

The Sun

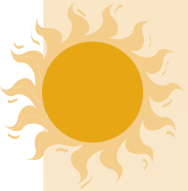
Newsletter

Summer 2020

Hey!

Your experience with autism may be helpful to other parents. By sharing it on [Autism Delaware's Stay Connected webpage](#), you'll be helping our community during a very difficult time.

The Sun's editor can help you get your ideas down. Send an email of interest to carla.koss@delautism.org, or call (302) 224-6020, ext. 207.



Our mission

To help people and families affected by autism spectrum disorder (ASD)



Clip Art

// Coping with the loss of someone or something you love is one of life's biggest challenges," notes Help-Guide.org. "You may associate grieving with the death of a loved one—which is often the cause of the most intense type of grief—but any loss can cause grief...." (<https://www.helpguide.org/articles/grief/coping-with-grief-and-loss.htm>).

In this issue

- A licensed clinical social worker practicing in Newark points out ways to explain the abstract concept of death to someone on the autism spectrum—**p. 4**
- Two Delaware parents share how they managed their children's grief—as well as their own—after the loss of a loved one—**p. 6, 8**
- A self-described "Aspie" explains how people with autism relate to death and loss and offers five recommendations for the difficult conversation—**p. 10**

Autism DelawareSM

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Moving through the grieving process

Like everyone living through the current COVID-19 pandemic, we in the autism community are not immune to the news of a loved one becoming terminally ill or dying. In turn, we may come face to face with the five stages of grief: denial, anger, bargaining, depression, and acceptance. This range of emotions was first described by Elizabeth Kübler-Ross in her 1969 book entitled **On Death and Dying**, and it's still relevant today. A person may move steadily through the process or revisit one or more of the stages during his or her personal journey. But an individual must move through all five stages of the grieving process to heal.

Knowing how intensely someone with autism spectrum disorder (ASD) will react to the loss of a loved one is difficult to predict. *Why?* Because people on the autism spectrum are complex and unique. Confronted with the same or similar loss, two people with ASD may react very differently. To illustrate this fact, turn to the articles on pages 6 and 8. They cover interviews with two Delaware parents with contrary stories about how their sons reacted to a death in the family.

Admittedly, the loss of a loved one creates a profound change. And generally speaking, people with ASD do not like change. So, it is reasonable for us to see someone on the spectrum experiencing the range of emotions along the lines of the Kübler-Ross model. Our job as parents and caregivers of people with ASD is to help them through their grieving process.

In addition to the personal stories told by our two parents, some of their advice and resources are offered for your consideration. This issue of **The Sun** also includes information and advice from a local professional who works one-on-one with families experiencing grief and loss.

What has my personal experience taught me about grief and loss? That we need to acknowledge it. I begin by saying "I'm sorry for your loss, and I'm here for you." When interacting with people on the spectrum who are verbal, I encourage them to talk about their feelings and tell them that it's okay to feel that way. Finally, I give them the time and space they need.

Granted, no one-size-fits-all advice will help someone recover from the loss of a loved one. And some people will get through their grief more quickly than others. But I've learned that three things are absolutely necessary: patience, attention, and love. Make these words your mantra, and you will successfully help your loved one move through the grieving process.

Please know that you can also look to Autism Delaware for resources to help you. For more information, visit AutismDelaware.org/Get Help.



Brendan O'Neill
President
Board of Directors

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Ask a parent is a new column that presents a question from a parent, grandparent, or caregiver—and an answer from parents in our community.

As a parent with a child on the autism spectrum, have you wondered how another parent would handle your particular situation? Or maybe you'd appreciate hearing about another parent's success story and how it was achieved.

To offer a question or your availability to draft an answer, send an email of interest to carla.koss@delautism.org.

Q What are some tips for toilet training?

—Anonymous parent

A The biggest thing for potty training is determining something that will be a really powerful reinforcer. Then withholding that thing until your child goes in the potty—and only when they go in the potty! You can't be inconsistent. Using a timer and taking your child at regular intervals is a great way to "catch" him or her in the act—and then swoop in with that reinforcer. It takes discipline to stick to a schedule, and it can be difficult, but it's so worth it.

I thought that we would never get Ethan potty-trained. He would walk around with his pants full of poop and not care! At first, we were a little wishy-washy with the reinforcer. (We used a Velcro® Picture Exchange Communication System [PECS]® selection for potty training.) I thought that we had something powerful for Ethan—a specific video that he liked—but when we finally caught him going in the toilet, he picked a different video as his reinforcer. That was a wake-up call: We needed to withhold ALL videos and stick to it until he started going regularly.

So, the keys are

- determine a really powerful reinforcer, and have the discipline to withhold it until your child goes in the potty and
- use a timer to give your child plenty of opportunities to go and then get that reinforcer.

It can be done! And it will—Don't worry.

—**Marcy Gause Kempner**

Parent of an adult son in the Autism DelawareSM adult services program

Toilet training can be difficult for any family but having a kid with autism can bring additional challenges. For example, my son Casey had sensory issues and relied heavily on visual feedback. Because of this, sitting down to pee (as many boys are taught to do when they are young) was not effective for him.

I realized this the day he successfully peed standing up and had a look of utter confusion on his face as he stared at the stream going into the toilet. This signaled to me that he was not making the association between the sensation of having to pee and the act of peeing; he needed to see it happening to make that connection. Although I knew Casey had sensory issues and physically felt things stronger or weaker than other kids, it hadn't occurred to me that he might not be able to feel himself peeing when it was happening. So, we got a stool to put in front of the toilet and

Continued in left column on p. 11



Explaining the abstract concept of death

by Kathy Hupp, LCSW

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An abstract concept like death can be scary. When dealing with anyone who has experienced the loss of a loved one, you must first decide how much information to share and the words to use.

As the messenger of this information, many people struggle with death and talk about it in a way that makes themselves feel good instead of in a way that the grieving person needs. Granted, the messenger may also be experiencing a deeply emotional reaction to the loss. Nonetheless, the individual receiving the message needs consideration.

For people on the autism spectrum, a messenger's deeply emotional reaction will lead to misunderstanding of the subject matter, especially if the death in the family is a first-time experience. The task can be complicated by how close the individual was to the person who died. Many conversations may be needed before an individual on the spectrum can understand what happened.

When determining how to approach the subject with people on the spectrum, know their developmental level for understanding the information you are sharing. An 8 year old and a 22 year old on the spectrum can be given the same information but think it through differently.

A guiding principle to remember

Each individual has unique strengths and challenges in mental functioning, including intellect, expressive and receptive language skills, reasoning, and emotions.

Generally, using words that are simple and direct is best, such as "Your aunt died." If you use a metaphor, such as "Your aunt fell asleep" or "Your aunt went to heaven," ask the grieving person "What did you hear me tell you?" or "What does it mean to you?" Some people on the spectrum translate "falling asleep" as a concrete concept and may think that they will fall asleep permanently when they go to bed. So, it's important that you find out if more information is needed to clarify what happened to the loved one.

For people on the spectrum with co-occurring conditions, such as anxiety or obsessive-compulsive disorder (OCD), more emotional support may be needed, especially when changes in routine arise. Present the individual with more coping skills as well as more information, more hugs, and more reassurance. A grieving individual on the spectrum may also want to engage in an activity that provides comfort and reinforces the idea that his or her world is stable and safe and will continue to be so.

After the loss has been communicated accurately, check in with the grieving individual; find out how he or she is feeling. Most people will want some reassurance that they are okay. If your loved one on the spectrum is okay, begin preparing him or her for what will happen during the funeral or

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burial service. It's also important to address the upcoming change in the daily routine.

A loved one on the spectrum will experience loss in his or her own way. Remember to share the grief message in a way that can be managed by the individual. And check in periodically to find out what he or she understands and how the individual is handling the situation.

Sun contributor Kathy Hupp, LCSW, specializes in cognitive behavioral therapy (CBT) at Mid-Atlantic Behavioral Health. Her focus is on the parents of children with special needs, such as those with autism spectrum disorder (ASD). She is also the parent of a 30-year-old son with ASD who participates in Autism Delaware's adult services program.

How can Autism DelawareSM help you through your time of grief?

With a comprehensive list of psychological and counseling services plus religious resources.

Turn to Autism Delaware's online resource directory:

[AutismDelaware.org/GetHelp/Resources Directory](http://AutismDelaware.org/GetHelp/ResourcesDirectory)

People with autism can read emotions

People with autism can read emotions, feel empathy was first published on [Spectrum News.org](http://SpectrumNews.org) on July 13, 2016, before being picked up by ScientificAmerican.com.

Authored by University of East London lecturer Rebecca Brewer and King's College London graduate student Jennifer Murphy, this well-referenced presentation offers insight into people with autism spectrum disorder (ASD) and how they process emotions:

"There is a persistent stereotype that people with autism are individuals who lack empathy and cannot understand

emotion. It's true that many people with autism don't show emotion in ways that people without the condition would recognize.

"But the notion that people with autism generally lack empathy and cannot recognize feelings is wrong. Holding such a view can distort our perception of these individuals and possibly delay effective treatments."

To read the rest of this article on the "Scientific American" website, do an on-site search for *People with autism can read emotions, feel empathy*.



Somehow, he gets it.

by Carla Koss



Clip Art



The Bashkow brothers: Michael, Ben, and Brian

The realization began to set in when Karen Bashkow asked her 34-year-old son with autism, Ben, if he wanted to go to the funeral mass for her 26-year-old son, Michael, who had overdosed in the family home in November.

“Ben immediately answered yes,” says Karen with the same surprise she felt at the time. “And he sat through the whole thing—yet at home, he’s up and down all the time! I wondered ‘What is he getting out of church?’ He’s calm and present. Personally, I think he’s closer to God than I am. Somehow, he gets it!”

The eldest of Karen’s three sons, Ben Bashkow participates in the Autism DelawareSM adult services program known as Productive Opportunities for Work and RecreationSM (or POW&RSM, for short). He is also the owner-operator of Big Ben’s Shredding, a business he maintains with support from his direct support professional (DSP), Bill Black.

To achieve this success, the nonverbal business owner had to learn a lot of new skills, but one skill, points out his mother, he seems to have been born with: “People think he doesn’t get much, wonder ‘What does he understand?’ I believe he’s more perceptive than some people who don’t have autism.”

To help Ben become a fully functioning adult in the community, the Bashkow family always included Ben in any activity that wouldn’t overwhelm his senses. This attitude extended to Ben’s first experience with a death in the family, his beloved Uncle George.

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Karen’s helpful resources for handling death and loss

- **Our family chose Spicer-Mullikin Funeral Homes & Crematory because it has a grief support person on staff and grief support groups for families who have lost adult children to addiction, suicide, or risky behaviors. I’m a reader so I also appreciated their library.**
- **Get support from friends and, if you’re a church-goer, from fellow church members.**

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“Ben and his uncle really loved each other,” notes Karen. “We took Ben to the viewing. We told him ‘Uncle George is in heaven with God and Jesus. We’re here to say goodbye.’”

After losing his uncle, Ben experienced the loss of all four of his dotting grandparents. “He was close to all of them,” continues Karen. “He saw my parents in their caskets. Ben could see their bodies. I didn’t explain a lot. When nobody came back, we told him ‘PopPop is in Heaven with God.’ Who knows if he was making those connections between life and death, where people go.”

Like Uncle George and his grandparents, his brother Michael enjoyed a great bond with Ben. Michael had been in recovery in the year before his death, and his presence was a joy to his family. When he overdosed, Ben was sitting with his back to the hallway to Michael’s room, so he was unaware of what was going on. Then, the police came in, treating the Bashkow home like a crime scene. Everyone was in shock, so the family decided to get Ben back to his group home as soon as possible.

When Ben came home as usual the next weekend, he was told that Michael had gone to Heaven with God and he’s not coming back.

“Ben sat on the couch and cried,” says Karen. “Every now and then, he still will sit and cry. I never really know what his tears are about, but I think he misses Michael. I tell Ben it’s okay to be sad. When he goes to his room, I leave him alone.”

Since November, the family visits Michael at the cemetery as well as Uncle George and all of Ben’s grandparents. Karen believes her son now associates these visits with where his deceased loved ones are: “There, we share tangible things, like ‘They’re in the cemetery.’ We talk about them and look at pictures. And Ben is present, in the moment. To think that he doesn’t understand is wrong.”

A disrupted routine

In March, the threat of COVID-19 disrupted Ben’s work routine. Quarantined in his group home with his four housemates, Ben faced the loss of his family support on weekends plus his hard-earned work schedule and time with his DSP, Bill. And there was no time to explain it all to him beforehand.

“Ben must be thinking,” believes Karen, “‘I go to work Monday through Friday, go home Saturday and Sunday. And where’s Bill?’”

“I told the staff ‘It’s really important that we make visual contact now because Ben just lost his brother. So, the staff brought in an iPad so I can FaceTime with Ben,’” notes a grateful Karen.

FaceTime with Ben served to confirm Karen’s realization about her son: “Yes, he’s a great guy. He has more personality than most people, brings up a lot of joy, and is the best hugger in the whole world. But Ben has grown up a lot since moving into the group home. He’s different there. He’ll step up; he’s done it before in hard situations.

“Ben seems to be taking it all in stride,” smiles Karen.



Ben, Michael, and Karen Bashkow



Ben and Michael

Karen’s advice

- Adhere to a daily meditation schedule—and pray a lot.
- Accept that all the people around you are not comfortable with deep pain and sadness.
- And accept that your child on the spectrum may need as much support as you do.

Thank you, Bill, for being with Ben at Michael’s funeral. Because of you, I was able to put one foot in front of the other that day.

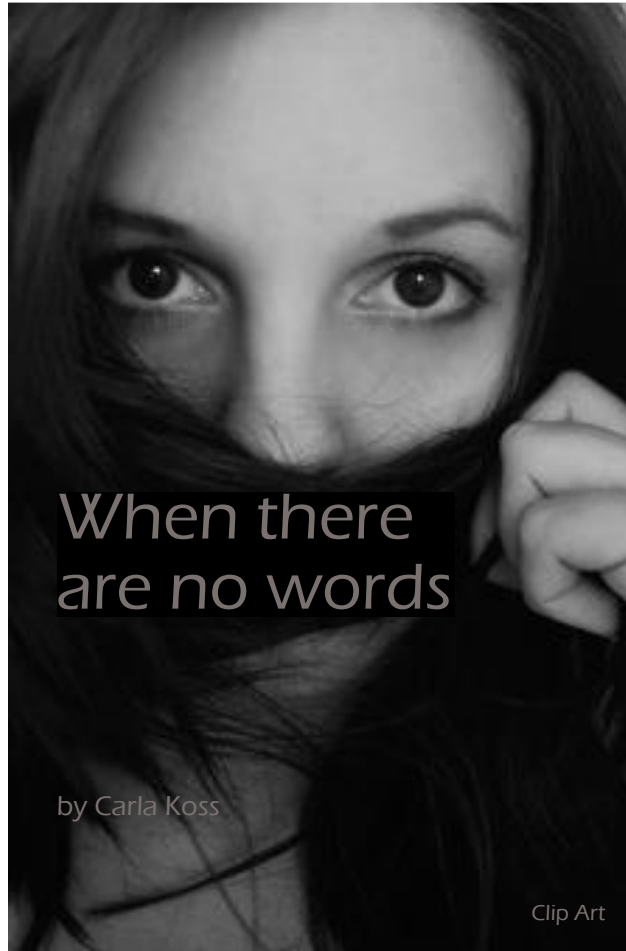
—Karen Bashkow

A self-described “good Catholic girl,” Shannon Liew has always turned to her faith to find the right words for explaining life to her children and helping them through difficult times. “We always pray in our family,” says Shannon of her lifelong practice. Plus, both children have received religious instruction. Today, her neurotypical daughter Roisin [pronounced “Rah-sheen”] receives religious education through her studies at Archmere Academy while Shannon’s 16-year-old son with autism, Devin, has attended special-needs religious education.

Because Devin is nonverbal, Shannon relies on a picture book to help explain many of her faith’s abstract concepts. Giving Devin something concrete to see reduces his confusion and helps ease some of the frustration at being unable to describe it.

When Shannon’s husband Fah Pow got sick in 2014, she took responsibility for telling their children. Choosing matter-of-fact words, she was as straight-forward and unemotional as possible. The effort required a lot of faith and energy when describing her husband’s deteriorating condition. On the morning that Fah Pow died, Shannon had to dig even deeper to manage her own grief and loss as well as her children’s. All the matter-of-fact language in the world couldn’t cool their anger or ease their overwhelming sense of loss.

While her daughter could talk to friends and counselors at a bereavement group and camp as well as with Shannon,



When there are no words

by Carla Koss

Clip Art

Devin had no words to help him work through his grief and anger. So, Shannon sat down with Devin, and together, they opened his picture book.

“I could figure Devin out, what he was feeling,” notes Shannon of her connection to her son. This communication process obviously works because Devin points upward, for example, to acknowledge that Jesus lives in Heaven. “He also understands that ‘Daddy is with Jesus’ and ‘Daddy lived his purpose,’” continues Shannon.

Unfortunately, Devin started going through puberty at the same time his father died and was swamped by his hormones. The resulting emotions sometimes overwhelmed the close-knit grieving family.

Shannon prayed about the problem, then remembered something important: “Kids on the autism spectrum prefer routine, right? I got proactive and created a new routine to deal with grief and loss.”

She began by making a list of the many meaningful things that both her children could do in their father’s name. One of their choices was planting a tree in their back yard. As a memorial, this choice included a plaque engraved with their father’s name and the release of butterflies.

The family also visited the cemetery on important anniversaries; however, taking Devin was not doable while his hormones were raging. “His behavior changed,” says Shannon of this period. “Then, I noticed ‘Devin never sleeps.’ He began to fail.”

Shannon knew her son needed more support. She looked at how Devin was faring overall, including as a student in the Delaware Autism Program (DAP), and thought a solution might be found in another educational program. After a lot of research into a DAP alternative, Shannon took a tour of the Benedictine School in Maryland and was impressed. She believed her son would benefit greatly from a transfer and applied to Benedictine’s residential program. With help from the Delaware Department of Education’s director of exceptional children resources, Mary Ann Mieczkowski, the transfer was completed.

“I know I made the right choice,” shares Shannon, “when I learned that he’d started bowling! The staff there told me ‘He’s the best kid here.’”

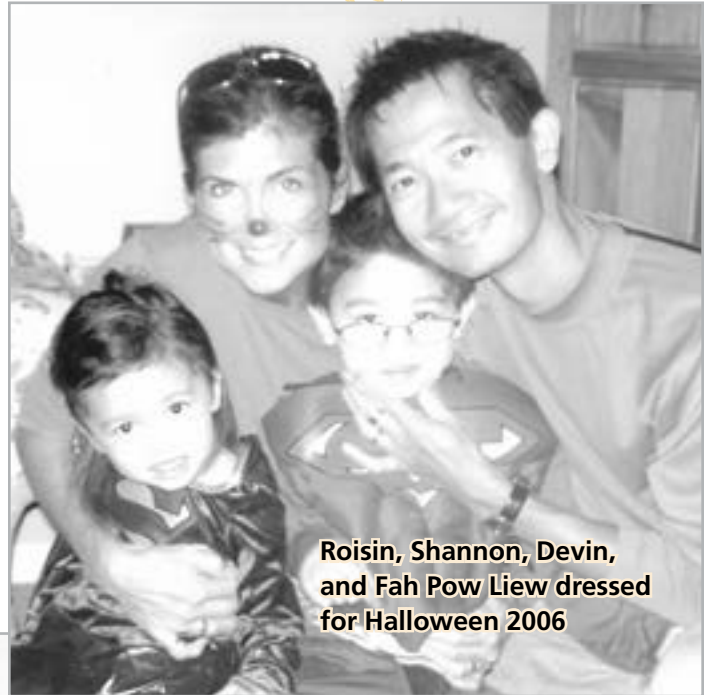
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A year and a half later, Devin was able to cope again. Now 16, he attends Glasgow High School’s DAP, and he’s thriving. “He’s learning good skills, like dressing himself,” boasts his mother, “and doing household chores, like folding laundry.”

In March 2020, Shannon helped her children mark the anniversary of their father’s death with a celebration of life under the shade tree they planted five years ago. Shannon was confident that her son would be able to handle the occasion as well as her daughter—and he did.

After telling her family’s story, the relief written across Shannon’s face spoke volumes. She needed no more words, yet admitted an obvious sentiment: “I would give my life for this kid.”



Roisin, Shannon, Devin, and Fah Pow Liew dressed for Halloween 2006



Devin, Shannon, and Roisin Liew together at home in March 2020

Shannon’s advice

- This is a huge loss in your life—and kids like routine. Create a new one.
- Work with all the tools you have. Ask for resources from everyone in your community, such as your kid’s school and PAC (parent advisory council) and your church.
- Get the school and students involved while your loved one is sick as well as after he or she passes on—Be creative!
- Make a place in your home to reminisce about the person, and be quiet with your thoughts.
- Don’t be afraid to talk about it.

Shannon’s helpful resources for handling loss

- Camp Kesem (<https://www.campkesem.org>)
- Delaware Hospice (<https://www.delawarehospice.org>)
- picture books
- church or priest
- family prayer
- annual visit to grave with butterflies to release
- kind acts for others in loved one’s name
- framed pictures of loved one

1 Autistic kids may be really blunt with language around death and dying as well as curious about the physical aspects (like what happens during a heart attack), but these kids may not connect with how the conversation might make a neurotypical person feel. Providing a social story about other people's feelings and the careful use of language may be useful. It may also be useful to provide an opportunity for autistic kids to talk bluntly with another autistic person who uses language similarly.

2 People who use augmentative and alternative communication (AAC) will probably need to update their boards to include language around death and dying, mourning, hospital or illness-specific experiences, nuances of feelings, and rituals (such as funerals and memorials). I recommend that you enable communication depth and breadth to reduce confusion, frustration, and mistakes in understanding.

3 I also recommend the use of concrete terms for death, illness, timelines, and expectations. It is common to use softer language around death, but this will usually increase confusion and misunderstanding for our kids. For example, the word "dying" means "has a terminal diagnosis" and "is actively dying right now." To an autistic child, Aunt Mary dying of cancer means we'll be visiting her every week for several months or a year or more, but the expectation for a grandparent dying from a stroke or heart attack is not the same. While both statements use the word "dying," the implications for what to expect not only are very different but are also implied rather than stated.

4 Provide an autistic child with social stories about your family's rituals and beliefs around death and dying, how people's behavior might change, and what grief might feel like. Be ready to answer these questions—and more: What happens to bodies when we die? What is cremation?



What kinds of feelings might happen in my body? What will my emotions be at different times? What happens at a funeral? How do we expect people to behave? Are they more sensitive or angry? Will they laugh and then suddenly cry—or do the opposite?

5 At times of grief and loss, internal experience and external expression may be very different for an autistic individual, and the degree of difference can increase with stress. Stress includes disruptions in schedules and changes in the behavior of trusted adults. If the individual's ability to access verbal speech and social

algorithms decreases, expect an increase in selective mutism, stimming variety, the degree of stimming, shutdowns, and meltdowns.

To help your loved one manage the increased distress, maximize self-regulation options by encouraging safer stims and comforting interests. Reduce the pressure on caregivers by normalizing any increase in outward behaviors. And be kind to yourself as well as to everyone around you in this very difficult situation.

This book can be a good resource for you and your loved ones: *Finding Your Own Way to Grieve*, by Karla Helbert. Written for youth and children on the autism spectrum, it can be used by anyone in the family. Parents may find it useful for processing their own grief, too.

More resources for you

Autistic Grief Is Not Like Neurotypical Grief (2012), by Karla Fisher, blog on [The Thinking Person's Guide to Autism](#) website.

Navigating Grief and Loss as an Autistic Adult, by Lynne Soraya, author of [Psychology Today's Asperger's Diary](#).

How People with Autism Grieve, and How to Help: An Insider Handbook, by Deborah Lipsky. Available on [Amazon.com](#).

Beyond Behaviors: Using Brain Science and Compassion to Understand and Solve Children's Behavioral Challenges (1st edition), by Mona Delahooke. Available on [Amazon.com](#).

A self-described "Aspie" and the parent of two children on the autism spectrum, Sun contributor Heather Petit is a business analyst pursuing a master of divinity degree with a social justice focus on neurodivergence. She is also a proponent of identity-first language.

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switched to peeing standing up. Another thing that helped with toileting was having a visual schedule. We had successfully used visual schedules in the past to develop other routines and behaviors, so we created a visual schedule for the bathroom. This visual aid was a simple strip of pictures with Casey at each stage of the toileting process, backed by cardboard and laminated. (See below.) Sometimes, Casey would refer to the visual schedule before going to the bathroom; other times, he would point to the different pictures as he went along, treating it like a checklist. (He was nonverbal at the time.) Because of the visual schedule, he knew when he was successful in the toileting process and would proudly point out when he had completed all the steps.

Toilet training is often stressful for everyone involved. Because our kids with autism have different needs and do things on their own timelines, it's important to remember to have patience and grace for your child and yourself in this process. Like everything else in the autism journey, it's a marathon not a sprint. So, be creative, give the process time, and celebrate the victories along the way.

—Cory Gilden
Parent of a son on the spectrum



Recommended by
Melissa Martin
Assistant Director
Autism DelawareSM adult services program

Gray's Guide to Loss, Learning & Children with ASD in the Jenison Autism Journal (Spring 2003) on the [Carol Gray Social Stories](#) website.

Supporting Individuals on the Autism Spectrum Coping with Grief and Loss through Death or Divorce, by Marci Wheeler, M.S.W., on the [Indiana Resource Center for Autism](#) website.

PFA Tips: Death and Grieving, by Nancy Grace, Ph.D., and Shelly McLaughlin, on the [Pathfinders for Autism](#) website.

Blog: Hospice & Palliative Insights, Coping with Grief posted 05/17/20 on [Crossroads Hospice & Palliative Care/More/Blog/Blog Categories](#).

Understanding Death and Illness and What They Teach about Life: An Interactive Guide for Individuals with Autism or Asperger's and Their Loved Ones, by Catherine Faherty. Available on [Amazon.com](#).



POW&RSM participant acknowledged for making great strides—and great chocolate!

Hope Pearce received the Exceptional Customer Care Certificate and Award in acknowledgment of the great strides she has made since joining the team at Kilwin's Rehoboth Beach. According to the chocolatier's owner-operator, Debbie Marchese, Hope found the greet-the-customers part of her job challenging when she first started, but today, her megawatt smile welcomes customers at the door, and she never fails to wish them a great day as they leave. Plus, Hope has not missed a single day of work since she joined Kilwin's team six years ago.

Hope has also been promoted to lead on the Hilliard's Chocolate System. She is responsible for melting, tempering, coating, and decorating chocolate. With Debbie's blessing, Hope shares samples of her delicious work with representatives of the Delaware General Assembly and Delaware's governor during Autism Delaware's annual



At the 2019 Smart Cookie Day, Hope Pearce enjoyed Delaware Governor John Carney's response after receiving the Kilwin's chocolate that Hope had made herself.

Smart Cookie Day. As an autism advocate, Hope relays how meaningful and enjoyable her work is and how much support she has received from Autism Delaware's adult services program, Productive Opportunities for Work and RecreationSM (or POW&R, for short). At the 2019 event, a senator ended his meeting by saying "It is time to adjourn this meeting so I can taste some of Hope's chocolate-dipped strawberries!"

Thank you, Help for Healthcare Workers Delaware!

"The mask fairies are making it possible for our staff to support our participants," smiles Katina Demetriou, Autism Delaware's director of the adult services program called Productive Opportunities for Work and Recreation (or POW&R, for short).

"Help for Healthcare Workers Delaware is lending a hand in teaching POW&R participants how to wear and become comfortable wearing masks correctly. With this help, our POW&R participants are preparing to return to their employment and community sites."

Many thanks, Beach Time Distilling!

To owner Greg Christmas, many heartfelt thanks for creating your own hand sanitizer—and donating it to Autism Delaware's POW&R program.

An update for readers of *The Sun*

Delivery of Autism Delaware's printed newsletter has been complicated by COVID-19. PDFs are available at [AutismDelaware.org/Stay Connected](https://AutismDelaware.org/StayConnected). Scroll down to PDF Downloads of "The Sun" (by Topic). For the spring issue, choose "Plan ahead"; for this issue, "Coping with grief and loss."