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## Information to Bereaved Families Following Catastrophic Losses. Why Is It Important?

Atle Dyregrov  and Pål Kristensen 

Faculty of Psychology, Center for Crisis Psychology, University of Bergen, Bergen, Norway

### ABSTRACT

Based on extensive experience from clinical practice and research, we illustrate the importance of information provided to the bereaved following the death of a family member. When something happens to loved ones, family members seek out information to reduce insecurity and to understand what has happened. The combination of good information and a caring climate is the basis of good grief crisis intervention. Facts help to replace chaos with coherence and structure, and information about one's own and others' reactions normalizes thoughts and reactions. We describe various strategies to help bereaved to "get a grip" on the situation.

### KEYWORDS

Information; critical events; death; disasters; crisis intervention

### Introduction

Over several decades we have worked as clinical psychologists with bereaved persons through day-to-day crisis situations and major disasters. In addition, we have conducted research on the topic. In this paper we apply our experience to present and discuss the importance of information following catastrophic losses.

We have been part of a historical shift from excluding children from getting information and participating in rituals to involving them in different situations related to illness and death. Our clinical experience includes working with children with cancer, working at the neonatal intensive care unit and working with bereaved family members after single and mass event losses. Over the years there has been a gradual acceptance of the idea that parents must truthfully inform children about their own impending death or the death of a family member. This "truth-telling" is now widely accepted and endorsed in industrialized countries and was recently featured (and promoted) in a special issue of *Journal of Pediatric Psychology* (Schepers, 2019). In our work with sudden catastrophic deaths (suicide, murder, acts of terror and other disasters) and with "expected" deaths, we have become familiar with the way information plays a major role in good

**CONTACT** Atle Dyregrov  [atle@krisepsykologi.no](mailto:atle@krisepsykologi.no)  Faculty of Psychology, Clinic for Crisis Psychology, University of Bergen, Fortunen 5, 5013 Bergen, Norway.

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care and crisis intervention for those who experience such events, whether children or adults.

In the late 1970s, when we interviewed parents about their experiences when they were informed that their child had cancer, we learned that many of them had visited several doctors without being given a diagnosis. This waiting time was extremely stressful and anxiety provoking. When their child was eventually diagnosed, the information often came as a relief, although their child's fate was still very uncertain. Facts, even very serious in nature, are better than uncertainty and fantasy.

In the following, we present various aspects of information and its importance following critical events. For illustration, we will cite examples from critical or catastrophic events (hereafter abbreviated as CEs).

### ***Information: Central to efficient crisis intervention***

Twenty years ago, based on our clinical experience, we described what we call mental mobilization in CEs (Dyregrov, Solomon, & Bassøe, 2000). When persons experience a CE, they usually experience a mental mobilization where their senses become acutely sharp to allow intake of incoming information; they focus their attention on what is deemed important to them, cognitively activate useful stored "learnings" and normally adequate behavioral responses. People mobilize previous experience and learning to handle the situation, and rapidly process information to meet the situation's demand for a response. Aspects of the experience having high survival value can be intensively memorized, while other parts are not registered. The response can be a temporary distancing or blocking of emotions that allows all resources to be used for processing the incoming information to facilitate an appropriate response. Simultaneously the emotional suppression allows people to take in what happened step by step. It is when CE victims are in this almost altered state of consciousness that emergency helpers of various kinds are able to assist them to take in and make sense of the situation. While this description is largely based on accumulative personal experience from clinical situations, Zerbi and coworkers (2019) described a neuronal basis for this activity in large-scale networks in the brain.

When we learn that something has happened to our loved ones, we immediately seek out information. Research confirms the need for information among the bereaved (Ngo, Matthews, Quinlan, & Bohle, 2019; Valdimarsdóttir et al., 2007) and that satisfaction with information is associated with lower grief and PTSD scores (Matthews et al., 2019). We want to know as soon as possible what has happened and the status of our family member(s). We seek out what we deem to be the best sources of

information and often travel to places (police station, hospital, community meeting, next-of-kin center) to be present in a place we can learn more. Family members often complain about lack of information and being left with unanswered questions (Merlevede et al., 2004); a lack of information can cause much distress in the next-of kin. For example, disturbing mental images of the deceased's final moments can recur if the next of kin have only fragmented knowledge of what led to the death. By asking a doctor what symptoms mean, or contacting the police, hospital or an assistance number on a TV screen following a disaster, we try to make sense of what has happened.

### ***Combining truthful information with a caring climate***

The best crisis intervention is a combination of direct, truthful information in a caring climate. A situation can easily become extra stressful if information in a CE is given without any warmth or caring, or a person, family or group is left to deal with uncertainty on their own. Imagine being in a group of next-of-kin following a transportation disaster where there is very little information from authorities, or even disinformation, such as that given to the parents after the loss of loved ones in the South Korean Sewol ferry disaster in 2014 (Chae, Huh, & Choi, 2018). In the absence of a caring climate such situations can easily lead to rumors and ensuing anger, frustration and aggressive actions taken by the people who are affected. The following example describes the opposite scenario:

The incidents involve a Norwegian oil company that was attacked by terrorists in In Amenas, Algeria in 2012, and five of their personnel were killed while 17 survived (injured/uninjured); and then later, in 2016, a helicopter from the same oil company crashed on an island near the mainland on its way from an oil platform to Bergen, Norway killing all 13 (passengers and crew) on board. A next-of-kin center was set up at a hotel near Bergen airport. On both occasions, all close family members were invited to come there. The centers were operational for nearly a week in 2012 and for three days in 2016. On both occasions, information was provided every hour during daytime. Especially during the terror event, there were many times when there was no new information to give. However, one of the company's leaders, sometimes assisted by police or others, appeared at the hourly meetings and gave information that might be described as "empty" of content, i.e. the information mainly described how information was gathered. Although "empty" in its content, it had a calming effect on the waiting group, and was highly appreciated. The climate was warm and caring.

Information can have a calming effect and counteract rumors in uncertain situations. Following road traffic accidents in which young people are killed, friends of the victims can gather at community centers or schools. This also occurs after murders and other CEs. If young people are left to themselves without proper information, they can easily become emotionally

upset and have intense feelings. This in turn is associated with autonomous activation and “stronger” memories. If activation can be lowered, the after-effects may be less severe (Dyregrov & Regel, 2012). If adults address such groups with accurate information about what has happened, what steps are taken to investigate the event, where and when they will get more information, and some advice on what they can do in the encounter with this new situation, for example, a joint action to show sympathy to the affected family(ies), the group can be calmed.

The way a person provides information is important for the way people perceive they are taken care of. A distant, non-caring attitude can elicit frustration and anger, while a person who looks people in the eye, speaks truthfully and readily acknowledges when he/she does not know sparks trust in the receiver. Truthful information is paramount, but the level of detail must to be tailored to what people can take in. Informing families can be a particularly difficult task since the need for details may differ between family members (Kristensen, Dyregrov, & Dyregrov, in preparation).

The use of people with high situational authority signals to receivers that the bereaved are recognized and treated with respect. If bad news such as death notifications must be conveyed, an honest display of emotions by the person informing, apart from breaking down, is acceptable. However, as bereaved people in CEs mobilize their sensory apparatus to take in information from the environment, they are very sensitive to false pretense. Leaving time for questions should be part of all interaction with people affected by CEs.

If information is provided to a group, the presenter should introduce her/himself and his/her role. The situation the group is in should be acknowledged. If there are casualties, what is known is conveyed. What will be done for the next of kin? If the cause of the incident is known, information is provided. If not, what steps will be taken to establish the chain of events? What will happen now (timeframes, schedules, plans)?

### ***Two types of information***

It is possible to distinguish two types of information, (a) facts about what happened including the cause of a CE, and (b) information that helps those affected to understand their own and others' reactions.

#### ***Factual information***

Following critical events, people seek out information about their loved ones, what has happened to them and their status (injured, dead or missing), what caused the event and what will happen in the near future. The sense of disbelief among the bereaved can be difficult to cope with, for

example, when it is not possible to view the body of the deceased. In such cases, information about the identification process can be particularly important in order to make the loss more real.

Information is a first priority for concerned family members. Right after an event, whether one that affects one family or many (disasters), the bereaved are almost obsessed with getting information. Following major crisis events, next-of-kin centers may be set up. The way these centers inform those that gather there is what determines the success of the early response. The police and other emergency personnel, together with health workers, must deal with a large demand for information in an environment where rumors flourish. The media publish validated and unvalidated information. In modern society, each citizen has a cell phone and readily post input on social media or send it to the news media, which at times causes problems for those responsible for providing reliable information. They must rely on verified information when they inform family members. The larger the gap between what is out in the traditional media and on social media and the verified information that authorities give, the more helpers are made to appear uninformed.

**The speed of information – social media.** Terror situations in larger cities may involve tens of thousands of people locked in areas of the city without knowing whether they are safe or not (Dyregrov, Djup, Barrett, Watkins, & Kärki, 2019). It goes without saying that such situations make it almost impossible to handle the information flow in the beginning, making the situation very difficult for those waiting inside or outside the perimeters set up by police. Flexible use of social media is part of how authorities communicate with the public and cannot be left to those speculating about motives and consequences.

Information travels rapidly during “single” CEs as well. While police used to be able to have control over death notifications, i.e., sending officers or other designated personnel to inform the family, cell phones and media coverage may divulge the death haphazardly to the family, thereby potentially exacerbating the trauma. A person may sit in one part of the world and read about a situation in their home community and suddenly realize that a loved one is dead. The trauma potential is of course higher when information reaches the bereaved in this way. This challenging speed of information calls for immediate, active outreach from emergency personnel to inform close family members. Although not ideal, death notification by phone from a calm professional may be better than finding out on one’s own or being notified by an intensely upset family member or friend.

**Unplanned exposure may have unintended “positive” effects.** In CEs, family members can be exposed to the critical event itself. It is easy to think that this exposure automatically adds to the trauma potential, but in

a psychological perspective, it is more complex. Jabre and coworkers (2013, 2014) showed that family members present at resuscitation fared better than those who were not present. Those present experienced less trauma symptoms, anxiety and depression in the aftermath. Omerov and coworkers (2014) did not find that parents who found a child that had committed suicide reported any stronger reactions than those who were not in on the discovery. Being present provides a direct, albeit strong, confrontation with what has happened, but it also means that one will have a more total overview of facts, leaving little to the imagination.

**Planned exposure to facts.** In the aftermath of a CE, there are many ways that facts can be accessed. A family/individual can seek out information from medical reports, police reports and commissions that investigate a disastrous event. Information may be forthcoming in a proactive manner from authorities, or family members may have to remove barriers that prevent them from information they need to gain an understanding of what happened. Lack of information or the absence of an investigation into a disastrous event prevents an understanding of underlying causes and opens for speculation. It also prevents placing responsibility.

Also, family members differ in their right of access to police files, autopsy reports etc. After the terrorist attack at Utøya, Norway, in 2011, those who lost siblings did not have the same legal rights to information from the police about what had happened to their brother or sister as their parents did. This was uncomplicated in most families where the communication was open, but in families with less open communication these legal barriers created problems for the siblings who wanted detailed information, but could not get it (Kristensen et al., in preparation). Ngo and coworkers (2019) points to the same restriction of information following fatal work incidents, resulting in strained family relationships. It goes without saying that having to struggle to get information adds to the difficult situation a family already finds itself in, and therefore systems that easily allow family members to access important information are much valued. Systems or procedures that facilitate such information transfer include

- Meeting rescuers and health professionals that were involved in saving lives
- Going through autopsy reports with medical personnel
- Reconstructing a CE
- Being given priority over the press when investigation reports are presented
- Meeting survivors or witnesses to what happened
- Visiting the scene of event

These different activities shed light on what has happened and help construct the total picture. Information that is whole or complete can more easily be integrated into long-term memory (known as the Zeigarnik effect, Zeigarnik, 1938).

Misconceptions about illness and death can be mitigated with good information from personnel with intimate knowledge of what transpired.

A 17-year-old girl committed suicide by jumping from the balcony on the fourth floor in an apartment building. Several months later, the mother received help from a psychologist. It became apparent that the mother was very angry at the hospital because they did not save the daughter's life. The daughter was alive when she arrived at the hospital and the mother believed that modern medicine was so advanced that her daughter's life should have been saved. She met with the nurse on duty where her daughter was admitted at the hospital. She explained what happened and what was done to try to stabilize her situation. Next, she met with the neurosurgeon who operated on her daughter. In a mild and caring way, he explained the extent of her injuries, that she died on the operating table, and why they were unable to save her. The mother almost instantly reevaluated the situation and came to the conclusion that everything possible had been done to save her daughter. The mother also visited the apartment where her daughter jumped and could see with her own eyes how high above the ground the balcony was, adding to her understanding of how very difficult it would be to survive the fall to the ground. She also placed flowers and lit a candle on the spot where her daughter had landed.

**Visiting the scene of event.** After CEs, a visit to the scene of the event or the place where a death occurred can provide important information for bereaved and survivors.

Following the capsizing of a ship that killed 17 people in Norway, mostly seamen from the Philippines, some 50 close relatives came from the Philippines to Norway. Together with relatives of the Europeans that were killed, they were taken to the accident site on a naval ship. In the Philippines, people can survive for many days, even weeks, in the warm sea. In January in Norway, in minus 6 degrees Celsius, a person's bodily functions can continue for only a short period of time. When visiting the site, the Philippine relatives could see the distances to the shore, feel the cold and understand how difficult, if not impossible, survival was.

In several studies, we have documented how important such visits can be psychologically, while at the same time they are very demanding (Kristensen, Dyregrov, Weisaeth, et al., 2017; Kristensen, Dyregrov, & Dyregrov, 2017). The visits help bereaved process the loss and make sense of what happened. However, such a visit can also be painful. Nevertheless, most bereaved say that the benefits outweigh the distress. Although the benefit is documented following disasters, more studies about visiting the site of death are warranted following individual deaths.

To increase knowledge about the cause of sudden infant death and to gather new knowledge about Sudden Infant Death Syndrome (SIDS), a Death Scene Investigation (DSI) has been used in Norway. The DSI is



undertaken within 48 h; it communicates preliminary results from the autopsy and includes a thorough interview with the parents about the death of their infant. It also entails a detailed and practical reconstruction of how the infant was placed in the bed and how he/she was found. For the reconstruction, a specially designed doll similar in weight and size to a real infant is used. The DSI team also answers questions from the parents (for a detailed description of the DSI, see Rognum, Wille-Sveum, Arnestad, Stray-Pedersen, & Vege, 2010). When we evaluated this procedure, we found, somewhat to our surprise, that instead of experiencing this as upsetting, 97% of the parents found it “positive” or “very positive” (Heltne, Dyregrov, & Dyregrov, 2016). This has later been confirmed in a study by Kristensen and Heir (*in preparation*).

When discussing the findings, we ascribed this positive evaluation to the quick relay of facts and information to the parents by professionals who were able to create a good relationship and climate with the parents. It also gave the parents an opportunity to go through what happened and fill in information for each other. Parents greatly appreciate getting information from the forensic doctor who conducted the autopsy, because the parents feel more confident when they get first-hand information. But here, as with visiting the scene of event, reactions can be triggered or exacerbated. Our experience is that this is particularly so with persons who are prone to use avoidance to cope with potentially painful situations.

**Short distance between what is helpful and hurtful.** Situations in which important information is presented can easily give rise to traumatic impressions. In the UK people have found aspects of the inquest process to be both insensitive and inappropriate, although important for providing answers and making sense of the event (Spillane, Matvienko-Sikar, Larkin, Corcoran, & Arensman, 2019). In Australia, inquests have proven very valuable as a source of information for families following fatal work accidents (Ngo, Matthews, Quinlan, & Bohle, 2018). In both countries, recommendations have been made on how to improve care in terms of the family members’ inclusion in the procedures. Following infant deaths, getting information is the primary reason why parents agree to a postmortem autopsy (Breeze, Statham, Hackett, Jessop, & Lees, 2012).

If a family member is murdered, information about how the judicial system works may reduce unnecessary distress concerning the time it takes, how much space the perpetrator is given in the court case, the media frenzy, etc. Procedural information can also be important when a family member is hospitalized.

Withholding information or lack of communication within families is commonly associated with increased problems in children (Acuña & Kataoka, 2017; Dyregrov, 2001; Sheehan et al., 2019). Open disclosure of

the cause of death following stigma-related traumatic death is associated with fewer grief difficulties and better self-related health (Feigelman, Cerel, & Sanford, 2018). Clinical experience has taught us to include children and adolescents in meetings where important information is conveyed, although information must be tailored to the individual needs of the child.

Following an avalanche that killed three people and caused almost 140 family members to be evacuated from their homes, information meetings for adults were held during which they could meet with geologists and officials to get information about what would happen to their houses and apartments in the future. There were two meetings held for parents to provide information about how best to care for children. At both meetings, parents asked if it was normal for children to read everything they could find on the Internet about the disaster. Obviously, children needed more information, but it was provided only for the adults.

The amount of information a person or family can take in differs. It depends on the type of information, the complexity involved, the receiver's capacity to take in and understand the information and the way and when it is presented. Different family members may also have different capacities to absorb and understand information. Verbal information can be supplemented by written information and web material.

### ***Information to understand one's own and others' reactions***

In a CE, we can benefit from information about

- Our own usual thoughts, behavior and reactions – immediate and long-term
- The reactions and thoughts of others; family members, friends and coworkers and ordinary people
- Information about how to cope and practical techniques that can help
- Societal systems such as the legal system, medical procedures, commission work etc.

Cognitive processes during and after CEs, including our interpretations of own and others' reactions and thoughts, are important for both onset and maintenance of problems following loss and trauma (Boelen, de Keijser, & Smid, 2015; Meiser-Stedman, McKinnon, Dixon, Boyle, Smith, & Dalgleish, 2019). We strive to understand how we react and think following critical events. When we suddenly face the loss of a loved one, we can react with a sense of unreality and experience that it as a dream. This immediate reaction of shock often keeps emotions at bay. Frequently people question their "lack of reactions" and start harboring thoughts of not having loved the person enough or being less than caring because they do not react strongly enough. A woman with an academic degree in the field of mental

health was ashamed and concerned about how she could talk about her father without any feelings, although he had died only a week before. Despite her knowledge of grief reactions, she misread her own shock reactions.

When reality gradually is taken in, the intensity of reactions can give rise to thoughts of going mad. Psychoeducation is important to counteract such thoughts and understand that reactions are not unique, that they are normal and temporary, and that most of them will fade with time. Likewise, following a death, others will usually be there for you in the beginning but can vanish sooner than anticipated, giving rise to frustration and anger. Being forewarned helps build sounder expectations and makes it easier to uphold good relations to people in one's social support system.

A 16-year-old girl became very angry at her cousin following her mother's death. "Why did she cry more than me at the funeral?". The anger created a distance between her and her formerly close friend. She was explained that her cousin could allow her feelings to show as she had her own mother beside her to comfort her, while she (the bereaved daughter) needed to take in her loss gradually. This led her to understand and accept her cousin's reactions.

**Children and adolescents.** Children who lack life experience can easily misinterpret their own reactions and may need more information than adults need about normal reactions. They easily misunderstand parental reactions and can harbor fear that they are responsible for the reactions they see among caretakers. They may need reassurance that what they see is not a result of their actions or thoughts, and that they do not have to take on caring roles for their parents. With their limited experience, they need more, not less, information to understand their own and others' reactions. Information must be given to children in a simple form that is easy to understand, and it must be followed up to check what they actually understood. Parents often need adequate information that helps them understand both themselves and others around them (cf. the legal barriers previously mentioned).

Moreover, children and adolescents need information about parents' grief reactions as they may have difficulty understanding the depth and how long their parents' grief will last. This is especially so if their parents struggle with prolonged grief. Their sense of security in the family may be threatened, and with reduced parental capacity, they may have to face their loss with less adult attention and care (Hardt, Jobe-Shields, & Williams, 2018).

**Psychoeducation.** Psychoeducation involving forewarning about possible reactions is a balancing act. If a symptom list is provided, it may make people aware of own reactions and lay the groundwork for a self-fulfilling prophecy. This is perhaps why studies of psychoeducational approaches

have produced variable results (Creamer & O'Donnell, 2008; Wessely et al., 2008). Whitworth (2016) discusses the role of psychoeducation in trauma recovery and concludes, "Psychoeducation for trauma is most optimally provided in a manner that acknowledges the challenging impact of trauma exposure along with concurrently emphasizing the many means of bouncing-back from such experiences. It should be offered as part of a supportive relationship and when possible, relatively early after the traumatic event (p. 450)." He also recommends helping participants to find sources of help and that trauma psychoeducation should be sensitive to the culture and background of recipients.

Information about helpful coping mechanisms and self-help techniques can sustain and increase self-efficacy and potentially diminish the need for clinical services. The way we think about an event influences our reactions, and information that helps us navigate the unknown territory we venture into may be paramount to our future.

### ***Meeting others in same situation***

Meeting others who have experienced the same situation as oneself will often lead to a better overview of a situation than just having one's own experience to rely on. Although a group talk-through – often termed a debriefing – has come under attack, it may often be very important to meet with others to be in a shared context for one's own experience. In CEs, the bereaved's attention may be limited to certain aspects of a situation (tunnel vision) deemed of importance for survival, while the broader picture or contextual information is lost. When the people present in the same situation gather to talk about what has happened, they can illuminate the event from different perspectives, adding structure, organization along a timeline, and wholeness and closure to the event. The family is one such group. The group members together have more facts about a situation in total, than each of its members. In addition, they often have a shared identity where they help and assist each other during the CE (Drury et al., 2019), an identity that can be used beneficially in the aftermath.

### ***Why is it important?***

We do not think there are simple answers to this question. Information may serve different needs for different people. Factual information helps in building coherence and structure in relation to a CE (Spillane et al., 2019). Bereaved family members want to know the exact sequence of events leading up to the death as it helps them understand how and why an event happened (Ngo et al., 2018, 2019). A timeline for what happened helps us

establish the sequence of events and fills in gaps in our knowledge. While CEs usually turn our lives upside down and create uncertainty, undermining our assumptions about, and beliefs in the world and in ourselves (Janoff-Bulman & Frieze, 1983), factual information helps reorder our world. Facts that explain what happened reinstate orderliness to our existence and help explain what we do not understand. Facts help us in making sense of and understanding what led up to what happened, and why, and it diminishes uncertainty. Holland and Neimeyer (2010) refer to the “fundamentally narrative structure of human thought” in the way that we seek to order temporal events to tell a good story. The time sequencing where an event is arranged into a beginning, a middle and an end is facilitated by access to facts. Not knowing means our minds remain open to different fantasy-based scenarios and more possibilities for rumination.

The “why” is paramount among the bereaved and survivors of CEs. Even when there are no explanations, knowing all the facts available and being assured that everything possible is done to get some answers, i.e., when searching for missing people, calms us. Especially following sudden and traumatic losses, many bereaved persons become obsessed with finding a plausible reason or explanation for the event, or a meaning in their loss (Davis, Wortman, Lehman, & Silver, 2000). It is easier when facts are available to facilitate this process, such as following an accident. It is more difficult when the incident is an “out-of-the-blue suicide” with no suicide note left behind.

The need for information varies, even within families. Although the majority seem to cope best when they receive as much information and as many facts as possible, there are people who deliberately stay away from information. Although such an avoidance pattern is associated with more problems (Marks, Franklin, & Zoellner, 2018), it is important to respect their decision and to tread carefully when trying to break down the avoidance barrier.

The value of information about one’s own and others’ psychological reactions also stems from various causes. Such information hinders the sense of being different, can normalize one’s own thoughts and feelings and may explain why others behave as they do. Information provides a “map” of the psychological terrain we are approaching and makes the future less uncertain. A post-event negative appraisal of one’s own reactions and suppression and maladaptive coping behavior, such as avoidance and suppression or rumination, can prolong reactions. Information can hopefully be important in counteracting subsequent problems (Marks et al., 2018). By understanding oneself and one’s surroundings, the “upside-down world” can be felt as less challenging and more manageable. By describing specific methods that people can use to dampen persistent posttraumatic

reactions that continue, i.e., to bring down intrusions, return to normal activities, techniques to stop unhealthy worrying, lower bodily activation, the post-crisis situation becomes easier to handle. Such information can also stimulate self-efficacy. Lastly, providing information on when further help is needed can help encourage the bereaved or CE victim to seek help at the appropriate time.

## Conclusion

Information is crucial in CEs. It is the backbone of good crisis intervention and ensures that those affected by the situation get the best platform for coping with their new life situation. Factual information provides context and structure in one's experience and allows it to be assimilated into one's life story.

## Notes on contributors

*Atle Dyregrov*, PhD, is a professor at the Center for crisis psychology, University of Bergen, Norway. He also works a clinical psychologist at the Clinic for crisis psychology. Dyregrov is the author of numerous publications, journal articles and more than 15 books. He has conducted research on various subjects relating to bereavement, trauma and disaster. He is one of the founding members of the European Society for Traumatic Stress Studies and the Children and War Foundation and has worked extensively for different humanitarian organizations. In 2014, he was awarded Knight 1st Class, Royal Norwegian Order of St. Olav by the Norwegian king for his pioneering work within the crisis and disaster field.

*Pål Kristensen*, PhD, is a research psychologist at the Center for crisis psychology/University of Bergen, Norway. His expertise and research interests concerns mental health consequences of sudden and/or violent deaths, and prevention/treatment of complicated grief.

## ORCID

Atle Dyregrov  <http://orcid.org/0000-0003-3281-030X>

Pål Kristensen  <http://orcid.org/0000-0002-8017-8495>

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