</td> <td style="width: 50%;">YES NO</td> </tr> <tr> <td>Loneliness or isolation</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Sadness or depression</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Worry, fear or anxiety</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Anger or frustration</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Guilt</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Difficulty making plans</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Loss of interest in usual activities</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Spiritual concerns</td> <td></td> </tr> <tr> <td>Loss of faith</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Loss of meaning or purpose</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> <tr> <td>Feeling regret about the past</td> <td><input type="checkbox"/> <input type="checkbox"/></td> </tr> </table>	Emotional Problems	YES NO	Loneliness or isolation	<input type="checkbox"/> <input type="checkbox"/>	Sadness or depression	<input type="checkbox"/> <input type="checkbox"/>	Worry, fear or anxiety	<input type="checkbox"/> <input type="checkbox"/>	Anger or frustration	<input type="checkbox"/> <input type="checkbox"/>	Guilt	<input type="checkbox"/> <input type="checkbox"/>	Difficulty making plans	<input type="checkbox"/> <input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/> <input type="checkbox"/>	Spiritual concerns		Loss of faith	<input type="checkbox"/> <input type="checkbox"/>	Loss of meaning or purpose	<input type="checkbox"/> <input type="checkbox"/>	Feeling regret about the past	<input type="checkbox"/> <input type="checkbox"/>
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Extreme Distress	10
	9
	8
	7
	6
	5
	4
	3
	2
	1
No Distress	0



<p>Other Information</p> <p><input type="checkbox"/> Less than 55 years of age</p> <p><input type="checkbox"/> Single, separated, divorced, widowed</p> <p><input type="checkbox"/> Lives alone/lack of social support</p> <p><input type="checkbox"/> Children younger than 21 years</p> <p><input type="checkbox"/> Previous mental health problems</p> <p><input type="checkbox"/> History of stressful life events</p> <p><input type="checkbox"/> Problems related to alcohol abuse</p> <p><input type="checkbox"/> Problems related to substance abuse</p>	<p>Comments</p> <div style="border: 1px solid black; height: 100px; width: 100%;"></div>
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Completed by: _____ Date: _____

Risk Factors (Bereavement Standards Vic 2012)

Risk factors that can 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

Resilience

(Bereavement Standards Vic 2012)

Resilient individuals tend to:

- draw upon past experiences of loss survival
- connect with their family and community of care
- draw upon religious and spiritual beliefs and practices
- identify internal and external strengths and resources
- reconstruct a world of meaning and personal identity following the loss
- draw upon the experience and support of other bereaved people
- have higher levels of practical support
- hold a belief in a just world and acceptance of death
- gain comfort from talking or thinking about the deceased

Grief Support

(National Palliative Care Standards 2018)

- Early identification and referral can improve outcomes for at risk people
- Preparation for death, understanding dying process may reduce physical and psychosocial morbidity associated with loss and grief
- Culturally appropriate routine loss and grief information and resources before and after the death
- Bereaved individuals should be given multiple opportunities to access bereavement support

Support in the Illness Phase

- Facilitated conversations or family meetings
- Documenting patient's wishes / ACD discussions
- Care around the time of the death
 - Site of care
 - Level of support/care
- Clear out-of-hours plan

Support in the Illness Phase

- Accurate information about what happens when someone is dying
- MDT referrals / external referrals to address support needs
 - (e.g . Financial; Legal Accommodation concerns; Childcare; Transport; Self-care)
- Referrals to specialist / mental health as indicated

Bereavement Support – after death

Online info and resources –

➤ Bereavement Portal (SA Gov)

- 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>

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Bereavement Support – after death

- Australian Centre for Grief and Bereavement
- MyGrief app



The advertisement banner for the MyGrief app features a smartphone on the left displaying the app's interface with two main options: "I am bereaved" and "I am supporting a bereaved person". To the right of the phone, the text "MyGrief" is prominently displayed in white, followed by the tagline "Helping the bereaved to manage their grief" in yellow. The banner also includes the logo for the Australian Centre for Grief and Bereavement, the text "Proudly supported by:" followed by logos for GANDEL PHILANTHROPY and THE JACK BROCKHOFF FOUNDATION. At the bottom, there are buttons for "Available on the App Store" and "GET IT ON Google Play", along with the text "Get the app today" and a yellow arrow icon.

- Referrals to specialist / mental health as indicated

Bereavement Counselling Support

(Normal vs. Prolonged grief)

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'
 - Coping skills and strategies (mindfulness; self compassion)
 - Psychoeducation
 - Self-care strategies
 - Support with relationships and connection to natural support networks

Bereavement Counselling Support

Prolonged Grief (beyond 12 months after the death)

- *Therapeutic interventions* to 'shift' problematic aspects of grief
- Co-addresses trauma/depression/anxiety
 - range of cognitive and behavioural interventions
 - CBT/ACT/Family Therapy

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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?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q4. Do you have trouble doing the things you normally do because you are thinking so much about the person who died?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q6. Do you have trouble believing that the person who died is really gone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q7. Do you avoid reminders that the person who died is really gone?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q8. Do you feel emotional pain (e.g., anger, bitterness, sorrow) related to the death?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q9. Do you feel that you have trouble re-engaging in life (e.g., problems engaging with friends, pursuing interests, planning for the future)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q10. Do you feel emotionally numb or detached from others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q11. Do you feel that life is meaningless without the person who died?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q12. Do you feel alone or lonely without the deceased?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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 vs Bereavements in other settings
- GP support
 - Short appointment times
 - Relationship dependent
 - Variable knowledge and skill to provide grief support
- Private Psychologist or Accredited Mental Health Social Worker – problems with this pathway
 - 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

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Thank you

Questions and comments?