

HOSPICE AND PALLIATIVE CARE SOCIAL
WORKERS GROUP

Bereavement Support Needs

Niamh Finucane

Co-ordinator of Social Work & Bereavement Services

Grief

Normal – a natural response to a significant loss, not just death

Dynamic - process, changes over times

As individual as a fingerprint

Occurs within a social context

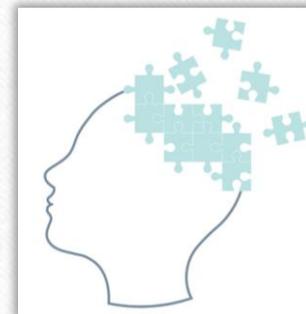
Skills for managing the loss – learning to live with grief



Physical



Emotional

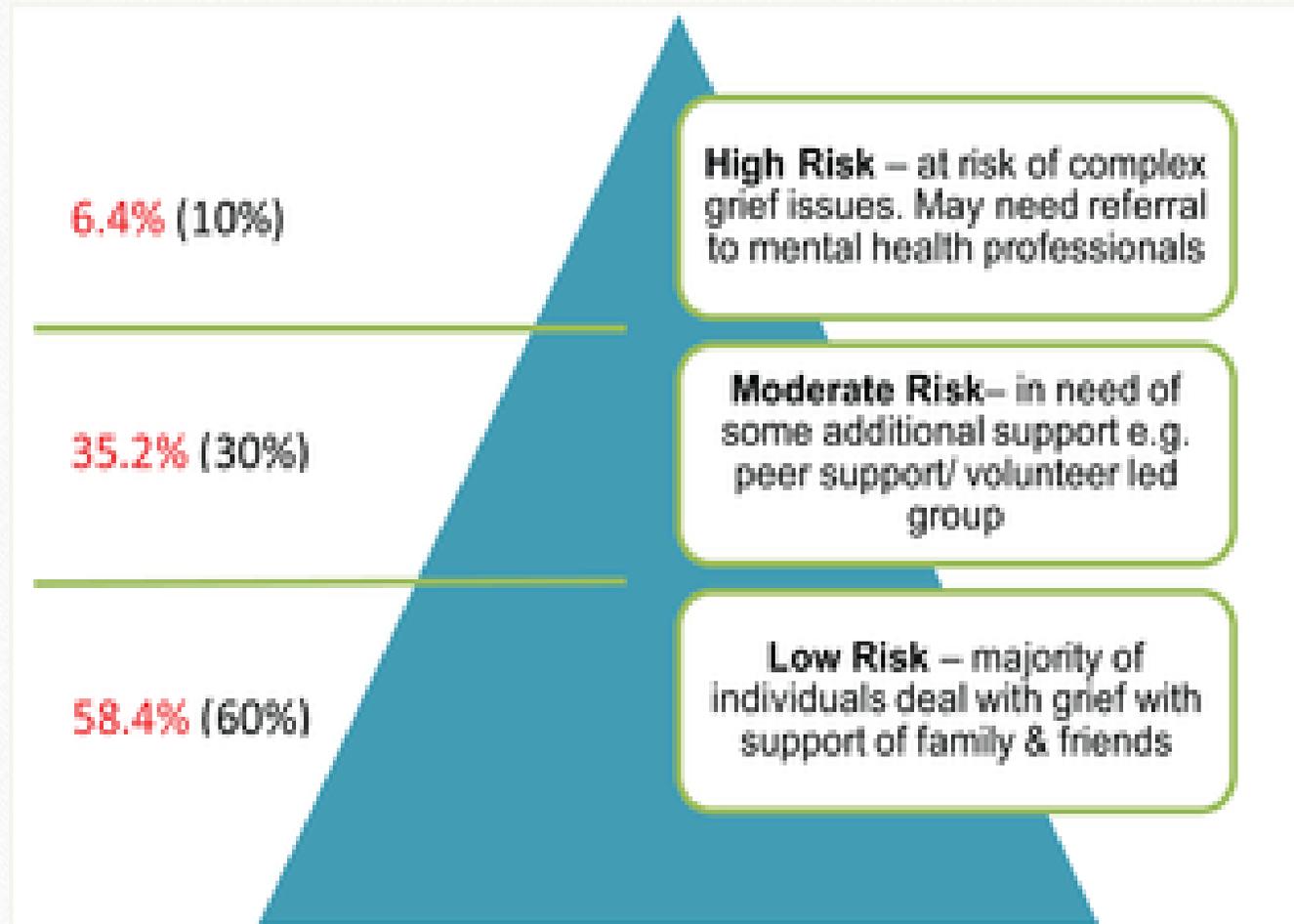


Psychological

Spiritual



Public Health Model

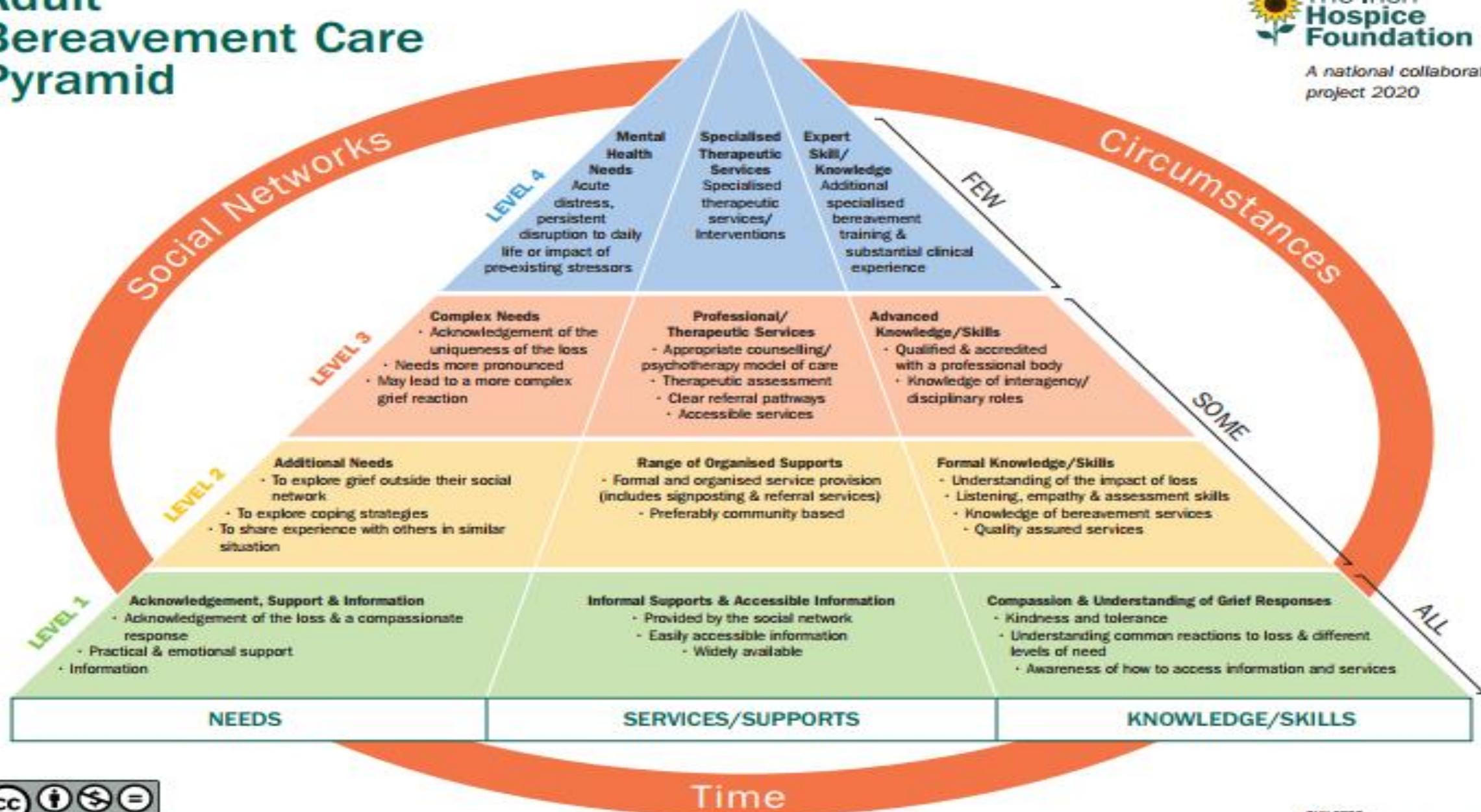


Aoun, S., Breen, L., Howting, D., Rumbold, B., McNamara, B. and Hegney, D., (2015) Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need, *PLOS* accessed 25/09/15 @ 15:07

Loss, Grief & Bereavement – what do we know?

- Most people will do well with the support of friends and family and provision of quality information on grief. People need information about what is “normal” in grief, including different expressions of grief – for adults, for children & for families
- Some will need some additional support outside of own family/social network to help them understand the impact of the loss and explore coping strategies
- Others will need professional help from someone with additional training in the recognition of and support for more complex grief
- A small number will need specialised care and/or mental health services
- Services should provide a tiered approach to services, empowering people to best support each other where possible

Adult Bereavement Care Pyramid



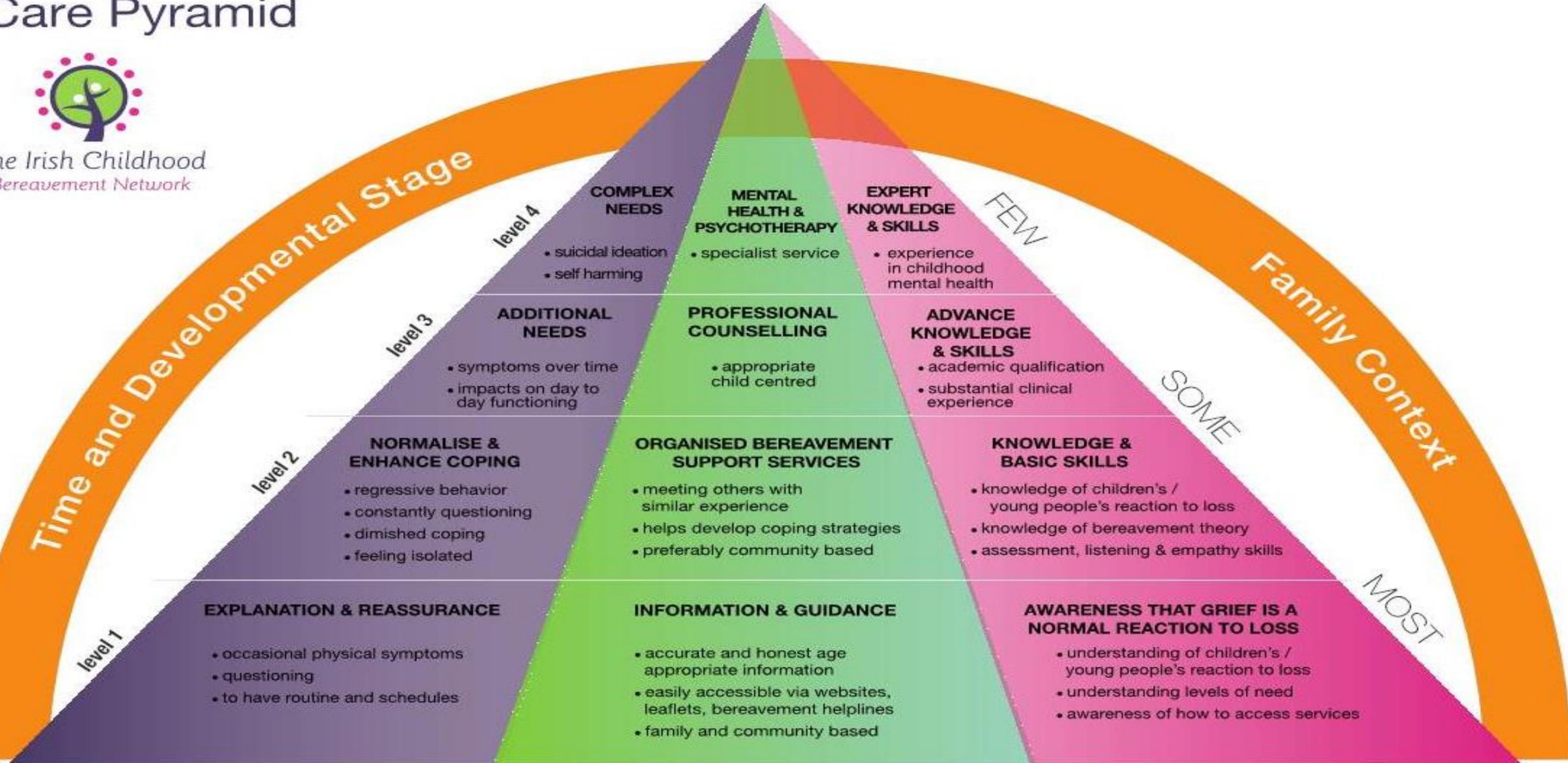
The Irish Childhood Bereavement Care Pyramid



The Irish Childhood
Bereavement Network

Time and Developmental Stage

Family Context



level 4

COMPLEX NEEDS

- suicidal ideation
- self harming

MENTAL HEALTH & PSYCHOTHERAPY

- specialist service

EXPERT KNOWLEDGE & SKILLS

- experience in childhood mental health

level 3

ADDITIONAL NEEDS

- symptoms over time
- impacts on day to day functioning

PROFESSIONAL COUNSELLING

- appropriate child centred

ADVANCE KNOWLEDGE & SKILLS

- academic qualification
- substantial clinical experience

level 2

NORMALISE & ENHANCE COPING

- regressive behavior
- constantly questioning
- diminished coping
- feeling isolated

ORGANISED BEREAVEMENT SUPPORT SERVICES

- meeting others with similar experience
- helps develop coping strategies
- preferably community based

KNOWLEDGE & BASIC SKILLS

- knowledge of children's / young people's reaction to loss
- knowledge of bereavement theory
- assessment, listening & empathy skills

level 1

EXPLANATION & REASSURANCE

- occasional physical symptoms
- questioning
- to have routine and schedules

INFORMATION & GUIDANCE

- accurate and honest age appropriate information
- easily accessible via websites, leaflets, bereavement helplines
- family and community based

AWARENESS THAT GRIEF IS A NORMAL REACTION TO LOSS

- understanding of children's / young people's reaction to loss
- understanding levels of need
- awareness of how to access services

NEEDS

SERVICE/SUPPORT

COMPETENCIES

Loss, Grief & Bereavement – what do we know?

- Grief is variable so responses vary. Different approaches seem to benefit different people. ‘One size does not fit all’, different trajectories (Bonanno)
- Differential grief – different expressions: Instrumental grievers and intuitive grievers (Doka)
 - at different points at different times in same family (Gilbert)
- Impacts on relationships AND vice versa (Hooghe; Stroebe)
- Family approaches (Shapiro; Nadeau; Kissane & Bloch)
- May be unacknowledged/disapproved – disenfranchised (Doka)
- Compassionate communities and the value of social connection (Aoun; Breen)

Loss, Grief & Bereavement – what do we know?

- Adjustment rather than acceptance (Carr)
- A Psychosocial transition (Murray Parks)
- Resilience and vulnerability in grief (Machin)
- Dual process model. Loss as ongoing.....Integrating, accommodating (Stroebe, Schut), but against background of other life stressors and challenges – potential for overload
- Biography, narrative approach - tell me about who died? (Walter)
- Meaning making (Neimeyer, Nadeau) - Some evidence for it being helpful (but not for all people)
- Relational factors (Neilson)
- Continuing bond (Silverman and Klass, Nickman)

What the research tells us:

- ❖ Help families to find or focus on aspects of the narrative that will help them in the weeks and months after the death. Families have continued to care for and support their relatives despite all the challenges and decisions were made in difficult circumstances – **not able to visit or see their relative during the illness or before death**
- ❖ Preparedness for death can influence more positive bereavement outcomes – **deaths from COVID more likely to be experienced as unexpected**
- ❖ Severity of the response after death – predicts severity of later responses (Boelen, PA and Lenferink, LIM (2020))
- ❖ The role of the family is key in providing support to bereaved children.
- ❖ The functioning of the surviving parent – predictor of adjustment for children (Worden; 1996)

Adaptation in Grief in the COVID-19 context

- Changed processes eg: registering a death – tangible/practical help and support
- Tangible or practical support (Kim et al 2020) – limited opportunities, added risk
- Funeral processes/rituals – do people need help to develop new rituals? creativity
- Safety and security – hierarchy of needs, altered sense of risk, increased anxiety
- Family contact, renegotiating family relationships (Kim et al 2020) – reduced, altered, virtual
- Social support – perception or experience of being cared for - reduced, altered, virtual, isolation
- Re-engaging with activities – function in terms of health, well being – many activities stopped/clubs closed/ not available to people
- Structure or routine provide predictability – may be changed, may no longer have routine

Adaptation in Grief in the COVID-19 context

- Memories – diagnosis, change, death – how memory processed. Can become intrusive – sign of trauma – **deaths from COVID may be more traumatic**
- Adaptation – **but what about when everything else in my world is different?**
- Cognitive factors can act as barriers to grief adaptation (eg: avoidance, intrusive thoughts, social disconnection) – **potential impact of COVID context**
- Self- care, exercise, chronic health issues – need to attend to their own health (Kim et al 2020)—**sports facilities/classes closed, health systems altered**
- Technology –**support at a ‘warm’ distance**

Possible Bereavement Risk Factors

- Nature of the death – inc. expected/unexpected
- Demographic factors – age, stage of life, culture, etc.
- Death of a child
- Nature of the relationship - Close or dependent relationship; estrangements/tensions
- Social Supports – presence and availability
- Communication issues, family stresses
- Financial/legal concerns
- Individual coping styles - insecure attachment
- Presence of other major life stressors

Possible Bereavement Risk Factors ctd.

- Mental Health issues – current and past
- History of previous losses
- Lack of resilience or adaptability to life changes
- History of previous losses
- Mental Health issues – current and past
- Drug and/or alcohol abuse – Addiction
- Health concerns
- Traumatic childhood experiences, such as abuse or neglect

What can help?

- Information and support around the time of death and in the immediate acute phase of grief – range of formats: spoken, written, visual
- Ensure people have the information and support they need to complete the associated formal processes and procedures – tangible support
- Seek ways to increase/maximise connectedness, social contacts
- Emphasise exercise, routine, self care
- Assess risk – isolation; fear; safeguarding
- Enable people to access support – what is available, how to access services
- Refer people for support if needed

References

-
- Aoun, S., Breen, L., Howling, D., Rumbold, B., McNamara, B. and Hegney, D., (2015) Who Needs Bereavement Support? A Population Based Survey of Bereavement Risk and Support Need, *PLOS* accessed 25/09/15 @ 15:07
 - Boelen, PA and Lenferink, LIM (2020) Symptoms of Prolonged Grief, posttraumatic stress and depression in recently bereaved people: symptom profiles, predictive value and cognitive-behavioural correlates, *Soc. Psychiatry Psychoatr. Epidemiol.* 55, 765-777
 - Health Service Executive and Royal College of Physicians in Ireland. (2019) Adult Palliative Care Services Model of Care for Ireland, the National Clinical Programme for Palliative Care
 - Irish Childhood Bereavement Network (2017) 'Standards for Supporting Bereaved Children & Young People – A Framework for Development' ICBN, Dublin.
 - Ishikawa, RZ (2020) I May Never See the Ocean Again: Loss and Grief Among Older Adults During the COVID-19 Pandemic *Psychological Trauma: Theory, Research, Practice and Policy* American Psychological Society 2020
 - Keleman, www.seriousillnessconversations.org
 - Kim, Y., Carver, C., Cannady, R (2020) Bereaved Family Caregivers' Unmet Needs: Measure Development and Validation *Annals of Behaviour Medicine* 54:164-175
 - Kissane, D. W., Zaider, T. I., Li, Y., Hichenberg, S., Schuler, T., Lederberg, M., & Del Gaudio, F. (2016). Randomized controlled trial of family therapy in advanced cancer continued into bereavement, *Journal of Clinical Oncology*, 34, 1921–1927.
 - Lobb et al., 2010: Systematic review of predictors of complicated grief *Death Studies*, Vol. 34, Issue 8, pg: 673 - 698
 - McGarry, S and Casey, A (2020) Discussion Paper: The case for a national psychosocial model of care from Acute Hospital Medical Social Work Departments in response to Covid_19, IASW, Dublin
 - Nielsen, M. J., Neergaard, M. A., Jensen, A. B., Vedsted, P., Bro, F. & Guldin, M-B., (2017) Predictors of complicated grief and depression in bereaved caregivers: A Nationwide Prosective Cohort Study *Journal of Pain and Symptom Management* March 2017, Vo. 53, Issue 3, Pg: 540 -550
 - Neimeyer, R. A., et al. (2014). "A social constructionist account of grief: Loss and the narration of meaning." *Death Studies* 38(8): 485-498.

References

- Newsom C, Stroebe M, Shut H, Wilson S, Birrell J, Moerbeek M. and Eisma MC. (2017) Community-based counselling reaches and helps bereaved people living in low income households, *Psychotherapy Research*, 1-13
- Otani, H., et al. (2017). "Meaningful Communication Before Death, but Not Present at the Time of Death Itself, Is Associated With Better Outcomes on Measures of Depression and Complicated Grief Among Bereaved Family Members of Cancer Patients." *Journal of Pain and Symptom Management* 54(3): 273-279.
- Roulston A, Campbell A, Cairnduff V, Fitzpatrick D, Donnelly C. and Gavin A. (2016) Bereavement outcomes: A quantitative survey identifying risk factors in family carers bereaved through cancer, *Palliative Medicine*, Vol. 31, Issue 2, Pg: 162 - 170
- Selman, L, Chao, D, Sowden, R, Marshall, S, Chamberlain, C, Koffman, J (2020) Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians, *Journal of Pain and Symptom Management*, May 4
- Stroebe, M & Schut, H (2021) Bereavement in Times of COVID-19: A Review and Theoretical Framework *OMEGA—Journal of Death and Dying* 2021, Vol. 82(3) 500–522
- Tavistock (2020) Covid 19 -Guidance for the Support and Wellbeing of Adult social workers and social care professionals in a pandemic crisis. NHS, the Tavistock and Portman foundation trust [Health and wellbeing of the adult social care workforce - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/531107/Health_and_wellbeing_of_the_adult_social_care_workforce_-_GOV.UK.pdf)
- Walter, T., 1996. A new model of grief: Bereavement and biography. *Mortality*, 1(1), pp.7-25.
- Worden, W. (1996) *Children and Grief: When a parent dies*; Guilford Publications, UK.

Additional Resources

- Guidance for Bereavement Support provided by Specialist Palliative Care Social Workers in Ireland,(Oct 2019) and Addendum - COVID-19 (2020)

http://www.professionalpalliativehub.com/resource-centre/guidance-bereavement-support-provided-specialist-palliative-care-social-workers_or

[https://www.iasw.ie/IASW COVID19 Resources](https://www.iasw.ie/IASW_COVID19_Resources)

- <https://www.basw.co.uk/resources/role-social-workers-palliative-end-life-and-bereavement-care>

Contact Details

Irene Murphy

Marymount Hospice

(021) 4501201

imurphy@marymount.ie

Niamh Finucane

St. Francis Hospice Dublin

(01)8327535

nfinucane@sfh.ie

If anybody is working in hospice or palliative care, please contact us if you would like to become a member of the national Hospice and Palliative Care Social Workers Group