Recent developments in bereavement risk assessment and bereavement care

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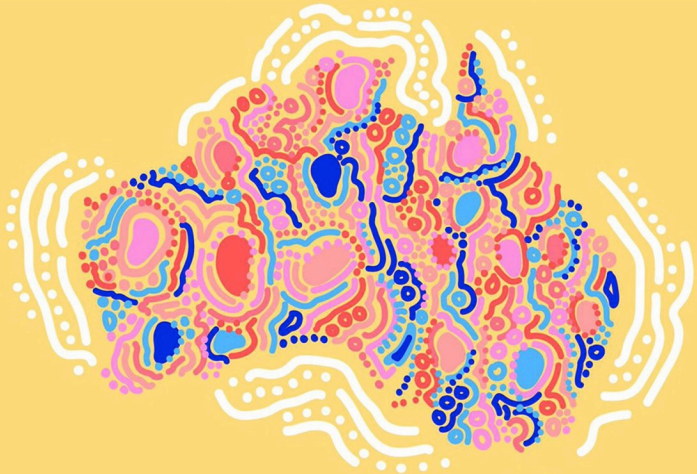
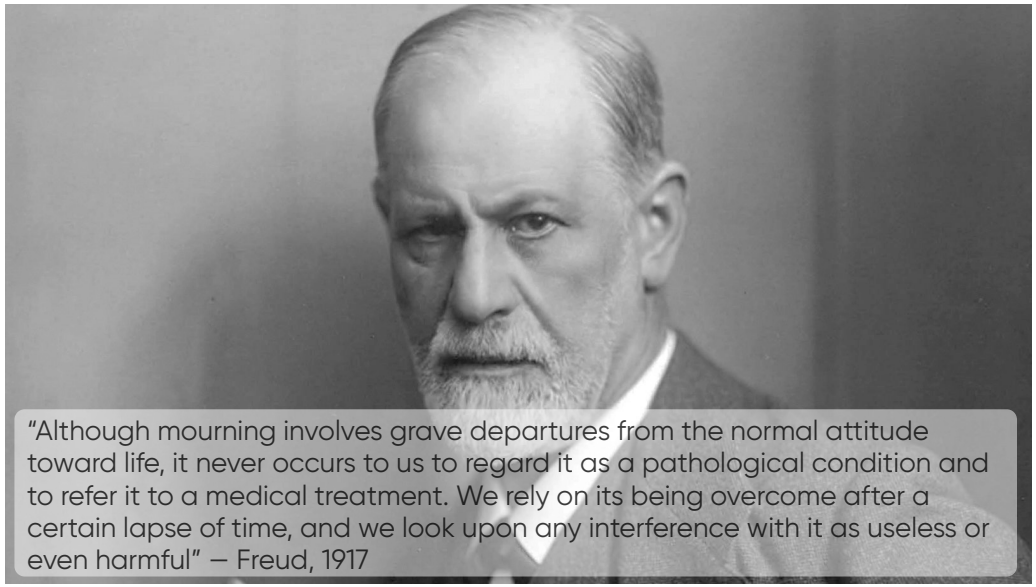


Acknowledgement of Country



"Although mourning involves grave departures from the normal attitude toward life, it never occurs to us to regard it as a pathological condition and to refer it to a medical treatment. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful" — Freud, 1917

Systematic Reviews and Meta-Analyses of Bereavement Interventions for Adults (2003-2019)

from Lichtenthal, Roberts, Prigerson, & Kissane, in press

Authors	No. of Studies	Study Selection	Effect Size Magnitude	Possible Conclusions
Wittouck, Van Autreve, De Jaegere, Portzky, and van Heeringen[33]	14	Randomized controlled trials for prevention or treatment of complicated grief	Treatment interventions: 0.53[a] Prevention interventions: 0.03[a]	– Treatment interventions for complicated grief appear effective and gains increase over time – Limited support for prevention interventions for complicated grief, though assessment tools differ
Currier, Neimeyer and Berman[32]	61	Randomized and non-randomized studies No-intervention control group	0.16[b]	– Generally, all participants (intervention and control) improved over time – Clinical and self-referrals associated with better outcomes, though differences diminished at follow-up
Schut, Stroebe, van den Bout, and Terheggen[5]	16 primary; 7 secondary; 7 tertiary[c]	Organized help Focused on treating grief Methodologically sound	Low to modest effects	– Strongest effects with individuals exhibiting psychopathology/pathological grief – Greater effects with self-referred
Jordan and Neimeyer[29]	4	Reviews and meta-analyses	N/A	– Generally low efficacy of interventions – Intervention may not be necessary for most bereaved – Need to develop new approaches – Need to improve methodology of studies
Johannsen, Damholdt, Zachariae, Lundorff, Farver-Vestergaard and O'Connor[28]	31	Meta-analysis of randomized controlled-trials of psychological interventions for grief	Pooled effects Post-intervention: g=0.41, p>.001, K=31 Follow-up: g=0.45, p>.001, K=18	– Larger effect sizes were found for one-on-one interventions, studies that utilized an inclusion screening threshold of grief symptoms, and studies that included bereaved individuals ≥6 months post-loss – Need to improve methodology of studies – Publication bias may contribute to large pooled effect sizes
Nseir & Larkey[35]	7	Evidence review of studies on grief interventions for older adults published between 1993-2013	N/A	– Only 3 of the reviewed interventions demonstrated preliminary effects on improving grief outcomes in older adults (i.e., emotional expression/support, psychoeducation and mind-body approach) with the mind-body approach being the only one to demonstrate statistically significant efficacy
Roberts, Walsh, Saracino, Fogarty, Coats, Goldberg, Prigerson, and Lichtenthal[15]	24	Systematic review of studies on grief interventions for older adults published between 2013-2019	N/A	– Grief interventions for older adults generally had small effects on grief-related symptoms – Findings suggest more effective treatment approaches for bereaved older adults are those incorporating behavioral activation and guidance on restoration-oriented coping
Waller, Turon, Mansfield, Clark, Hobden & Sanson-Fisher[27]	76 intervention studies	Systematic review of studies published on grief counselling and evaluated based on Cochrane Effective Practice and Organisation of Care (EPOC) methodological criteria	59% of studies met Effective Practice and Organisation of Care (EPOC) design criteria; no overall effect sizes reported	– Numerous methodological limitations – Lack of theoretical rationale for many interventions studied – Complicated Grief Treatment and Family-Focused Grief Therapy were the strongest quality studies and demonstrated efficacy

Who Benefits from Bereavement Interventions?

"most uncomplicated grief is probably naturally self-limiting…. one of the most important trends in these reviews is the recognition that **there are subgroups of mourners who are at elevated risk for dysfunction and who respond well to formal interventions."**

(Jordan & Neimeyer, 2003)

It takes an average of 17 years for research evidence to reach clinical practice.

Morris, Z. S., Wooding, S., & Grant, J. (2011). The answer is 17 years, what is the question: Understanding time lags in translational research. *Journal of the Royal Society of Medicine, 104*(12), 510–520.

The gap between policy and practice

Policy and Guidelines

National Standards Assessment Program (NSAP)

World Health Organisation (2004)

Bereavement Support Standards for Specialist Palliative care Services - Vic. (2012)

Sealey, M., Breen, L. J., O'Connor, M., & Aoun, S. M. (2015). A scoping review of bereavement risk assessment measures: Implications for palliative care. *Palliative Medicine, 29*(7), 577–589. https://doi.org/10.1177/0269216315576262

CareSearch resources for the National Palliative Care Standards

Standard 8

Standard 8: Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to **bereavement care**, information and support services.

National Palliative Care Standard			Relevant Evidence *(to read)*	
Standard 8			CareSearch Review Collection: eg Bereavement, Grief & Loss Bereavement PubMed Searches	
NSAP Quality Element		Location of health professional resources *(to read)*	Location of consumer resources *(to recommend)*	Things that you can do
8.1	The organisation has policies and procedures that guide its bereavement support program.			
8.2	The interdisciplinary team includes professionals with culturally appropriate education and skills to meet the needs of the Service's patients and their families when they experience loss, grief and bereavement.	A page on Bereavement Counsellors is available		Bereavement Grief and Loss DVD is available in Greek, Italian and Cantonese.
8.3	Families are clinically assessed to identify those at risk of complicated grief and bereavement.	Clinical Evidence / Bereavement and Grief / Complicated Grief		

CareSearch resources for the National Palliative Care Standards

Standard 8

NSAP Quality Element		Location of health professional resources *(to read)*	Location of consumer resources *(to recommend)*	Things that you can do
8.4	Clinical assessment is undertaken to identify those family members suffering depression, anxiety and sadness associated with loss, grief or bereavement.	Clinical Evidence/ Patient Management includes psychological symptoms		
8.5	The family's need for support is reassessed on an ongoing basis, including after the death of the patient.			
8.6	Culturally appropriate information and resources about loss, grief and the availability of bereavement support services is routinely available to families before and after the death of the patient.		For Patients, Carers and Families / Bereavement, Grief and Loss section	Provide families with the CareSearch leaflets on bereavement. Recommend the web pages to the family
8.7	The staff and volunteers involved in bereavement support undergo a formal education program and are provided with support in their role.			There are online forums (communities of practice) on CareSearch. Does your Social Worker belong to one?
8.8	Referrals to specialist mental health and counselling professionals are made when clinically indicated.			

Bereavement Support Care Pathway

1. Between intake and the client's death
2. Imminent death
3. At death (as soon as practicable following death)
4. At 12 weeks after death
5. Around 6 months after death
6. Around 12 months after death

Standard 4: Screening and assessment.

Pre-death: "A comprehensive bio-psychosocial, spiritual & bereavement risk assessment…as soon as possible after client is admitted to the PC service."

"A structured risk assessment based on a conversational exploration of the risk factors…"

The assessment "…requires structured documentation, review in team meetings…"

"The … assessment process begins on intake…continues throughout the PC service's involvement…& beyond…" (p.12)

Standard 4: Screening and assessment.

At-death: "assessment of the level of trauma the family experienced as a result of the death…"

Post-death: "At 12 weeks after death, a follow-up phone call to all primary carers is undertaken to determine if further assessment/support is required."

"**At around 6 months following the death:**
to people identified as being at elevate risk of developing PGD/CG … using a validated tool (e.g.PG-13)."

(Hall, Hudson, & Boughey, 2012, p.13)

Kent, K., Jessup, B., Marsh, P., Barnett, T., & Ball, M. (2019). A systematic review and quality appraisal of bereavement care practice guidelines. *Journal of Evaluation in Clinical Practice*. doi:10.1111/jep.13225

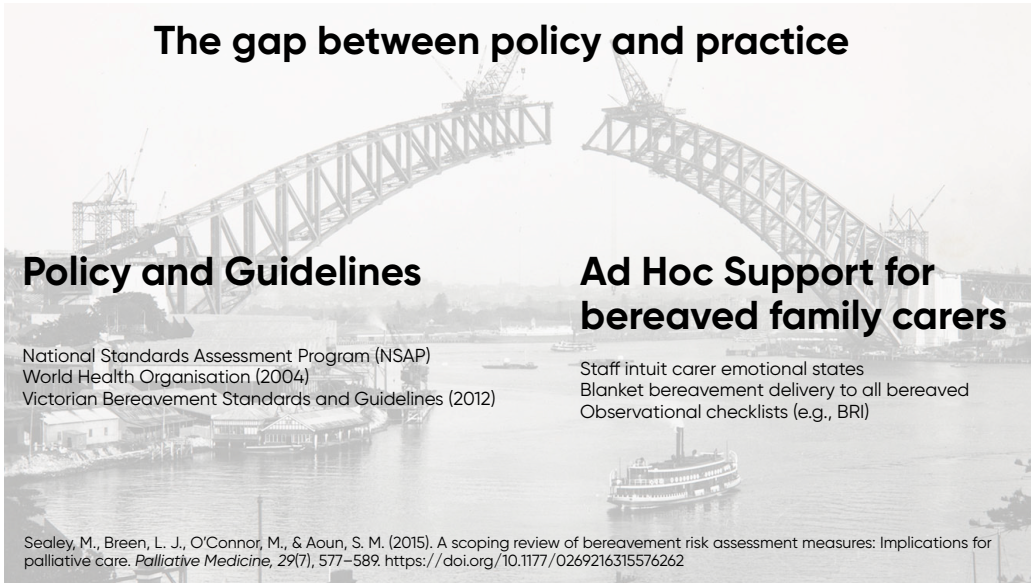
Sixteen guidelines were identified. The practice guidelines were from six Western countries including the UK (n = 6), Australia (n = 4), Ireland (n = 2), the USA (n = 2), Canada (n = 1), and New Zealand.

… three could be recommended for use without modification, indicating few of the bereavement care practice guidelines identified met the quality standards related to the process used to develop the article. (p. 9).

Hall C, Hudson, P., Boughey, A. (2012). *Bereavement Support Standards for Specialist Palliative Care Services*. Melbourne Australia.

Hudson P, Remedios C, Zordan R, et *al. (2010). Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients*. Melbourne, Australia: Centre for Palliative Care, St Vincent's Hospital.

The MidCentral District Health Board (MDHB) 2015. *Palliative Care District Group. Palliative Care Bereavement Support Guidelines*. New Zealand: The MidCentral District Health Board (MDHB) Palliative Care District Group.



BRI questionnaire instructions: Circle **ONE** number in each section. Add all circled numbers to find total score

B. Risk Index Risk score = High (19 or higher), Moderate (13–19), Low (12 or lower)

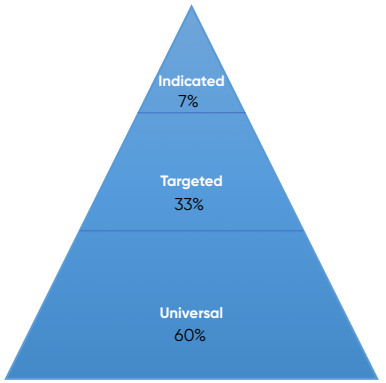
	Risk factor		Score
A	Children under 14 at home	None	0
		One	1
		Two	2
		Three	3
		Four	4
		Five or more	5
B	Occupation of principal wage earner. This may be the person deceased. Record even if retired	Professional and executive	1
		Semi-professional	2
		Office and clerical	3
		Skilled manual	4
		Semi-skilled manual	5
		Unskilled manual	6
C	Anticipated employment of bereaved person	Works F/T	1
		Works P/T	2
		Retired	3
		Housewife/home duties	4
		Unemployed	5
D	Clinging or pining (resistance to reality of patient's death)	Never	1
		Seldom	2
		Moderate	3
		Constant	4
		Constant intense	5
		Sub total	

	Risk factor		Score
E	Anger	None (or normal)	1
		Mild irritation	2
		Moderate (e.g. occasional outbursts)	3
		Severe (spoiling relationships)	4
		Extreme (always bitter)	5
F	Self-reproach (self blame/guilt, feeling bad and/or responsible for something)	None	1
		Mild (vague and general)	2
		Moderate (some clear self-reproach)	3
		Severe (preoccupied with self-blame)	4
		Extreme (major problem)	5
G	Current relationships	Close intimate relationship with another	1
		Warm supportive family permitting expression of feeling	2
		Family supportive but lives at a distance	3
		Doubtful (patient is unsure whether family members are supportive or unsupportive)	4
		Unsupportive	5
H	How will key person cope?	Well (normal grief and recover without special help)	1
		Fair (probably get by without special help)	2
		Doubtful (may need special help)	3
		Badly (requires special help)*	4
		Very badly (requires urgent help)*	5
		Sub total	

Total score (Sum of circled numbers A-H)…

*All scoring 4 or 5 on H will be followed up

A three-tiered public health model of bereavement care
Target interventions



At risk of complex grief issues; may need referral to health professionals.

Potentially 'at risk'; may need some additional support e.g. peer support group.

Majority of individuals; deal with grief with support of family/friends. Information on grief may be sufficient for most in this group.

National Institute for Health Clinical Excellence (2004). Guidance on CancerServices: Improving Supportive and Palliative Care for Adults with Cancer. The Manual [Internet]. London (UK): NICE.

Aoun, S. M., Breen, L. J., O'Connor, M., Rumbold, B., & Nordstrom, C. (2012). A public health approach to bereavement support services in palliative care, PLOS. 36(1), 14–16.

A three-tiered public health model of bereavement care
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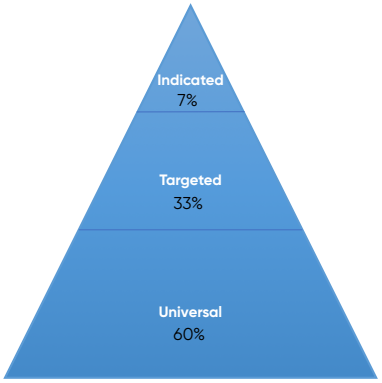


Mental health services, bereavement services or psychotherapy. *Professional specialist interventions*

Trained volunteers, mutual-help groups, community supports. *Non-specialist support.*

Family and friends (information supplied by health and social care professional). *Information about bereavement and bereavement supports.*

National Institute for Health Clinical Excellence (2004). Guidance on CancerServices: Improving Supportive and Palliative Care for Adults with Cancer. The Manual [Internet]. London (UK): NICE.

Aoun, S. M., Breen, L. J., O'Connor, M., Rumbold, B., & Nordstrom, C. (2012). A public health approach to bereavement support services in palliative care, PLOS. 36(1), 14–16.

Why *Not* to Intervene?

Stroebe's, Walter and others concerned that professional intervention:

- Thwarts natural assistance from family and friends
- Inhibits bereaved person's self-esteem and sense of efficacy
- Implies certain forms of grief are not socially acceptable; intervention gets unruly grief in line with cultural expectations
- Wastes resources
- Is stigmatising

Why Intervene?

Vast majority fine and gradually . . .

- Move from very upset, disturbed to diminished distress, eventual adjustment
- Questionable whether would benefit from intervention

Significant minority ***not fine*** and at risk for enduring distress and dysfunction

- Interventions improve their quality of life; potentially reduce adverse outcomes:
- Social withdrawal, suicidality, alcohol abuse, high blood pressure, functional disability, loss of productivity

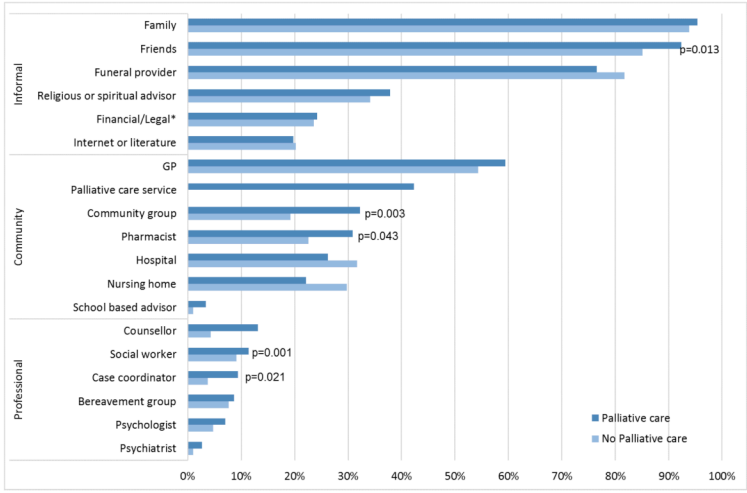
Worst case scenario scenario

(Schut, Stroebe, van der Bout & Terheggen, 2001)

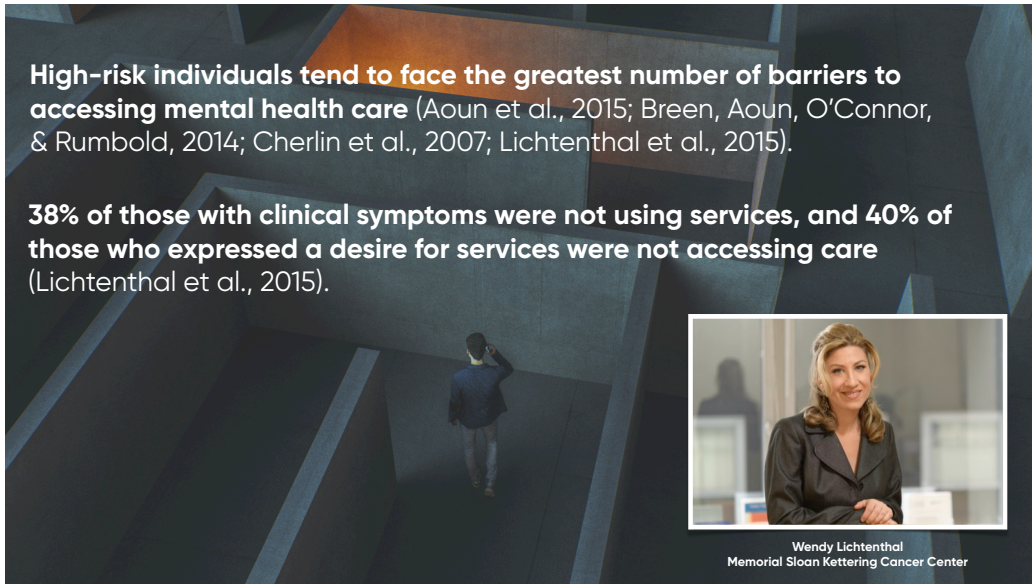
Unsolicited, routine referral, shortly after bereavement for no other reason than that the person has suffered a bereavement.

Best practice bereavement support for resilient individuals

- identifies and reinforces their coping and positive achievements
- avoids interfering with their innate capacity for recovery
- avoids undermining or replacing their family and community as sources of social support.



Aoun, S M, Rumbold, B., Howting, D., Bolleter, A. & Breen L. J. (2017) Bereavement support for family caregivers: The gap between guidelines and practice in palliative care. *PLoS ONE* 12(10): e0184750. https://doi.org/10.1371/journal.pone.0184750



How can we improve the situation?

1. **Improve screening** efforts
2. **Reduce barriers** to accessing support
3. Improve our ability to **assess** the bereaved
4. **Improve the fit and efficacy** of therapies

Lichtenthal, W. G. (2018, Aug). Supporting the bereaved in greatest need: We can do better. *Palliative & Supportive Care. 16*(4):371-374. doi: 10.1017/S1478951518000585.

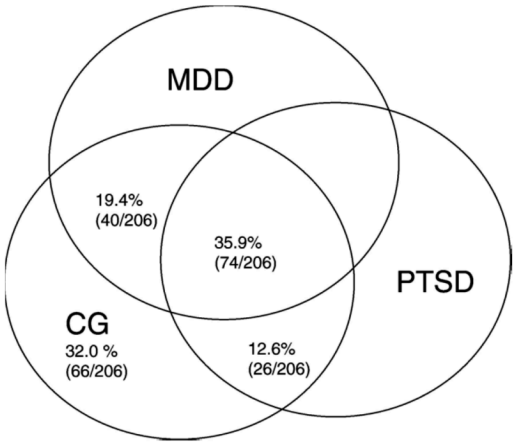
1. Improve Screening

Systematic screening of those who are likely to face a loss as well as the recently bereaved can **help us identify those who face the greatest risk of challenges in bereavement** (Aoun et al., 2015; Sealey, Breen, O'Connor, & Aoun, 2015; Sealey, O'Connor, Aoun, & Breen, 2015).

Screening provides an initial connection to support providers and resources. It can help us funnel the often **limited bereaved** resources to those in greatest need of support.

Assessing bereavement risk factors can also help clinicians **interpret presenting symptoms more critically**, and thus can prevent over-diagnosing and under-diagnosing bereavement-related mental health challenges (Roberts et al., 2017).

Overlap between CG, MDD and PTSD



Current PTSD and MDD comorbidity in treatment-seeking individuals with CG disorder (n=206)
Simon et al (2007)

2. Reduce Barriers to Accessing Bereavement Support

Access involves:

- scheduling and dedicating time to receive the service
- motivating to engage in the appointment,
- and, in some settings, paying for services.

The bereaved quite often have lost the very person who helped him/her access resources. They are often exhausted by the physical impacts of grief.

Seeking support means confronting their pain. This is most pervasive among those who are most distressed.

Video-recorded testimonials - why they think it is important to seek support despite the challenging feelings that may arise through the process.

3. Improve Assessment

- A crucial component of facilitating grief support for those in greatest need is having an understanding of **what kind of support is indicated**.
- Assessment obviously plays a critical role in treatment selection, and thus it is imperative to **hone clinicians' skills** in these areas. When the assessment is inaccurate, the selected treatment can be ineffective. This can result in treatment drop-out (Lichtenthal et al., 2015a) and promote beliefs about the unhelpfulness of therapy in bereavement and in general (Aoun, Breen, White, Rumbold, & Kellehear, 2018).
- Assessment needs to acknowledge **the fluid and dynamic nature of grief**.

4. Improving Therapeutic Fit

The most common reason that clients in one study discontinued therapy in bereavement was because **they felt it was not helping** (Lichtenthal et al., 2015).

Some studies have shown that nearly half of people who begin psychotherapy — individual, group, or couples — quit, dissatisfied, against the therapist's recommendation.

1. **Client selection**
2. **Preparation** - the process and hopefulness
3. **Appointment reminders** - (SMS)
4. **Short-term or time limited therapy**
5. **Negotiation.** Therapist and client should agree in advance on the means and ends of therapy — what this person needs to accomplish and how it is to be accomplished.
6. **Alliance** - Establishing a strong therapeutic relationship

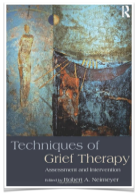
How do we at ACGB determine the most appropriate support?

- Inventory of Social Support (ISS)
- Integration of Stressful Life Experiences Scale–Short Form
- Prolonged Grief Disorder (PG – 13)

- Download these measures from:
  http://bit.ly/acgb-tools-intake

The Inventory of Social Support

Nancy Hogan & Lee Schmidt



- The Inventory of Social Support (ISS) is a 5-item self-report questionnaire, with clients instructed to identify their level of agreement or disagreement with each item using anchors ranging from does not describe me at all to describes me very well. The five items are summed to arrive at a total social support value.

- A score of five would indicate very poor social support and a score of 25 would indicate excellent social support. Below 12 would merit clinical attention.

The Integration of Life Experiences Scale (ISLES)

Holland, Currier, Coleman, & Neimeyer, 2010

Making meaning out of life stressors is a crucial mechanism by which individuals adjust to these experiences.

The Integration of Stressful Life Experiences Scale (ISLES) ***assesses the degree to which a stressful life experience has been adaptively incorporated into a broader life story that may promote a sense of internal coherence and foster a secure and hopeful view of the future***.

Three items measuring ***footing in the world*** and three items measuring ***comprehensibility*** are summed.

The PG-13

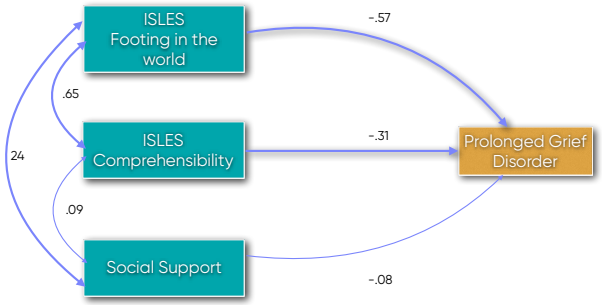
- The Prolonged Grief Disorder Scale (PG-13) is a 13-item assessment of the nine identified symptoms indicative of Prolonged Grief Disorder or complicated grief. Items describe an emotional, cognitive, or behavioural state associated with complicated grief. The diagnosis of complicated grief requires:

- **Two** "separation distress" symptoms (either yearning, intrusive thoughts of the deceased or pangs of separation distress), and **Five** of the following nine symptoms experienced at least once per day; feeling emotionally numb, feeling shocked, feeling that life is meaningless, role confusion, mistrust of others, difficulty accepting the loss, avoidance of the reality of the loss, bitterness, and difficulty moving on with life.

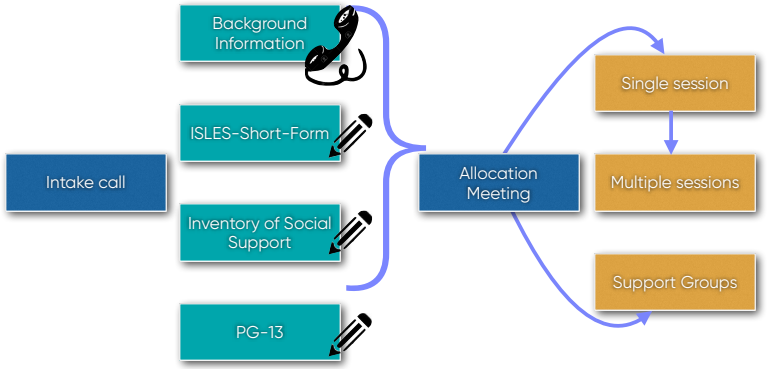
The PG-13

- Identified symptoms must be associated with functional and social impairment, and must have been present for at least 6 months.

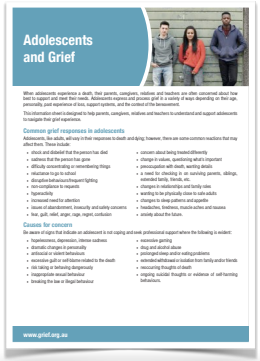
- Respondents rate the frequency with which they experience each item on a 5-point Likert scale, ranging from "not at all" to "several times/day", or, "not at all" to "overwhelmingly." The total score is a sum of scores ranging from 11 to 55. **The PG-13 has a demonstrated association with severity of depressive symptoms and a general measure of grief suggesting a valid, yet distinct, assessment of emotional distress.**

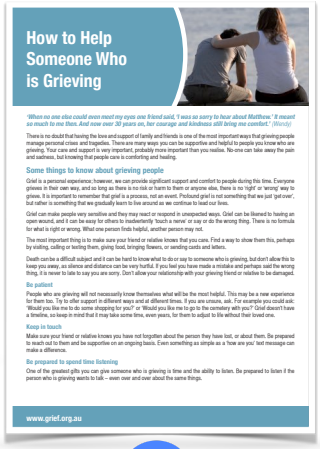


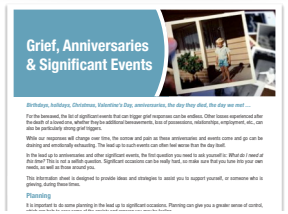
Factors impacting Prolonged Grief Disorder using ACGB data (Crompton, 2014)

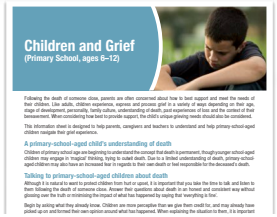


ACGB intake pathway

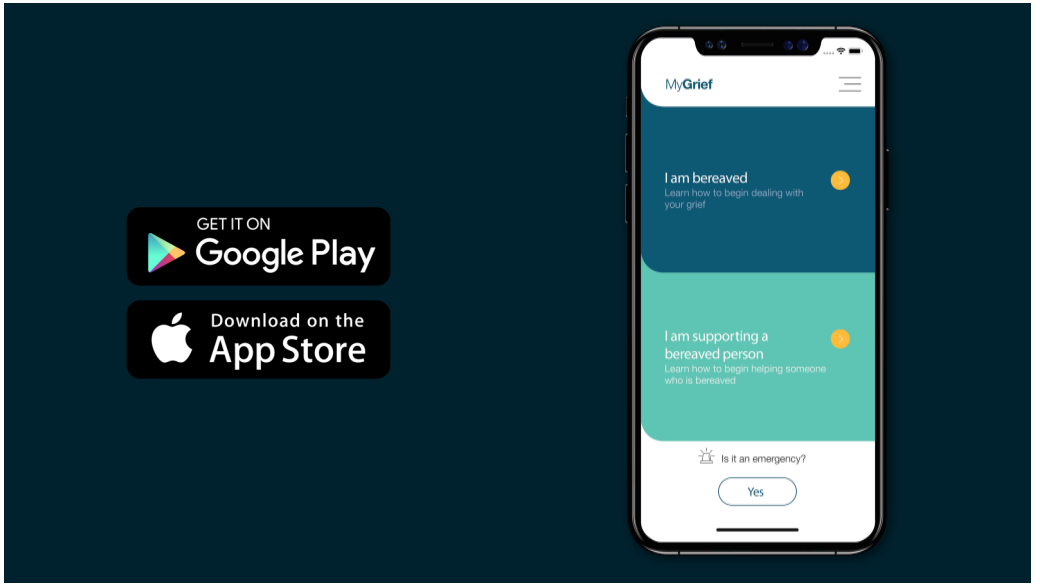








www.grief.org.au



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