

In a disaster, the size of the psychological 'footprint' greatly exceeds the size of the medical 'footprint'

Health care providers are often highly skilled in recognizing and supporting anticipatory grief and factors that may affect a person or family's ability to cope after a death. The circumstances surrounding COVID-19 provide added challenges for supporting families in a medical setting. While baseline factors that potentially impact bereavement continue to be relevant (such as highly medicalized death, disagreement between family and medical team, feeling unheard, misunderstandings regarding severity of medical condition, etc.), this pandemic may introduce new challenges for end of life emotional support, anticipatory grief, and bereavement. It is important for health care professionals to take precautions and consider additional factors to avoid minimizing a family's experience or contributing to disenfranchised grief.

Here are some things to think about:

- Disruption of cultural rituals, including, but not limited to funerals, memorial services, vigil sitting, mourning periods, gathering at bedside, etc.
- Social and/or physical isolation for the patient and family members. While a primary relative (such as spouse) may be allowed to be bedside, other family members may be excluded (such as a parent). This can result in an isolated experience with far ranging and varied implications for each family member.
- Protective measures may restrict physical human touch. Family members may not be able to touch the person who is dying or may have conflicted feelings if the touch has occurred (especially if counseled not to do so) and may result in further isolation precautions and guilt responses. Families should be made aware of any risks or precautions to take regarding touching the body after death.
- Face masks and other protective gear may hinder communication through facial expressions and body language.
- Financial considerations for care and treatment are common, but with widespread closures, previously secure families may be in an unfamiliar situation of having to consider financial and practical factors in an uncomfortable way. This can potentially include loss of health or life insurance as well as increased domestic responsibilities due to school closures.
- Families may feel frustration in the practical task of planning for cremation/purchasing a casket/arranging burial in a timely fashion in light of closures or shortages of equipment or personnel.
- There may be stigma surrounding a death at this time, regardless of whether it is caused by COVID19. The uniqueness of a person's experience may feel compromised or taken over by the collective experience around them.
- Many people are feeling heightened anxiety regarding their health and safety on top of a normal grief response, this heightened anxiety can lead to an elevated level of sensitivity or loneliness that can exacerbate grief reactions.
- Families may be unable to provide caregiving due to risk of infection which can result in intense guilt feelings of "not having done enough."

- Repeated exposure to death and news of the death of others can lead to excessive thoughts and worries regarding death and dying (themselves or the people around them). This includes fear that may spread through social media and news sources and can lead to further social isolation and increased anxiety.
- Significant existential or spiritual crisis, particularly at a time when many churches, synagogues, mosques, and other social/spiritual gathering places are closed for services.
- The person dying may be the primary source of physical/emotional/financial/psychological strength and support.
- Baseline mental health issues may be exacerbated.

Here are some things we can do:

- Health care providers sometimes feel powerless to be unable to fix or change these circumstances; it is important to remember, while families may have strong grief reactions expressed through anger or tearfulness, acknowledging these dilemmas with compassion, empathy, and respect can provide comfort and the feeling of being heard. Sometimes we can just listen.
- Be careful not to minimize a person's experience with platitudes or clichés (disenfranchised grief responses). Empathetic responses that affirm an emotional response (such as, "I can understand your frustration"; "this is a very difficult situation"; "I wish it could be different") are usually helpful.
- Remind families to take care of their own health with adequate nutrition, hydration, and reminders to continue taking all routing medications, including those for emotional or psychiatric support.
- Be gentle and supportive without being intrusive in interactions; ask them what they need and how you can help.
- Don't assume you know how or what they are feeling, listen and provide silence and space for them to express themselves.
- Refrain from judging or using "should" (such as, "you should be grateful it wasn't you"; "you shouldn't feel that way").
- Avoid talking about your own concerns or somebody else's story.
- Remember you don't have to solve the problem. Often being present and simply listening can help a person or family through an emotional moment.
- Be aware of your own thoughts and feelings, including fears and potential feelings of insufficiency. It is important to recognize what we are bringing into the room with us so that we can avoid inadvertently communicating these things to families through words, emotional response, or body language.

Reminders for Families with Children

Children respond differently than adults to crisis and grief. Here are some ways to advise caretakers:

Infants

- Keep them warm and safe.
- Keep them away from loud noises and chaos.
- Keep a regular feeding and sleeping schedule, if possible.
- Speak in a calm and soft voice.

Young children

- Give them extra time and attention.
- Remind them often that they are safe.
- Explain to them that they are not to blame for bad things that have happened.
- Whenever possible, avoid separating young children from parents and caregivers, siblings, and other loved ones.
- Keep to regular routines and schedules as much as possible or help create new ones in a new environment. The key is to establish a dependable routine and structure to each day.
- Give simple answers about what has happened without scary details. Use child friendly language.
- Allow them to stay close to you if they are fearful or clingy.
- Be patient with children who start demonstrating behaviors they had when they were younger, such as sucking their thumb or wetting the bed.
- Provide a chance to play and relax, if possible.

Older children and adolescents

- Give them your time and attention.
- Help them to keep regular routines, including school/ learning. If this is not possible due to school closures, help them establish new routines.
- Provide facts about what has happened, explain what is going on now and give them clear information about how to reduce their risk of being infected by the disease.
- Encourage and allow opportunities for them to be helpful in concrete, purposeful common interests (e.g., taking on safe but relevant tasks in the community as part of the overall outbreak response).
- Allow them to be sad. Don't expect them to be tough or resilient.
- Listen to their thoughts and fears without being judgmental.
- Set clear rules and expectations.
- Link them with existing networks of adolescents, youth, and other community and social support groups. This can be achieved through social media but be careful to monitor information that is being shared to ensure its accuracy.