Supporting individuals with grief: Using a psychological first aid framework

Barney Dunn, July 2020



My background and acknowledgements

- Professor of Clinical Psychology at Mood Disorders Centre, University of Exeter and co-lead AccEPT clinic (NHS 'post IAPT gap' service)
- Main area depression but been involved in developing some grief guidance as part of COVID response with Kathy Shear (Columbia) and Anke Ehlers (Oxford)
- These materials developed to support counsellors/therapists to work with grief with principals of psychological first aid.
- Thanks to Kathy Shear for letting me use some of her centre's materials and videos

Overview

- Part 1: Understanding grief
- Part 2: Supporting individuals through acute grief
- Part 3: Use of psychological first aid framework for grief (and more generally)
- Part 4: Prolonged grief disorder

Learning objectives

- Be familiar with range of grief reactions
- Be able use your common factor skills and knowledge around bereavement from workshop to respond empathically and supportively to people who are grieving in a non-pathologizing way
- Be able to use the psychological first aid framework to help people look after themselves while grieving
- To know who and how to signpost on to further help
- You are <u>not</u> expected to be experts in grief or to 'treat' grief

Optional core reading

Supporting people with grief:

- Shear, M. K., Muldberg, S., & Periyakoil, V. (2017). Supporting patients who are bereaved. BMJ (Clinical research ed.), 358, j2854. <u>https://doi.org/10.1136/bmj.j2854</u>
- See also material for clinicians and public on this website: <u>https://complicatedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/</u>

Prolonged grief disorder:

- Jordan, A. H. & Litz, B. T (2014). Prolonged Grief Disorder: Diagnostic, Assessment and Treatment Considerations. Professional Psychology: Research and Practice, 45(3), 180-187. <u>https://psycnet.apa.org/record/2014-24102-004</u>
- Note this slightly misrepresents diagnosis/assessment but is helpful on treatment (see Mauro et al., 2019).

Psychological First Aid:

 Psychological First Aid: Guide for Field Workers (World Health Organisation) https://www.who.int/mental_health/publications/guide_field_workers/en/

Part 1: Understanding grief



Understanding the grieving process

- Acute grief is a painful but natural experience to a significant loss
- It is an adaptive process that helps us reconfigure a key attachment relationship after someone dies
- Hallmark is intense yearning, longing and prominent thoughts and memories of the deceased



Common elements of acute grief

- Yearning/ thoughts of deceased accompanied by some or all of:
 - Emotional pain
 - Feelings of disbelief and difficulty accepting the death
 - Difficulty thinking clearly about other things
 - Avoidance of situations that trigger increases in longing or sadness
 - Efforts being made to stay close to the person who died through sensory stimulation (look at pictures, smell clothes, listen to recordings)
 - Physical pain, symptoms and/or fatigue
 - Disturbances in sleep and eating behaviour
 - Loss of interest/meaning in the future without the deceased
 - Being troubled by change in role/identity
 - Sometimes experiencing presence of loved one
- Although the above is written in 'clinical' language, these reactions are entirely natural in the acute stages of grief (loss of my dad as an example)

Unique and variable nature of grief

- There are commonalities in grief, but each person will experience this differently as a function of:
 - \odot Relationship to deceased
 - Personal history (including of loss)
 - Circumstances of death
 - Context of death
- Grief usually evolves gradually over time, but follows an idiosyncratic and erratic course
- Individuals typically move back and forth between accepting the reality of the loss (loss oriented processing) and restoring wellbeing (restoration oriented processing) (Stroebe & Schut, 1999)
- There is no empirical support for 'stage' models of grief



Adaptation and integrated grief

- Most individuals move over time to a position of 'integrated grief' grief that has a place in the person's life and where it can help them learn and grow
- Adaptation involves accepting the reality of the loss, including
 - The finality of the loss
 - The changes this brings (including a changed relationship to the deceased)
 - The permanence of grief
 - Restoring a sense of wellbeing (including autonomy, relatedness and competence)



The continuum of grief response

- Grief is a normal process and should not be pathologised
- There is a continuum of reactions, with individuals differing in intensity, duration and 'stuckness' of response
- Those who are moderately 'stuck' may benefit from referral for grief counselling
- Those who are very 'stuck' may meet criteria for prolonged grief disorder (PGD) and benefit from specialist treatment using evidence-based protocols



Part 2: Supporting individuals to move from acute to integrated grief



Grief naturally evolves without need for formal intervention

Supporting individuals with grief 1

- For a majority of individuals (even following death in traumatic circumstances), grief evolves naturally over time without the need for formal intervention
 - Nevertheless, bereaved people often benefit from a brief opportunity to speak about the loss then they come into contact with helping professionals
 - This is not a formal intervention, just an opportunity to be listened to and heard, and to share the pain of the loss
- Aim to provide support around, rather than formal assessment and intervention of grief, to avoid bereaved feeling judged or pathologized
- Signpost the bereaved person to information about the grieving process (for example, <u>CRUSE</u> or <u>Centre for Complicated Grief</u>)

Supporting individuals with grief 2

- Do assess (and treat/refer on) as appropriate for other mental disorders in early period after bereavement
- Unexpected loss elevates risk for a range of conditions including depression, PTSD, panic, mania, and alcohol misuse (Keyes et al., 2014)
- There are also a rage of other physical health conditions which can be exacerbated after loss, so advise individuals to see GP if they report these
- Do identify individuals who are 'stuck' and/or are at risk for or meet criteria for complicated grief reaction

Supporting individuals with grief 3

- Meet the person where they are without trying to guide or direct them only offer advice when requested
- Let the bereaved person know it can be helpful to both have times to confront the pain and at other times to set it aside; people need to find their own balance here
- Don't be afraid to ask about the person who died
- A sub-group of individuals will have a more sustained, extreme and 'stuck' grief response and may benefit from signposting to other additional support

Facilitating loss oriented processing in general

- Empathically acknowledge pain of the loss
- Give person time to talk about loss, including how the person died as well as what else has changed in their life
- Normalize their experience
- Validate how they are feeling
- Show interest in bereaved, their relationship with decreased, circumstances around death and range of feelings/challenges they are facing
- Expect responses to be highly individual

Helping people accept reality of the loss in COVID context

- It may be helpful to allow the patient to voice concerns about end of life period that may drive distress and find ways to make peace them. In a COVID context, this may include concerns about:
 - How someone became infected
 - Steps taken to ensure dignity and comfort in final stages of life
 - Whether individual died alone
 - Decisions made to alter or ration care
 - Change in death rituals in the context of the pandemic
 - Lack of physical presence presence of comforters (not being able to give the bereaved a hug)
- If COVID disrupted end of life rituals, support the patient in considering whether they wish to find another way to mark or acknowledge the death (there is no right or wrong way or time to mark a death, so be flexible here)



Helping people restore a sense of wellbeing

- Support the client to allow themselves to experience positive emotions and to start to think about their own lives moving forwards, even if only for brief moments
- Listen out for and reinforce signs of positive adjustment, including:
 - Envisioning a future where it is possible to have meaning, purpose and happiness
 - Findings ways to connect to memory of decreased
 - Reconnecting with other people
- It may be useful to discuss individual's current self-care and bolster this as appropriate, as much as possible trying to draw on their existing strengths/resilience and support (see later section on Psychological First Aid)
- It may be useful to focus on buildings individuals self-compassion (and listen out for self-criticism)
 - Particularly later on in grief, client and network around client may become critical of not 'getting back to normal' – try and reframe this



Reinforce Grief HEALING milestones (Kathy Shear)

These are signs individual is adapting to the loss:

- Honour loved one and yourself; discovering your own interests and values
- Ease emotional pain; open self to both painful and pleasant emotions, trust you can deal with the pain and that it doesn't control you
- Accept grief and let it find a place in your life
- Learn to live with reminders of your loss
- Integrate memories of your loved one; let them enrich your life, and help you learn and grow
- Narrate stories of the death for yourself; share them with others
- Gather others around you; connect with your community; let people in and let them support you



Help people notice potential grief DERAILERS (Kathy Shear)

These are patterns of thinking, feeling and behaving that block transition from acute to integrated grief

They are both common and natural, but can be problematic if they become 'stuck'

- Doubt that you did enough for person who died
- Embracing ideas about grief that make you want to change or control it
- Repeatedly imagining scenarios where the death didn't happen or happened differently ('if only' thinking)
- Anger or bitterness you can't resolve or let go of
- Insistent beliefs that this death was unfair or wrong or shouldn't have happened
- Lack of faith in the possibility of adapting to the loss and having promising future
- Excessive avoidance of reminders of the loss
- Rejecting support from others, unable to let others help, feeling hurt and alone
- Survivor guilt that is stopping you from experiencing joy and satisfaction



Identifying who may become 'stuck'

- Individuals at risk of becoming stuck if they:
 - Show little progress through HEALING milestones
 - If they exhibit multiple **DERAILERS**
- This framework can be useful to hold in mind when assessing risk of becoming stuck
- It can also be a useful acronym to share with individuals who have experienced bereavement
- A copy can be downloaded from the Complicated Grief Centre at Columbia in the resources of the 'For the Public' section



Recognising prolonged grief disorder (PGD)

- Relatively new diagnosis, now in same section of ICD-11 diagnostic taxonomy as PTSD, with following criteria
- Persistent and pervasive grief response characterized by intense longing and persistent preoccupation with the deceased (lasting at least six months after bereavement) and accompanied by
 - Intense emotional pain (sadness, guilt, anger)
 - Inability to experience positive mood and/or emotional numbness
 - Difficulty accepting death (avoiding reminders or acting as though it hasn't happened)
 - Difficulty engaging with social or other activities
 - Feeling one has lost a part of one's self
- Reaction exceeds expected social, cultural or religious norms for individual's culture or context
- Causes significant impairment in functioning
- Broadly similar definition in DSM-V, apart from cannot be diagnosed until 12m after loss
- Note: PGD is not qualitatively distinct from normal grief but more severe, long lasting, impairing and 'stuck'

Screening: Brief Grief Questionnaire (Shear et al., 2006)

- How much are you have difficulty accepting the death?
- How much does your grief (sadness and longing) interfere with your life?
- How much are you having images or thoughts of the decreased when he/she died or other images about the deceased that really bother you?
- Are there things you used to do when the deceased was alive that you don't feel comfortable doing anymore, that you avoid
- How much are you feeling cut off or distance from other people since the deceased died, even people you used to be close to like family or friends?

All scored 0 (not at all), 1 (somewhat), or 2 (a lot). Scores of 4 or more should be assessed more fully.

For a more detailed assessment can use PG-13: <u>https://endoflife.weill.cornell.edu/sites/default/files/pg-13.pdf</u>

People who might need more than simple grief support

- Consider offering psychological first aid (*)
- Consider signposting on to additional support
 - For more moderate difficulties, grief counselling (for example, CRUSE or in house counselling)
 - For more severe or comorbid difficulties, high intensity therapy or other specialist services (if available)
- Remember, acute grief is associated with intense emotions/preoccupying thoughts and DERAILERS are very common. Therefore, avoid referring people on who don't need it, as this can be iatrogenic
 - $\,\circ\,$ If in doubt, a 'watch and wait' approach can be useful.
 - If possible, continue to follow patients (possibly at low frequency) for at least 6 months post loss (the minimum time point for ICD-11 prolonged grief disorder)





Optional post workshop pairs role play

- Bring to mind a client you have worked with that had experienced loss (or if none come to mind create one)
- Role play having a 10m conversation as part of an assessment that:
 - Gives the client a chance to talk about their loss and respond in a validating, empathic way
 - Help individual accept reality of the loss and to restore wellbeing
 - If appropriate, listens out for and strengthens any progress through HEALING milestones
 - If appropriate, notices and provides psychoeducation any potential DERAILERS
- The main aim is to have an empathic, human conversation, so you don't need to do all of this at once, just focus on what comes naturally in the conversation
- Each take a turn being a client and being the therapist and then reflect on the experience. If you like, record this conversation via teams and watch back to help you reflect.

Part 3: Psychological First Aid As a Scaffold





Overview of Psychological First Aid in Grief Context

Common-sense approach to build coping resources, not in depth psychological therapy. Three steps (step 3 adapted for grief context):

- 1. ensure basic needs are met
- 2. ensure social support is in place
- 3. develop a self-care plan that helps a) work through loss and b) re-engage with valued and wellbeing enhancing activities



Step 3 assumes individuals have been introduced to loss-orientation and restoration-oriented framework and DERAILERS before completing self-care plan

You don't need to do all of this for everybody – focus on areas they are neglecting, are struggling with, or may be particularly helpful for that individual





Ensure basic needs are met

In the midst of acute grief, people can easily forget to look after their basic needs. Review as appropriate if the following are in place:

- Keep hydrated and fed
- Be well rested
- Take some form of regular exercise
- Make home comfortable, clean and a good temperature
- Have clean clothes to wear
- If working, ensure workload is manageable and discuss with line manager if need any reasonable adjustments making
- If have caring responsibilities, discuss with others how to ensure these are manageable and if any contingency plans need making to support client
- Individuals likely to have financial/legal/benefits paperwork they need to attend to as a result of loss

There may be some basic tasks like shopping for food, cleaning the house, doing the laundry, managing money that the individual has not had to perform before and this may require practical problem-solving



Maximise social support

- Partner
- Family
- Friends
- Broader social network: clubs, societies, church
- Other community options



Check in to see if these people are being helpful. If not and there are problems engaging with social support, explore and trouble shoot barriers:

- Psychological: worrying will be a burden, lacking motivation, feeling guilty about look after self etc
- Practical: geographical distance, limited mobility, limited finances, lacking technological expertise etc
- Take into account how social distancing/COVID may impact on social support
- Develop concrete plans to engage with this support network, including how to turn this into a habit
- Some people may benefit from role play/reflection on how to ask for help (including being concrete about what they need)



Reflect on client strengths and past experiences

Review what has worked for client when coping with past losses

- Focus on both what helped individuals accepted the reality of the loss and how they were able to build wellbeing afterwards
- Explore what aspects of this they can put into practice while grieving now, including adapting for COVID context
- Try to build client sense of agency and that how they feel will likely change over time
- Recognize each loss is unique and different, so not all past coping will fit the present loss
- Avoid being too 'upbeat' and 'Polly-Anna-ish' while doing so. Losing a loved one is often the most difficult thing any of us ever experience and it is hard to be at our most resilient in the midst of acute grief.



Ideas for working through loss

- A key task of grieving is moving from having a person physically and mentally present to just mentally present (having memories and knowledge of the person we carry forward)
- This is one function of death rituals like funerals, which are likely to have been disrupted during COVID
- Some things that might help the individual accept the reality of the loss include:
 - Spending time telling the 'story' of the death
 - o Remembering and sharing memories of individuals that capture their 'essence' or values
 - Having photos or reminders of the deceased
- It is natural for this process to be very emotional a mixture of painful distress and poignant and pleasurable reminiscence
- Encourage people to accept the emotions that come about as they go through this process but also to build in self-care around it (and to notice DERAILERS that lead them being stuck in loss-oriented processing with no respite into restoration-oriented processing).
- Allow people to take their own path here do not impose any expectations on them
- For me immediately afterwards, talking through with my brother final few days
- For me now, driving my dads old car, a photo of him playing rugby as a young man, a few landmark memories, and taking pleasure whenever I channel his inner essence and 'stick it to the man'

Engage in activities that build wellbeing

Connect: engage in social contact to feel close to/valued by others

Be active: engage in regular physical exercise

Take notice: be aware of senses in the moment (mindfulness)

Give: participate in social and community life, appreciate others

Learn: engage in learning to enhance self-esteem

5 ways to wellbeing



Be realistic given individual is grieving and likely has other demands on their time:

- Look for 30s or 5m moments that can be scheduled when needed
- Aim for 30m 1 hour a couple of times a week

Tips for engaging in wellbeing activities

- Make self-care a habit
- Plan specific activities (what, where, how, when)
- Personalise activities to interests and values (and possibly to values they liked in deceased)
- Include lots of small 'everyday pleasures' not just 'big ticket' items: doing what you already do but differently
- Client may have to adapt usual wellbeing due to social isolation
- Don't be too ambitious and show you understand doing this is hard to client
- Anticipate clients will be ambivalent in anticipation about doing these things, especially if this was
 something they used to do to together with the deceased, reminds them of the person they have lost, or if
 they are experiencing survivor guilt.
- Work through this ambivalence much like BA for depression
- Don't set expectation these activities will always bring wellbeing; early on it is likely they may be mixed experiences (moments of wellbeing and moments that trigger grief response)
- Try to help them accept rather than judge mixed feelings and trust they will pass; over time and repeated engagement with activity ambivalence will likely fade and pleasure will increase
- Use memory prompts to help client remind themselves of plans



Trouble shooting wellbeing activities

If client is tired/lack motivation

- Plan in advance how to make easy to do (e.g. running kit ready at door)
- Just try first 5m and see what happens
- Recruit social support to 'nudge' you to complete activity

If worry/rumination/grief stops you enjoying activities

- For example, 'I wont enjoy this alone', 'its wrong to feel happy', 'I don't know how to do this alone', 'others will thing its wrong I am trying to be happy'
- Label them as thoughts not necessarily reality ('I am thinking that....')
- Bring attention back to present moment (mindfulness)
- Rehearse what you would say to a friend/family member/colleague thinking the same way
- Be kind to self these thoughts are normal, especially when grieving





Tips for sleep



- Establish a regular sleep routine
- Minimise alcohol, exercise, caffeine and screen time 1hr before bed
- Engage in relaxing activities before bed
- Ensure a quiet, dark room
- If mind is racing, 'count sheep' or practice mindfulness
- If still cant sleep after 20m, get up for a few minutes and do something calming
- Don't worry if you cant sleep you will function fine the next day!
- Consider referral for sleep intervention if marked

Develop a self-care plan

Take a few minutes to develop a self-care plan

- What steps do you need to take to ensure your basic needs are met?
- What steps might you take to connect with social support?
- What steps might help you work through the loss?
- What do you need from others when you are working through the loss?
- What steps might you take to look after your general wellbeing?
- What do you need from others to help you engage in these wellbeing activities?
- What are any early warning signs that you are becoming 'stuck' in grief DERAILERS?
- What will you do if you notice these early warning signs?
- What will help you remember and follow this plan?

[note: this assumes client has been introduced to psychological first aid, loss-orientation and restoration-oriented processing framework, and concept of DERAILERS. It is probably best used as a handout, which begins with some general psychoeducation about grief and how to manage it and then is a structured tool to work through]

Optional post workshop pairs exercise

In pairs:

a) take it in turns to develop your own 'psychological first' aid around work related stress, with the other person guiding you through (adapted) questions on the plan. You will need to replace 'grief' with 'work-related stress'.

b) If you wish, role play developing a self-care plan with a client who has recently been bereaved

c) If you wish, reflect on what other presentations/situations this psychological first aid approach could be used

Part 4: Prolonged Grief Disorder



Specialist treatment for PGD A short video illustrating how grief can become stuck

https://www.youtube.com/watch?v=wJgviSyPz6I



Prevalence and risk factors for PGD

- Roughly 7-10% of individuals bereaved by natural courses will develop PGD following non-traumatic loss (Lundorff et al., 2017)
- Rates rise up to 30% following traumatic/violent loss in troubling circumstances
- Risk factors for PGD include:
 - Person-related (previous loss experience, prior mental health problems, insecure attachment style)
 - Relationship-related (loss of child or spouse, exceptionally close/positive relationship with the deceased; less evidence for ambivalent relationship with deceased)
 - Circumstance- and context -related (violent or traumatic death, troubling circumstances such as dying alone, inadequate social support, fragile socio-economic situation, perception of injustice)

Risk of Prolonged Grief Disorder during pandemic

- Many of risk factors listed previously present for both COVID and non-COVID related deaths
- In addition risk likely to be exacerbated by:
 - High degree of contagion
 - Likelihood of sickness in bereaved family members
 - People dying in alone
 - Difficulty in respectfully care for remains
 - Inability to gather for mourning rituals lack of physical comforting
 - Exposure to COVID 'catastrophizing' media (cf. Kristensen et al., 2016)
 - Having to adapt to broader changes as result of physical distancing

Differential diagnosis and comorbidity

Differential diagnosis

- Hard to tell apart from depression, especially since bereavement exclusion removed from depression criteria
 - In PGD yearning/longing is marked, whereas in depression it is rare
 - In PGD anhedonia is restricted and there is still some capacity for positive emotion (especially towards the deceased), whereas in depression anhedonia is more pervasive
- In PTSD primary emotion is fear, whereas in PGD it is yearning/longing.
- Nightmares are nearly always present in PTSD and rarely in PGD
- Reliving may be more ruminative and have less of a sense of 'nowness' in PGD than PTSD
- Do not assume that just because someone you assess with depression/PTSD has also experienced recent loss that they are better thought of as having PGD – it depends on presentation

Comorbidity

- In many cases, especially following traumatic/unnatural death, PGD, depression and grief may well be comorbid
- These are typically cases to refer onto specialist treatment if available, where a decision will need to be made as to which to treat as 'primary'

Evidence for treating PGD

- No NICE guidelines as yet
- However, PGD specific therapy protocols have been shown to be effective in clinical research studies, including a total of 5 RCTs
- PGD protocol outperform non-PGD specific protocols or medications (including supportive counselling, IPT and citalopram) and show sustained benefit over follow-up (for example, Shear et al., 2016)
- A variety of protocols exist, which all include an exposure like exercise to tell the story of the death.
- These are supplemented with:
 - Exercises to identify maladaptive mechanisms that maintain the grief reaction and to problem solve-these (DERAILERS for Shear)
 - Strategies to reconnect individuals to valued life goals (HEALING milestones for Shear)

Q&A with Kathy Shear (developer of prolonged grief treatment)

Interview with Irish Hospice Foundation, 2014: <u>https://www.youtube.com/watch?v=aAEfYSOS8W8</u>



If you want to learn more about her (high intensity) treatment (60m talk): https://www.youtube.com/watch?v=7BNHgelRzv4

Summary

- Grief is a normal and adaptive reaction
- You don't need to be an expert that can 'treat' grief just a human being that uses knowledge in this webinar and your interpersonal skills to support people
- Avoid pathologizing
- Provide people with psychoeducation about what to expect
- Psychological first aid can be a useful framework to use to bolster self-care, including developing a personal wellbeing plan
- Focus on HEALING milestones and DERAILERS as a scaffold
- Take into account how COVID may have impacted on grief reaction
- Do treat/refer on for other physical and mental health conditions
- Do signpost people who are stuck for grief counselling
- Do identify prolonged grief disorder this is intense, long lasting and stuck grief reaction but is not qualitatively different than 'normal grief'
- Careful thought needed about what is referral option for prolonged grief disorder, taking into account comorbidity and what services are available locally
- A lot here but don't think you need to do it all do a few things, well, that meet the client where they need to be met!

Final reflection exercise

- A workshop is only as useful as what you then do with it
- Make a concrete commitment about next steps to consolidate and apply this knowledge