



Case Studies on Autism & Grief

Cassie is a 21-year-old autistic woman who lived with her grandmother for her entire life. Following the recent death of that grandmother, Cassie was moved from California to Virginia to live with her Aunt Chrissy. While Cassie has a good relationship with her aunt, she reacts strongly to the myriad changes happening all at once: the death of her beloved grandmother, moving across the country, working with new providers, and having to develop a new routine. Initially, Cassie would repeat “Grandma’s coming back” over and over and would cry when Aunt Chrissy reminded her that Grandma had died. This pattern persisted for nearly a month until Cassie became fixated on watching the recorded livestream of the funeral. She became quieter and more withdrawn. Her appetite diminished and Aunt Chrissy could hear her watching television late into the night. Recently a new direct support professional named Kim began working with Cassie. Kim had observed similar reactions to death in previous clients and gently encouraged Cassie to complete her daily tasks, even if she didn’t feel like it. Kim and Cassie often walked near the pond close to Aunt Chrissy’s home, and Cassie grew to love watching the ducks feed each evening. One evening, Cassie admitted that being able to watch the ducks at the pond reminded her of her grandma, who had also loved bird watching. Little by little, Cassie’s appetite returned and she was able to sleep more easily at night.

Reflection Questions

- Name three manifestations of Cassie’s grief.
- Describe Kim’s approach to working with Cassie.
- What might be a next step for Cassie?

Laurel is 23 years old and lives in a facility for adults with developmental disabilities. She attends occupational therapy and is working to achieve greater independence in tasks of daily living. She is highly attached to her father, but he lives two hours away had been visiting less and less frequently. Recently he stopped visiting altogether and instead calls Laurel every few days. Due to the shifting rotation of care providers, Laurel frequently asks when her father will visit, even though she was already told that he is unable to come anymore due to failing eyesight that limits his ability to drive at night. She calms down when staff tell her that he will be there “soon.” Unfortunately, when she asks a different person and is told her father isn’t coming anytime soon, she becomes argumentative and aggressive and slams doors and tips over chairs in frustration.

Reflection Questions

- What strategies might you use to help Laurel when she experiences frustration?



- How might you work with staff for greater continuity of care, and to help the staff understand that Laurel may be expressing loss and grief even though her father is alive?
- How could a care plan be developed with the goal of better connecting Laurel and her father?

Case Studies on Spirituality & Role of Religion

Mary, 50, was unsure if she wanted to attend her father's funeral, as she had never been to one before. The funeral director invited Mary and her sister to the funeral home and walked them through what would happen during the visitation, funeral services, and at the meal following the service. Mary asked what she should say to people as they arrived and what to do if she felt she needed personal space. Because Mary's sister and family were also grieving, the funeral director offered to have a staff member available to sit with Mary during the service and provided an option to signal that Mary needed to leave or step outside at any time. This allowed Mary to feel comfortable with the expectations of the funeral and choices in how and when she wanted to participate.

Reflection Questions

- How can funeral directors help families in this situation?
- Should the funeral director assume or wait to be told about an autism diagnosis?
- If Mary had not be included, how might that have affected her grief experience?

Eli, 26, finds being around crowds of people stressful; he rocks back and forth and hums to himself when he is overwhelmed. Others who do not know him well find his type of self-soothing behaviors distracting or confusing. During the planning for his grandfather's funeral, the rabbi asked Eli how he might want to participate. Eli chose to sit in the front with his family; focusing on the rabbi rather than the crowd behind him was less stressful for him. He also left first so he didn't have to pass the crowd and chose not to participate in the receiving line.

Reflection Questions

- What did they do right?
- What are some other options for Eli?
- How can characteristics inherent to ritual be potentially supportive for autistic grievers?



Case Studies on Disenfranchised Grief

Arthur is a 48-year-old man who lives in a group home with two other residents. Arthur, Noah, and Benjamin have lived together for nearly 15 years. Their friendship has been a constant in their lives, despite staff changes and other life events. Last month Benjamin underwent what was supposed to be routine surgery but suffered serious complications and died in the hospital. Staff at the group home notified Arthur and Noah of Benjamin's death, but never told them details, including where and when the funeral had been held. One day the men returned from grocery shopping to see Benjamin's room being cleaned out by a moving company. This greatly upset Arthur. He shouted at the movers, telling them not to touch Benjamin's things, and then started crying uncontrollably. Arthur eventually retreated to his own bedroom and cried himself to sleep.

Reflection Questions

- Was Arthur's grief disenfranchised? Why or why not?
- If you were a staff member at Arthur and Noah's apartment, how might you approach the current situation?
- What kind of ritual might be helpful here?

Sarah is 65 years old and lives in a community setting with three other women. Her older brother George, with whom she used to live, developed dementia and recently died. No one communicated with Sarah about George's illness due to fears it would cause her distress. She has since been told about George's death, but staff assumed she would quickly forget about her brother and move on. Sarah understands that George is dead and is upset that she wasn't able to spend time with him after moving to the group home. When staff members take vacations or are off work for extended periods of time Sarah worries that they will never return, often losing sleep. Recently, after Sarah shared with her social worker that she is afraid that everyone will leave her, the social worker invited Sarah to write a letter to George and visit his grave.

Reflection Questions

- Why might the letter writing exercise be a helpful therapeutic step in Sarah's grief journey?
- What could make visiting the grave meaningful to her?
- What could staff members do to ease Sarah's fears that they will not return?

Juan is 45 years old and does not use spoken communication; he uses adaptive communication through an iPad. He has lived with his mother, Roberta, his entire life and they have a close bond. While Roberta normally can identify Juan's wants and needs, lately Juan has become aggressive and distraught, and Roberta does not know why. A neighbor told Roberta that her dog, Trixie, recently was euthanized. She



asked how Juan was doing, given that he would often watch for them and wave during their daily walks past his bedroom window. Roberta realized Juan probably was distraught wondering where Trixie was and why she wasn't taking her usual walks. Roberta and the neighbor told Juan about Trixie's death and allowed him the opportunity to communicate any questions he had. Juan asked several questions; and Roberta and the neighbor answered to the best of their abilities and provided him with links to websites about euthanasia of older animals. After a few weeks, Juan reached out to the neighbor and asked to hold a memorial service for Trixie. The neighbor appreciated the opportunity to recognize and process her own grief over Trixie's death. Juan, Roberta, and the neighbor held a modest ceremony during which Juan placed a stone on the spot where Trixie was buried.

Reflection Questions

- How did Juan's mother and neighbor help Juan with his grief?
- Why and how are animal deaths disenfranchised?
- What was the significance of ritual in this case?

Case Study on Grieving Styles

Su Li is 50 years old and her boyfriend Sam was killed in a car accident. Since Sam's death, Su Li's friends have pressed her to talk about her feelings about the death, she prefers to avoid the subject. Her feelings are deeply intimate; she has been struggling with nightmares about the phone call from the police to notify her of the accident and her frantic drive to the hospital to see him. Sam died during surgery, before she could say goodbye. Su Li has never been one to talk about her feelings, so the additional pressure to do so now has left her feeling disconnected from her usual social network. In the past, Su Li has found that when she is distressed, she processes better when she stays mentally engaged and active, so she finds herself focusing on work to cope with Sam's death. Unfortunately, Su Li's closest friend is not familiar with the more instrumental style of grieving and is continually pressuring her to attend a grief group. Her friend is blaming Su Li's resistance to talking about Sam's death on her autism, when in fact, Su Li's inherent coping strategies are cognitively focused.

Reflection Questions

- How can Su Li's friends better support her grief process?
- How might Su Li's unfinished business affect her grief?
- How could a social worker help Su Li communicate her needs to her friends?



Case Studies on Serious Illness

Charley, 21, who uses they/them pronouns, is very close to their grandfather. The grandfather has lost significant weight and attends frequent doctor appointments. Charley asked the family to tell them what is going on, and even asked the grandfather, but no one has honestly shared what is happening. Finally the oncologist offered to meet with Charley during the grandfather's next visit to explain more about the type of cancer he had and the treatment options being pursued. Charley was encouraged to bring a phone to the visit to record the conversation, so that they could listen to it again later and more fully process the information. After that visit Charley found that although the situation was still upsetting, the information given helped them be more supportive rather than anxious or suspicious each time the grandfather left the house or received a phone call.

Reflection Questions

- How might Charley's grief experience have changed if they had not been told of the illness?
- How might you, as a professional in this case, support Charley's relationship with their grandfather at the end of his life?
- In what other ways can professionals interact honestly with grieving autistics, and honor their need for trustworthiness?

Roger is 80 years old and has congestive heart failure. Roger is cognitively impaired and lives with his autistic wife, Rhonda, who is 77. The couple rely on Rhonda's brother Henry to take them to appointments and to help explain information from the doctor. At home, Roger's breathing is aided by an oxygen tank and cannula, and he also has a wheelchair. His health has declined considerably in the past few months and he finds it increasingly difficult to catch his breath, even with the help of the oxygen. The doctor has made the determination that Roger would benefit from hospice care and asks Roger about his end-of-life care preferences. Roger wants to avoid the conversation, but Rhonda shares that she would like Roger to know his care options and discuss his medical treatment preferences should he become unable to make his own decisions. Roger develops his own plan, known as an advance directive, with Henry and a hospital social worker's help. Henry and the hospice social worker come to Roger and Rhonda's home and explain that hospice teams support not only the patient but also the family. The couple is eligible to receive help at home from a registered nurse, a nursing assistant, a chaplain, and also from a volunteer who can stay with Roger for an hour or two to give Rhonda and Henry a break from caregiving. While this information is scary for Rhonda because she's uneasy having people she doesn't know come into the house, Roger is happy to hear that Rhonda and Henry will be supported.



Reflection Questions

- Without Roger completing his advance care plan, how might Rhonda have experienced the end of Roger's life?
- What does the hospice care team need to know about Rhonda?
- How can the hospice team work to make the family's experience the best that it can be?
- What kind of rituals might be helpful for Rhonda and Roger as they approach the end of Roger's life?

Francine is a 68-year-old woman who has worked in environmental services at the local hospital her entire adult life. She loves the routine of cleaning up the same places in the same order each day and has come to see her work colleagues as a kind of extended family. Recently, a new man named Bill began working as the head of human resources, and he gently encouraged Francine to start to think about retirement. Francine was devastated and felt panicky at the idea of losing her work family but did not share this. "Okay," she said calmly. "I'll retire then."

Reflection Questions

- How could Francine's retirement have been handled differently?
- If you were counseling Francine, how would you approach her anticipatory grief?
- If Francine is having difficulty naming her feelings, what is another modality you might use to help her process this loss?

Melissa is a 40-year-old autistic woman with epilepsy. Her service dog, Luna, has been trained to detect her seizures before they happen, and Melissa naturally has grown quite close to Luna over the years. One day Melissa finds a small lump on Luna's ribcage and takes her to the vet right away. The veterinarian completes extensive testing and delivers the worst possible news: Luna has advanced cancer and is experiencing a great deal of pain. He strongly recommends euthanasia to avoid further suffering. Melissa screams and begins to hyperventilate in his office. She frantically calls her mother to come and be with her; when her mother arrives, she finds Melissa alone in an exam room holding Luna's leash, rocking, and sobbing.

Reflection Questions

- How might Melissa have been better supported through this event?
- What can Melissa and her mother do to memorialize Luna?
- How might the intensity of Melissa's grief be worked through?



Case Studies on Communicating the News of Death

Jean-Pierre, 32, lives at home with his parents and younger sister Marguerite. Marguerite has struggled with substance use disorder for nearly a decade and fatally overdosed on heroin in the early hours of the morning. Jean-Pierre discovered his sister's body several hours after her death and felt confused and overwhelmed when his parents began screaming and called 911. The house filled with people Jean-Pierre didn't know—police, firefighters, paramedics, and finally the medical examiner. He felt afraid, and his usual coping strategy of bouncing on a small trampoline in his bedroom while humming didn't seem to be working, so he sat rocking on the floor of his darkened bedroom closet. A police detective and Jean-Pierre's favorite aunt, Corrine, found him a while later. The detective and Corrine joined Jean-Pierre on the bedroom floor for nearly an hour as Jean-Pierre communicated about what he had seen using his iPad's text-to-speech program. The detective asked questions and responded to those from Jean-Pierre; she was gentle but direct. She told him that Marguerite had taken too many drugs and that she had died. She acknowledged when she didn't know an answer to a question and gave Jean-Pierre time to process what was going on. Corrine was pleased to see that the detective spoke directly to Jean-Pierre and treated him with respect. When the questioning ended, the detective left, and Jean-Pierre had time to grieve privately with his aunt and parents.

Reflection Questions

- Which aspects of Jean-Pierre's experience were triggering, and how did he cope with them?
- What are three things that are important to remember in working with a client or patient who uses technology to communicate?
- How might Aunt Corrine and Jean-Pierre's parents facilitate healthy grieving for him?

Ethan, 43, was at home when the hospital contacted him and his mother about his father's car accident. They quickly drove to the hospital and waited anxiously in a family waiting room of the emergency department. After a few minutes, a doctor and a chaplain came into the room and sat down across from Ethan. His mother began to sob as the doctor explained that Ethan's father had been in a terrible wreck, that it took emergency responders a long time to free him from his car, and that he had been badly injured in the crash. On the ambulance ride to the hospital, his father's heart had stopped, and despite the EMTs' best efforts, he died. Ethan's mother continued to cry and moan, while Ethan sat as still as a statue, his face revealing none of the intense sadness he felt. The chaplain expressed his condolences to the family and asked both Ethan and his mother how he could best support them in that moment. Ethan sat and rocked back and forth while playing a game on his phone. The chaplain sat nearby, quietly providing solidarity and a ministry of presence.

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Ethan didn't want to talk or cry, and the chaplain and doctor gave him the space to simply sit quietly.

Reflection Questions

- Describe the difference in Ethan's and his mother's outward displays of grief.
- Did the hospital chaplain help Ethan in a way that worked for him? Why or why not?