#### COVID TRAUMA RESPONSE WORKING GROUP RAPID GUIDANCE

## Clinical guidelines for delivering bereavement and grief support in the context of COVID-19

The COVID-19 pandemic is associated with increased mortality and therefore bereavement. There are a range of factors that are likely to interfere with the normal grieving process for all bereaved people, regardless of cause of death, including potential separation at time of death and not being able to say "goodbye", family member's own potential COVID-19 illness, the unexpectedness of the death, limits on attending and conducting funerals and social isolation due to lockdown. Together these may increase the risk of traumatic bereavement and complex grief reactions in bereaved family members of people who have died from both COVID-19 and other causes of death. Therefore, enhanced planning for bereavement and grief support in the current context is required.

These guidelines aim to help services and clinicians consider relevant factors when planning bereavement and grief support in the weeks and months after a death during the COVID pandemic. They do not focus on end of life care, which is covered elsewhere (see Association for Palliative Medicine <u>advice</u>). In the absence of NICE guidelines around bereavement, this guidance represents evidence where available and expert opinion.

## Key points

Clinical staff supporting individuals who have been bereaved during COVID-19 should:

- Have sufficient knowledge of the natural grieving process and how to support individuals.
- Understand general and COVID-specific risk factors for and be able to identify clinical
  conditions following bereavement including post-traumatic stress disorder (PTSD), which can
  diagnosed one month after a loss; depression, which can be diagnosed early on after loss;
  and prolonged grief disorder (PGD), which can only be diagnosed six months after loss. This
  is particularly relevant to staff conducting clinical assessments, including doctors working in
  primary and secondary care, and psychological therapists.
- Clinicians including therapists should know if, when, and how to signpost to other care or intervene in cases of traumatic grief, PGD, PTSD and depression linked to loss.
- There is an emotional impact when supporting individuals through bereavement and staff should be mindful to support their own wellbeing when doing this work including careful management of case load, regular clinical supervision, peer support, and engaging in emotional self-care.

From our experience of working with the bereaved after mass casualty events we learnt that it is important that those planning any commemorative events or gestures (including sharing images of the deceased) discuss this with families first.

## Understanding "typical" grieving processes

- Acute grief is a natural experience in response to a significant attachment loss i.e. a significant other with whom the bereaved had a relationship. Some do not follow this process, and even in the first few months it becomes clear that they are having more complicated reactions to their loss
- The hallmark of grief is intense yearning, longing and prominent thoughts and memories of the deceased. Grief is typically accompanied by emotional pain, feelings of disbelief and difficulty accepting the death, prominent thoughts and memories of the deceased with difficulty thinking clearly about other things, avoidance of situations that trigger increases in longing or sadness, efforts to feel close to the person who died through sensory stimulation (looking at pictures, smelling clothes, listening to recordings of the person), loss of

- interest/meaning in the future without the deceased, physical pain, disturbances in sleep and eating behaviors, and being troubled by change in role/identity.
- There are commonalities in grief, but the uniqueness of each person's relationship to the deceased, as well as unique features of personal history and context of the death, means grief is experienced differently by each person and for each loss. It changes erratically over time, as different aspects of the loss are evoked and processed. Grief usually lessens over time, gradually receding into the background.
- Adapting to the death of a loved one requires accepting the changed circumstances and changed relationship to the deceased as well as restoring wellbeing (e.g. Bowlby, 1980). This process does not follow a predictable or a linear course. Rather, acceptance of the loss and restoring wellbeing proceed in tandem, while alternating between confronting emotional pain and setting it aside as they engage in "loss-oriented processing" and "restorationoriented processing" (1).
- For the majority of individuals, even following death in traumatic circumstances, the grieving process resolves naturally over time as people adapt to the loss, without the need for formal intervention. However, bereaved people often benefit from a brief opportunity to speak about the loss when they come into contact with professionals (hospital staff, general practitioners, charity counsellors, therapists). If so, they usually need only to be listened to and heard, to share the pain of the loss, without any formal psychological intervention
- Some individuals may however become 'stuck' during grieving. Some individuals will not
  warrant a mental health diagnosis but will benefit from referral to grief counselling (for
  example, third and voluntary sector organisations like CRUSE). Others with more
  pronounced problematic grief reactions may meet criteria for post-traumatic stress disorder
  (PTSD), major depressive disorder and/or prolonged grief disorder (PGD) and will likely
  benefit from specialist mental-health input.

# Grief support in the first weeks or months after bereavement (2,3)

- Aim to provide support around, rather than formal assessment of, grief reactions to avoid the bereaved person feeling judged or pathologized.
- However, do formally assess for, and if appropriate refer on for treatment of, suicidality and current mental disorders in the early period after bereavement. Unexpected loss has been associated with elevated risk for depression, PTSD, panic disorder, phobia, mania, suicidality and alcohol misuse (4). Given the likelihood of challenging and traumatic loss during the pandemic, clinicians should be particularly vigilant for PTSD.
- Simple support from clinicians, including GPs and mental health professionals, can be helpful during acute grief and might include the following:
  - Empathically acknowledge the pain of the loss, give the person time to talk about loss and normalize their experience; show interest in the person talking about the deceased and their relationship with the deceased as well as specific circumstances around the death and the range of feelings/challenges the person is facing (expecting this to be highly individual). It may be helpful to allow the bereaved person to voice concerns around the end of life period that may drive distress and find ways to make peace with these
  - Let the bereaved person know that it can be helpful to both have times to confront the pain and at other times set it aside; people need to find their own balance of confronting pain and allowing respite from it.
  - Encourage the patient to allow themselves to experience positive emotions and to start to think about their own lives moving forwards, even for brief periods of time; listen out for, acknowledge and normalize feelings of survivor guilt associated with this whilst still encouraging wellbeing enhancing activities.

- People may benefit from having time to discuss and problem solve both idiosyncratic and practical issues around the loss (including financial and legal processes). A Psychological First Aid framework may be useful here to help individuals cope with challenging circumstances in a non-pathologising way, including exploring if individuals' basic needs are met, adequate social support is in place, they have a coping plan in place that builds on their existing resources and strengths to work through the loss and gradually re-engage in wellbeing enhancing activities.
- People may benefit from space to explore religious, spiritual and cultural dimensions of the loss (including funeral planning) and some may benefit from signposting to spiritual leaders to assist this process.
- o "Meet" the patient where they are emotionally without trying to guide or direct them; give advice only when requested; and validate how they are feeling.
- Consider signposting the bereaved person to information about the grieving process (e.g. <u>CRUSE</u> in the United Kingdom or <u>Center for Complicated Grief in the United</u> States of America)
- Listen out for and reinforce signs of positive adjustment, including finding ways to reconnect with other people, accepting the reality of the loss, envisioning a future where it is possible to have meaning, purpose and happiness, and reaffirm ways to connect to the memory of the deceased.
- Notice the presence of any 'derailers' that may block the normal grieving process including trying to control or judge grief; survivor guilt or excessive ruminative self-blame or anger; "if only" thinking, imagining ways to "rewrite history" in ways that the death did not happen; excessive commitment to avoiding reminders of the loss; inadequate social support; and PTSD symptoms. However, be wary of over-emphasizing these initially as they are natural reactions to loss and become a problem only when they become too pervasive or persistent and in the case of PTSD, if they last longer than a month.
- o It may be useful to discuss the individual's current self-care and gauge their capacity for self-compassion and to explore ways to further bolster this, as much as possible trying to draw on their existing strengths, resilience and support. This may include sleep, eating, exercise, social contact and support, engaging in wellbeing enhancing activities, and making adaptations as required depending on the current status of infection control measures including 'lockdown' restrictions.
- The relevant clinician should consider follow-up assessment to see whether any difficulties resolve naturally or whether they continue to interfere with life.
- As appropriate, refer on for further support. The majority of individuals may not need any intervention except signposting to relevant information, some may benefit from making use of grief support or counselling, and a minority may (now or in the future) require interventions from mental health specialists to treat prolonged grief disorder or other mental health conditions like depression or PTSD linked to the loss. In general, follow a stepped care approach, except if there is PTSD where individuals should be referred for evidence-based PTSD treatment (5). Consider the complexity, comorbidity and extent of impairment to inform where mental health treatment should be provided in the healthcare system.
- In a UK context, the major public sector psychological therapy workforce is situated in Increasing Access to Psychological Therapy (IAPT) services in primary care. IAPT services have been advised to signpost to CRUSE where the primary presenting problem is needing support in the context of bereavement. Where the primary presenting problem is depression or anxiety, but this is complicated by a recent bereavement, IAPT services should offer evidence-based treatment for the specific condition. If the primary presenting problem is PTSD associated with traumatic bereavement, this may be treated within IAPT using NICE recommended PTSD

protocols (unless local CRUSE pathways have equivalent or stronger provision for these presentations) where this is clinically appropriate to do so for the patient in terms of clinical complexity and where there is appropriate trauma expertise and supervision amongst therapists. Complex cases should be referred on to specialist trauma and/or secondary mental health services if these are available.

# Grief support for traumatic loss in the context of the pandemic

- The pandemic will likely increase the number of people who experience loss in traumatic circumstances and impact on the normal grieving process in a number of ways (for both COVID and non-COVID deaths; 6-8). This may increase the risk of individuals becoming 'stuck' during grieving and therefore requiring further intervention. In addition to the general guidance above, clinicians should consider the following additional points.
- Assess for risk factors for becoming stuck (9):
  - Circumstances of the death including violent, traumatic or untimely death, dying alone, not having opportunity to say goodbye, having care de-prioritized, rationed or withdrawn, not having time to prepare for death, and not being able to see the loved-one's body after death. For deaths caused by COVID, family members may have anxieties about the source of infection and if more could have been done to prevent it and also may have multiple family members who have been affected due to the contagious nature of the illness and/or be part of the community that has experienced losses.
  - Context around the death including lack of social support, change in funeral practices due to social distancing, fragile socio-economic situation, experienced other losses in their community or their organisation, perception of injustice, anger at government around response to pandemic.
  - o *Person-related risks, including* previous loss experience, prior mental health problems, and insecure attachment style.
  - o *Relationship-related* risks, including loss of a child or spouse, and exceptionally close, positive relationship with the deceased.
  - These risk factors increase the likelihood of unhelpful counterfactual thinking (imagining alternative scenarios), guilty or angry ruminations, social disconnection (10) and survivor guilt.
- Determine who may benefit from signposting to additional support based on the presence of these risk factors and the extent/severity of the grief reaction.
- Allow individuals to voice and process concerns about how the pandemic impacted on end of life. This could include, for example, concerns about how someone became infected, steps taken to ensure dignity, comfort and presence of others in the final stages of life, decisions made to alter or ration care, not being able to be present in the last stages of life, and changes in death rituals due to physical distancing. Listen carefully to the context of how the person died and to the meanings that the individual attributes to these circumstances. Ask open ended questions that avoid perceived attribution of blame and/or minimization of loss.
- Processing these concerns may be assisted by being able to talk to staff who were present at
  the death or to other residents who the patient/relative knew prior to the pandemic. Further,
  seeing pictures, virtually visiting, and/or physically visiting the place where the person died (if
  this can be done safely) may also be of benefit.
- If COVID disrupted end of life rituals, support the person in considering whether they wish to find
  another to mark or acknowledge the death (there is no right or wrong way to mark a death, so
  be flexible here).
- Take into account the social, spiritual and religious context for that individual (for example, disturbances of 'washing' of the body at end of life may be highly distressing for individuals of Muslim Faith). These cultural factors can be extremely important and deviations from death

- rituals cannot be "rectified" after they have occurred. These have the potential to cause significant and lasting distress.
- Monitor for and gently discourage excessive checking of COVID media, given evidence that media checking exacerbates problematic grief reactions.
- Signpost individuals to psycho-educational materials that discuss bereavement in the COVID context, for example <a href="CRUSE">CRUSE</a> guidance.
- If using a Psychological First Aid framework to guide support, take into account how pandemic and social distancing will impact on the individual deploying their coping resources. This may include challenges in meeting basic needs (for example, accessing shops), not being able to have physical contact with support network and having to develop digital alternatives, activities that have previously brought wellbeing not being accessible and/or having a different meaning if they are accessible (for example, provoking anxiety due to risk of infection).

# Assessment and treatment of prolonged grief disorder

- As prolonged grief disorder is a relatively new diagnosis, it is possible clinicians will be less familiar at diagnosing and treating it than other mental health reactions seen following loss like depression and PTSD. Therefore, the following sections provide an overview of assessment and treatment of PGD specifically.
- This is not meant to imply that PGD will necessarily be the dominant reaction that will be seen following traumatic loss in the COVID context and clinicians should assess, signpost and treat for the spectrum of mental health reactions that are likely to present including PTSD and depression. Where depression and/or PTSD are the primary presenting problem(s), these should be treated using disorder specific protocols for these presentations, making adaptations to take into account the loss. Moreover, where depression and/or PTSD are present in a case that is highly likely to meet criteria for PGD but six months have not yet passed since the loss, the depression and/or PTSD should be treated first.
- In a subset of individuals, grief does not naturally subside and this can lead to prolonged grief disorder (PGD). According to ICD-11 classification (which is broadly similar to the DSM-5.1 proposed criteria) PGD is defined as:
  - persistent and pervasive grief response characterized by intense longing for the deceased or persistent preoccupation with the deceased lasting at least six months after bereavement.
  - accompanied by intense emotional pain e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities.
  - The grief response has persisted for an atypically long period (for more than 6 months after loss at a minimum), exceeds expected social, cultural or religious norms for the individual's culture and context, and causes significant impairment in functioning.
- A rough estimate is that 10% of those bereaved by natural causes develop PGD following non-traumatic loss (11). Rates are higher following traumatic/violent loss in troubling circumstances (up to 30%). Given the context of the pandemic, rates of PGD will likely be closer to this upper estimate.
- PGD can be screened for using the 5-item Brief Grief Questionnaire (12) and assessed using the Prolonged Grief Disorder 13 (PG-13; 13)
- It is useful to differentiate PGD (yearning, preoccupation with the deceased) from depression (yearning/longing rare, more pervasive anhedonia) and PTSD (flashbacks and nightmares) where possible. However, in many cases these may be comorbid (14-15)
- A variety of specific psychological treatment protocols have been found to be effective in treating prolonged grief disorder in randomized controlled trials, leading to superior short-

- and long-term outcomes compared to non-specific treatment like interpersonal therapy or supportive counselling (16 –20)
- Each of the protocols involves telling the story of the death to help process and accept the loss (using exposure like exercises), finding ways to honour the memory of the deceased, adapting to the new reality and roles in life after the death, and gradually re-engaging with wellbeing enhancing and valued activities (using behavioural activation exercises). They also identify and problem solve coping mechanisms that may be maintaining the grief reaction, including difficulty managing emotions, problem sleeping, and ruminating on the causes, meaning and consequences of the death.
- Staff may require additional training to deliver these approaches: those with an existing CBT background are relatively well positioned to learn these approaches.

## Treatment planning around complex cases

- More complex cases including severity, co-morbidity, atypical presentations, presentations
  with multiple biological, social, and/or psychological factors interacting to trigger and maintain
  distress, unhelpful help-seeking behaviours and increased risk may present with features of
  and potentially meet criteria for depression, PTSD, and prolonged grief disorder. Clinicians
  will need to develop a treatment plan that takes into account this comorbidity and complexity.
- There is currently no established evidence-based guidance about how to best deal with comorbidity or how to stage treatment.
- These cases will likely require more detailed assessment (including risk) and longer duration
  of therapy, so will benefit from referral to specialist (secondary care) services including
  specialist psychological trauma clinics where these are available.
- Clinical assessment can help to determine which problem is causing the most impact and so should be targeted first (the primary problem) in treatment. The clinician will need to consider the pattern of symptoms and their relative severity and functional relationship as well as the degree of interference with everyday life and risk to guide individual treatment decisions. It is also useful to consider patient preference as to what would feel the most useful place to start and/or to focus on the area that is causing the greatest degree of distress and/or impairment for them. Select the appropriate treatment protocol that best targets this primary problem.
- Whichever treatment pathway is chosen, there is a key role for thoughtful case
  conceptualization and formulation to ensure comorbidity is addressed. This includes, for
  example, adapting a depression or PTSD treatment plan to also focus on factors impeding
  adjustment to the loss (for example see case presentation for comorbid PTSD and PGD at
  <a href="https://oxcadatresources.com/covid-19-resources/">https://oxcadatresources.com/covid-19-resources/</a>). This maximises the chances of clinical
  improvement on both the primary presenting problem and associated comorbidities.
- Where the primary treatment offered was not sufficient to resolve all diagnoses, consider referring on for further work This could include, for example, if a PTSD protocol resolved PTSD and depression but not prolonged grief disorder, then consider a PGD specific intervention as the next step.
- Depending on what referral options are available, decision-making may in part need to be pragmatic and go beyond the current evidence-base. For example, where PGD is the primary diagnosis but no PGD treatment is available, individuals may benefit from loss-focused CBT that includes accepting grief and fostering emotion regulation, strengthening ongoing relationships, telling the story of the loss, honouring the deceased and relationship, resuming activities, reducing unhelpful cognitions, and reducing unhelpful coping strategies such as avoidance and rumination.
- The field would benefit from the development of NICE guidance to inform bereavement care, particularly for more complex presentations.

The COVID Trauma Response Working Group has been formed to help coordinate trauma-informed responses to the COVID outbreak. We are made of psychological trauma specialists, coordinators of the psychosocial response to trauma and wellbeing leads at NHS Trusts. The working group is being coordinated by staff at University College London and the Traumatic Stress Clinic based at St Pancras Hospital in Camden and Islington NHS Trust. We are very grateful to our clinical and scientific colleagues in other NHS trusts and universities who are contributing to this work. We hope that this work is helpful to our colleagues involved in the care of patients affected by the COVID pandemic.

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#### Author contributions and methods

An iterative approach was adopted to developing these guidelines. An initial version of the guidance was developed by a multidisciplinary working group comprised of clinically practicing and academic clinical psychologists and psychiatrists (BD, KS, MB, AE, JW). Meetings were held via video-conference to discuss the draft until consensus was achieved. The document was then augmented and reviewed by the Trauma Response Working Group. The revised guidance was circulated to the working group members, and discussed via video-conference for further input and refinement. Finally, consensus was reached regarding this guidance through review by all authors.

#### Key resources

Webinar on treating PTSD after traumatic bereavement at <a href="https://oxcadatresources.com/covid-19-resources/">https://oxcadatresources.com/covid-19-resources/</a>

Resources and information on bereavement and prolonged grief disorder at <a href="https://complicatedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/">https://complicatedgrief.columbia.edu/professionals/complicated-grief-professionals/overview/</a>

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