

Autism & Grief Project

Case Studies



Autism & Grief

Cassie is a 21-year-old woman with high support needs who has lived with her grandmother her entire life. Following the death of her grandmother, Cassie is 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 that all feel like they're happening at once—the death of her beloved grandmother, a move, 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 She grew quieter and more withdrawn. Her appetite diminished, and Aunt Chrissy could hear her watching television late into the night. In the midst of this, a new paraprofessional named Kim began working with Cassie. Kim had seen similar reactions to death in previous clients and gently encouraged Cassie to complete her daily tasks, even if she didn’t much feel like it. Kim and Cassie spend time walking 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 made her remember 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 classes in occupational therapy and is working on goals for achieving greater independence on tasks of daily living. She is highly attached to her father, but he lives two hours away and visits infrequently. He has recently stopped visiting altogether and instead calls Laurel every few days. Due to the shift changes of rotating care providers, Laurel is frequently asking them when her father will be coming to visit, even though she has already been told he is unable to visit due to failing eyesight that limits his ability to drive at night. She calms down when told he will come “soon.” Unfortunately, when she then asks a different person who reminds her he can’t come anytime soon, she becomes argumentative and aggressive and slams doors or tips over chairs in her frustration.

Reflection Questions

- What behavioral strategies might you use to help Laurel when she is experiencing frustration?
- How might you work with staff for greater continuity of care?
- How could care plan be developed with look the goal of better connecting Laurel and her father?

Michael, 35, and lives with his wife and three young children. He works as a software engineer and volunteers at his local church. He loves his children but finds it difficult to tolerate the general chaos that can come with children. Michael relies heavily on his wife to manage the day-to-day frustrations of keeping three kids clean, entertained, and behaved. Occasionally he is abrupt with his family but works diligently to not show anger in front of the kids. His wife has asked him to go to therapy with her, as she is feeling like a single parent even though he is a loving husband and father. Michael is resistant to going, as he sees no need to talk to a stranger about feelings and is honestly puzzled as to why his wife is constantly so distraught.

Reflection Questions

- Michael struggles to see his wife's point of view. How might you approach this in a counseling setting?
- How might you help Michael verbalize his feelings, since he is resistant to sharing them?
- Would role playing conversations be a good tactic for Michael and his wife? Why or why not?

Communicating News of the 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 later 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 skills of bouncing on a small trampoline in his bedroom while humming didn't seem to be working. Finally, he sat in his darkened bedroom closet rocking back and forth. A police detective found him there a while later, accompanied by Jean-Pierre's favorite aunt. His Aunt Corrine sat with him as he communicated with the detective using his iPad text-to-speech program about what he had seen. The detective joined him on the bedroom floor, sitting for nearly an hour while she asked questions, and responded to Jean-Pierre's questions as well. The detective 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 the answer to some of his questions and gave him time to process what was going on. Aunt Corrine was pleased to see that the detective spoke directly to Jean-Pierre, and that she treated him respectfully as an adult. When

the questions were done, the detective left, and Jean-Pierre had time to grieve privately with his aunt and parents.

Reflection Questions

- What aspects of Jean-Pierre's experience were triggering, and how did he cope with those elements?
- 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?

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 only a few minutes, a doctor and chaplain came into the room and sat down in the chairs 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 gravely injured in the crash. On the ambulance ride to the hospital, his heart had stopped, and despite their best efforts, his father had 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 repetitively while playing a game on his phone. The chaplain sat nearby, quietly providing solidarity and a ministry of presence. Ethan didn't want to talk or cry just then, and the chaplain and doctor gave him the space to simply sit quietly for a moment.

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?

Disenfranchised Grief

Arthur is a 48-year-old man who lives in a group home with two other men with similar needs. 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 was scheduled for routine surgery, but suffered serious complications and died in the hospital. Staff at the apartment notified Arthur and Noah of Benjamin's death, but never told them many details, including where and when the funeral was held. One day the men returned from grocery shopping to see Benjamin's room being cleaned out by a moving company, which greatly upset Arthur. He began shouting at the movers, telling them not to touch Benjamin's things, and then started

crying uncontrollably. Arthur retreated to his own bedroom, where he 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 this situation?
- What ritual might or might not be helpful here?

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

Reflection Questions

- Why was the letter writing exercise a helpful therapeutic step in Sarah's grief journey?
- What made visiting the grave meaningful to her?
- What could staff members do to ease Sarah's fear 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 is usually able to identify Juan's wants and needs, lately Juan has become aggressive and distraught, and Roberta is uncertain as to why. A neighbor told Roberta that their dog, Trixie, recently was euthanized and asked how Juan was doing, since he would often watch and wave at their daily walks past his room. Roberta realized Juan was distraught wondering where Trixie was and why she wasn't going on her usual walks. Roberta and the neighbor told Juan of Trixie's death and allowed him the chance to communicate any questions that he had. Juan asked several questions using his iPad, and Roberta and the neighbor answered what they could to the best of their abilities and gave him links to websites about older animals and euthanasia. After a few weeks, Juan contacted the neighbor and, using his iPad, asked if they could hold a small memorial for Trixie. The neighbor was appreciative of the chance to recognize her own grief over Trixie's death, and they proceeded to hold a small ceremony where Juan was able to place a stone on the spot where she was buried.

Reflection Questions

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

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?

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 been 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?

Serious Illness

Charley, 21, who uses they/them pronouns, is very close to their grandfather. The grandfather has lost significant weight and has frequent doctor appointments. Charley asked the family what is going on, and even asked the grandfather, but no one has shared what is really happening. The oncologist offered to meet with Charley during the grandfather's next visit to explain more about the type of cancer and the treatment options being pursued. At the visit, Charley was encouraged to bring a phone to record the conversation, to relisten later, in case additional questions might arise. After the visit, Charley found that, although still upsetting, the information given helped them be more supportive instead of anxious or suspicious each time the grandfather left the house or received a phone call.

Reflection Questions

- How might have Charley's grief experience changed if they had not been told of the illness?
- How might you support Charley's relationship with their grandfather at the end of his life?
- How important are honesty and trust for people with autism?

Roger is 80 years old and has congestive heart failure. Roger has cognitive impairment and lives with his wife, Rhonda, 77, who is autistic. The couple rely on Rhonda's brother Henry to take them to appointments and help explain information from the doctor. Roger uses oxygen at home as well as a wheelchair fulltime. His health has declined in the past few months and finds it more difficult to catch his breath, especially after long conversations with Rhonda. The doctor has determined that Roger would benefit from hospice care. Henry and the hospice social worker come to Roger and Rhonda's home to explain that they are eligible to receive some support at home from a nurse and a

volunteer a few times per week. While this information is scary for Rhonda, Roger is happy she will have some support. The social worker helps Roger complete an advance directive and asks what will make him most comfortable and happy in the next few weeks and at the end of his life. Roger finds the conversation silly and wants to avoid it but Rhonda shares that she likes to have a plan and know exactly what will happen next.

Reflection Questions

- Without the advance care plan, how might Rhonda have felt during the end of Roger's life?
- What would the hospice team (nurse, volunteers, chaplain) need to know about Rhonda's autism?
- Are there any rituals that might be helpful for Rhonda and Roger?

Francine is a 68-year-old woman who has worked in environmental services at the local hospital her entire adult life. She loves the simple routine of cleaning up the same places in the same order each day and has come to see her work colleagues as a sort of extended family. Recently, a new man named Bill began working as the head of human resources, and he gently encouraged her to think about retirement. Francine felt devastated and panicky at the idea of losing her work family but said nothing. "Okay," she said calmly. "I'll retire then."

Reflection Questions

- If you were counseling Francine, how would you approach her anticipatory grief?
- If Francine were having difficulty naming her feelings, what's another modality you might use?

Melissa is a 40-year-old woman with both autism and epilepsy. She has a service dog named Luna who has been trained to detect her seizures before they happen, and Melissa has grown incredibly close to Luna through the years. One day, she 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 lot of pain. He advises humane euthanasia to avoid further suffering. Melissa begins to scream and hyperventilate. She frantically calls her mother to come be with her, and 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 throughout this event?
- What might Melissa and her mother do to memorialize Luna?
- How might the intensity of Melissa's grief be worked through?
