



The Communicator

A Publication of the Autism National Committee



Introduction

As we shift into summer, we are excited to bring to you this issue with summer reading and links to information that we hope you will check out. There are insightful articles on autism and grief, on the importance of creative expression, and on exciting success of advocates in Washington state. We also remember a long-time AutCom member who recently passed. You will find a link to our recent webinar on employment, and a long list of New and Exciting books, videos, and other resources. We encourage you to renew your membership to AutCom or to become a new member to support our all-volunteer work to promote autistic voices, understanding, and inclusion.

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Thoughts

By Jaime Burke



In order to feel understood in how I feel about my creative art, it's paramount to be able to express my emotions to others when asked about this. I love working with water, sound, and earth goods. It is so natural for me, and it's great to be able to importantly express with words.

I utilize the keyboard to fully communicate. I can use my speech, but it is better for me to be able to type in order to communicate with my full thoughts and expression.

For some people there is something so challenging for them to overcome when I am both typing and speaking. I mean that they struggle to accept deep and full expression from our fundamental personhood; when the physical abilities to move easier, understanding motor initiation and planning would be accepting our processes. Needing emotional support is just the being able to successfully communicate for me.

I am a person that does many sensory things every day to help balance my body and my brain to work together in a smoother connection. I have discovered that creating art through painting, sculpting, and glass fusion artwork, can be helpful in utilizing a more connected and effective patterning of movement. Doing painting, supported by excellent art teachers, was a scaffold for my ability to do handwriting and letter formation.

There must be the freedom to express our thoughts and emotions and be able to do what can bring not just joyous feelings of creativity, but also skills that can assist in carrying our lives forward.

Communication in every form is everything to everyone. Thank You



Jaime Burke is 36 years old and a graduate of Syracuse University with a Bachelor of Arts Degree from the College of Arts and Science. Jamie has used supported typing since age five, and has progressed from supported typing, to independent typing, and typing with two hands. At age 12, he became able to use his voice to read his typing, and continues to develop useful and reliable speech. He is a frequent presenter at Syracuse University School of Education and also at conferences throughout the United States. Jamie has been invited to England, Wales, and Germany, to speak about inclusion and the process of typed communication and the life-changing impact it can have for those who have difficulty speaking. Jamie continues to advocate for typed communication as a gateway to speech, literacy, and connection. He is an active advocate and shares this journey at conferences and classrooms throughout the United States. He attributes much of his life's success to years of innovative therapies, and most importantly, to full access of regular education classrooms.

New & Exciting - Resources

Books

A Neurodiversity and Gentle Parenting Journey...in Color. A new FREE ebook released by Autistic Women & Nonbinary Network (AWN), in English and Spanish language versions. Written by Morénike Giwa Onaiwu, PhD, in collaboration with Autistic Women & Nonbinary Network (AWN), and with contributions from Ally Grace, Sharon daVanport, Erin Casey, Natasha “Supernova Momma” Nelson, Kayla Rodriguez, & Cathy Ricotso. <https://awnnetwork.org/ebook-bipoc-parenting/>

English language: https://awnnetwork.org/wp-content/uploads/2023/11/A-Neurodiversity-and-Gentle-Parenting-Journey.-in-Color.final_.pdf

Spanish language: https://awnnetwork.org/wp-content/uploads/2023/11/Mi-experiencia-a-Color-con-la-neurodiversidad-y-la-crianza-con-ternura.final_.pdf

Spectrums: Autistic Transgender People in Their Own Words edited by Maxfield Sparrow. <https://us.jkp.com/products/spectrums>

The Autistic Experience: Silenced Voices Finally Heard by Joe James and Marie-Laure Del Vecchio (October 20, 2023)

<https://www.amazon.com/Autistic-Experience-Silenced-Voices-Finally/dp/1399806858>

Coming in January 2025: Snoopers & Sneakers, a middle grade novel written by autistic advocate Lydia Wayman and Cristina Rouvalis. Orange Blossom Press. <https://www.orangeblossombooks.com/lydia-wayman.html>

Videos

Nigh Functioning Autism. Practical and Useful Autism Advice from an Autistic Parent of Neurodivergent Childre. <https://www.youtube.com/@nighfunctioningautism/featured>

Articles

Communication FIRST: Federally Funded Research About AAC Needs to Change. November 7, 2023. Communication FIRST. "Flaws and biased 'research' conducted over the years and paid for with federal funds continue to be used to justify the unspoken indignities, mislabeling, abuse, and violence many of our members endure endlessly." <https://communicationfirst.org/federally-funded-research-about-aac-needs-to-change/>

The Joy of a Sensory Friendly Home Life by Johnny Profane and Shannon Rosa. “What do I hope for your readers, Shannon? They think about how they want their living space to support their lives... and ADD to them. Forget social conventions. Make your

home work for you.” <https://thinkingautismguide.com/2024/03/the-joy-of-a-sensory-friendly-home-life.html>

Literacy in nonspeaking autistic people. Vikram K Jaswal , Andrew J Lampi and Kayden M Stockwell. Note: This article has a lay abstract. “Many autistic people who do not talk cannot tell other people what they know or what they are thinking. As a result, they might not be able to go to the schools they want, share feelings with friends, or get jobs they like. It might be possible to teach them to type on a computer or tablet instead of talking. But first, they would have to know how to spell. Some people do not believe that nonspeaking autistic people can learn to spell. We did a study to see if they can.” <https://journals.sagepub.com/doi/10.1177/13623613241230709>

The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. Monique Botha, Robert Chapman, Morénique Giwa Onaiwu, Stephen K. Kapp, Abs Stannard Ashley, and Nick Walker. Includes a Lay Abstract. “We conclude that both the concept of neurological diversity or neurodiversity, and the body of theory surrounding it, should be understood as having been collectively developed by neurodivergent people.” <https://journals.sagepub.com/doi/10.1177/13623613241237871>

Newsletter

The Listening World: Dispatches from our neurodiverse future. By Unrestricted Interest. <https://thelisteningworld.substack.com/p/the-listening-world>

Tools and Toolkits

The Masking Regulator by Autism Level UP: “This tool is meant as a starting point to begin to think about what the mask is and what is the authentic self. It is not a comprehensive guide to unmasking and that journey will be different for everyone. We cannot predict what that process will look like, but we hope to provide a concrete place to start. You can download the whole support in pdf form for use or exploration with a screen reader.”

<https://cdn.sanity.io/files/p6bm7moz/production/4de925ca8a61578a68a0a9bc506484fdbf1f9e27.pdf>

ASAN Toolkits: “Institutions: The Old, The New, and What We Should Do” and “Cycle of Institutions. These toolkits “focus on the history of institutions from the 19th century to the present, and what we can do to make community living possible for everyone.” Both toolkits are available in Easy Read Edition and Plain Language Version.

<https://autisticadvocacy.org/policy/toolkits/institutions/>

Course

CHICKENS TO LOVE (AAL) – COURSE. By Australian autistic advocate Summer Farrelly. Learn, develop, and apply skills to effectively facilitate Animal Assisted

Learning Program Chickens to Love. “Chickens to Love is designed from a neurodivergent and animal (Chicken) perspective to better understand social dynamics, emotions (ours and other people’s), other people’s perspectives, consent, respectful touch, resilience, self-acceptance, empowerment and how to self-advocate. Animals can change our lives. Never underestimate the power of the chicken!”

<https://summerfarrelly.com.au/animal-assisted-learning/>

We applaud . . .

The many autistic people who are finding their voices through communication access methods of their choosing and who are making their voices heard and heeded to advance the lives of themselves and others. An increasing number are taking the lead locally, regionally, and nationally in advocacy, training, and social change for education, rights, and inclusion. Jordyn Zimmerman, Communication First’s Board Chair recently was interviewed on the CBS Morning television show about her life and advocacy.

<https://www.cbsnews.com/video/nonspeaking-autistic-woman-embarks-on-journey-to-advocate-for-disability-rights/>

The undaunted families of autistics who seek out communication methods when their autistic family members who are without speech, have limited speech, and/or for whom speech alone does not work effectively at times. Access to communication methods should provide them a means of reliable, effective communication, so that their voices are heard and heeded, and so that they have access to advocacy, a general education, including lifelong learning, and full lives in their communities.

The researchers and others who are working to honor “Nothing About Us Without Us” by making research more inclusive, with autistics and others with disabilities collaborating as researchers and participants in research design, as members of IRBs (Institutional Review Boards), as publication reviewers, as readers of research results in the general public, and so forth. A new article provided an example of this.

Researchers Vikram K Jaswal , Andrew J Lampi and Kayden M Stockwell provided a lay abstract in their article “Literacy in nonspeaking autistic people.” Well done! Making research accessible to a broad audience of non-researchers is of utmost importance. It is encouraging to see these researchers doing the right thing and making sure that their research can reach and be useful to more people.

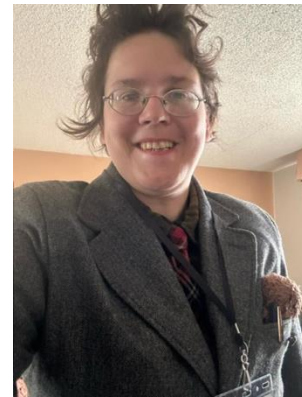
<https://journals.sagepub.com/doi/10.1177/13623613241230709>

The business leaders striving to build truly inclusive workplaces and workforces by listening to autistics and encouraging others to do so. Neurodiverse Talent Brings New Perspectives to Manufacturing. Smart Manufacturing magazine.

<https://www.sme.org/technologies/articles/2023/october/neurodiverse-talent-brings-new-perspectives-to-manufacturing/>

Washington State’s “Nothing About Us Without Us” Act By Ivanova Smith

The “Nothing About Us Without Us” Act was first focused on people with disabilities. Lots of policy decisions around services and housing were done in legislatively appointed workgroups, task forces and committees, and people with intellectual and developmental disabilities were not being invited to the table when it directly impacted them.



We realize that many people with disabilities have other identities, too, and other communities had not had representation.

We decided we would connect with other communities with lived experience and extend the reach of this bill.

The spirit of Nothing About Us Without Us is stronger with more people with direct lived experience involved there. We created a Nothing About Us Without Us coalition which connected with other communities, and we worked together to get it passed in spring 2024, when it was signed by Governor Inslee.

This act will require that anytime the legislature makes a workgroup, task force and committee, they have to invite people who be directly impacted by policy to the table. It promotes the idea of extending the constitutional intent of no policy without representation! We now working on implementation with Governor’s Office for Social Equity. And we hope to help people in other states create a version of this bill for their states and eventually federally.

Ivanova Smith, BA., self advocate, Faculty UW LEND, and activist advocate for Atwork.



Gov. Jay Inslee signs HB 1541, the “Nothing About Us Without Us Act,” on Tuesday, March 26, 2024, surrounded by advocates who had worked for its passage.

Autism and Grief: A Guide to Compassionate Support

By Maxfield Sparrow

Introduction



Grief is a complex and deeply personal experience. For autistic children and adults, the journey through grief can present distinct challenges that differ significantly from neurotypical experiences. I want to shed some light on these unique challenges and explore effective strategies for helping autistic friends, family members, and clients navigate grief.

As much as possible, I have used the words and experiences shared by autistic individuals themselves (as well as brief insights from my own experiences with autistic grief) to explain the variety of autistic grief, what was helpful, what was not helpful. I've also shared advice from non-autistic professionals where that advice highlights, expands on, or illuminates what the autistic writers have shared.

You can find links to all the sources I drew upon in the works cited list at the end of this article. I especially recommend reading the essays written by autistic people: they are as moving as they are educational.

Autistic individuals might experience and express grief in ways that are not typically recognized by those around us. These expressions can vary widely, with some people showing more easily interpreted signs, while others may appear unaffected to observers or may process their emotions in a more internalized manner. Additionally, autistic adults often face hurdles in communication that can complicate the conventional processes of grieving. Recognizing and understanding these diverse expressions of grief is crucial in providing appropriate support.

I hope this article offers valuable insights for autistic adults navigating their own paths through grief, as well as for families, friends, and professionals who support autistic adults or children. Through a better understanding of the grieving process as experienced by autistic individuals, we can enhance our approach to compassion and care, fostering a more inclusive and supportive environment.

Unique Challenges in Autism and Grief

Understanding Grief in Autism: It's Different for Everyone

When it comes to grief, there's no one-size-fits-all, but especially for folks with autism. The way autistic people experience loss can be quite different from person to person in addition to being different from the way the rest of the people around us grieve.

One helpful essay I read was by Karla Fisher, an autistic woman who discovered her autism through her attempts to heal from grief and burnout. She points out that for some autistic people, grief might show up as more intense versions of the usual challenges they face: "Grieving may manifest via increased ASD symptoms such as sensory processing issues, shutdowns, meltdowns, and decreased social abilities." This means that during tough times, things like lights being too bright or noises too loud can feel even more overwhelming.

Fisher also notes something pretty important about needing space: "Autistic individuals might have an increased desire to be alone to work things out, in contrast to neurotypicals who might feel better by sharing their feelings." So, if someone autistic is pulling back more during a loss, it's not that they're not feeling the grief; they're just processing it in their own way.

Jess Hudgins, an autistic marine biologist who wrote a moving essay about the impact of her father's death shares a vivid image of her grief, saying her dad feels like "a decompiling computer...Christmas ten years ago and this year are all memories I have at the same time. It's unsettling. I hate it so much. It hurts to process things this way." Hudgins finds some solace by keeping close to physical reminders of her dad, like his replacement joints from the crematorium, which she holds close when she feels lonely.

Elizabeth Graham is an autistic woman who wrote about grief for The ARC. She explains how some autistic people might really dive deep into their memories or thoughts about the person who's passed away: "With the tendency for those with autism spectrum disorder to perseverate on topics of their interest, matters surrounding the death can become their new interest." She notes that this might make moving on harder, as a person continues to ruminate, seeking answers that feel satisfying.

According to social worker Marci Wheeler, the way an autistic person shows their grief can vary a lot: "An individual with ASD may respond to divorce or a death situation very similarly to other family members. Their reaction might also be delayed and/or more intense than expected." This range of reactions needs flexibility and understanding from those around them.

In 2024, Mair and Nimbly published an academic article, a literature review of academic writing about autism and grief as well as studying "grey literature" such as blogs and memoirs. Mair and Nimbly's paper points out that, "Autistic grief is not like neurotypical grief... People on the spectrum can actually feel grief over many things, not just over losing someone important."

This observation is backed up by a quote in Maxfield Sparrow's analysis of a 2017 survey conducted by Thinking Person's Guide to Autism (TPGA), in which survey respondent JAL wrote: "NT [non-autistic] people often grieve in a set of specific ways... Autistic people may grieve in different ways (i.e., Shutdown/meltdowns, extra hypersensitive, avoidance, frustration) or not at all. Grieving differently is ok, and no one is doing it wrong."

Yes, that was me who analyzed that survey and I wish I'd been able to read my article 27 years earlier, when my beloved great-grandmother died. Family members got angry with me because I went with everyone else to stand before her open coffin and was so overtaken by grief I started to laugh uncontrollably. A cousin pulled me away, trying to convince the shocked people standing around me that I was actually crying. She rushed me off to a bathroom where we both dissolved in giggles until we couldn't breathe.

I don't think my cousin is autistic. I think she was having one of those reactions where someone else's laughter makes us laugh, too. We both dearly loved our great-grandmother. My cousin was just the only person compassionate enough about my differences to recognize that I needed "rescuing" in that moment and not judgment or shame.

So, what's the takeaway for families and professionals? It's all about giving space for the unique ways autistic individuals process loss. Avoid jumping to conclusions about what our grief should look like and offer the kind of support that respects our individual experiences.

Breaking Down Communication Barriers in Autism and Grief

Talking about death is rarely easy, but for autistic individuals, clear and concrete communication is crucial to avoid misunderstandings. The way we typically discuss death often doesn't translate well for those who perceive the world differently.

Fisher points out a significant hurdle: "Autistic individuals may be unable to articulate what is wrong or discuss their feelings," which highlights the need for patience and understanding from those around them. Similarly, Fisher notes that "Their language might sometimes be sufficiently different, finding comfort only within their own kind," suggesting that autistic individuals might communicate their grief in ways that feel natural to them, even if it seems unusual to others.

Graham touches on the challenges of discussing abstract concepts like feelings and fears, recommending "Finding tangible ways to routinely and regularly communicate these feelings and thoughts would likely be helpful." This approach can bridge the gap between different ways of processing emotions.

Hudgins shares a poignant example of these communication challenges during grief: "I couldn't even open my mouth to speak. I had never been non-speaking before...I remember the bizarre sensation of making words come out of my mouth for the first time in weeks." This personal account illustrates how intensely grief can impact communication abilities.

The social nuances of grief can also be perplexing. Graham discusses the "literal interpretation of common phrases at funerals, like 'He is sleeping,'" which can lead to fear or confusion for those who take words at face value. This literalness in understanding can complicate the grieving process significantly.

Wheeler expands on this, explaining that "The concept of death can be particularly challenging for those who have difficulty with abstract concepts." Misinterpretations can arise from literal understandings of phrases meant to soften the harshness of death, such as euphemisms that are commonly used in emotional support settings.

Moreover, Wheeler points out an intriguing contradiction in emotional expression: "People with an autism spectrum disorder often have a hard time expressing their feelings. Sometimes the emotion felt, in this case grief, is displayed in a manner which is the opposite of the emotion they are feeling." This can manifest as inappropriate laughter during a sad moment, just as I experienced at my great-grandmother's funeral, further complicating how their emotions are perceived by others.

Mair and Nimble reflect on the internal conflict some autistic individuals face, noting they often worry about burdening others with their grief, leading them to withhold their feelings or struggle to find someone they feel comfortable talking to.

My survey analysis quotes BGP, emphasizing the need for autonomy and understanding from others: "I knew about death. I needed to be allowed to NOT respond to everyone else's emotions all the time. I needed some kind of explanation of why people were acting the way they were, crying and touching me."

For autistic individuals, navigating grief requires a communication approach that is both explicit and sensitive to our unique needs. Encouraging open, straightforward conversations and recognizing our distinct expressions of grief can significantly alleviate the emotional and cognitive burdens we face during such times.

Strategies for Support

The Power of Routine in Navigating Grief for Autistic Individuals

Sticking to a regular routine can be a lifeline for anyone during the upheaval of grief, but this can be especially true for autistic individuals who already tend to thrive on routine. Keeping things steady and predictable can be a big help in managing the emotional storms of loss.

Fisher highlights how engaging with personal interests can be therapeutic: "Discovering/exploring new areas of interest or maintaining involvement in special interests helps in managing grief." This shows that diving deeper into hobbies and passions can provide a much-needed distraction and sense of normalcy. I have

experienced this in my own life: grief or other intense emotions will often find me crocheting skein after skein of yarn as the familiar repetition soothes my nervous system.

The basics matter too, as Fisher reminds us: "Taking care of the physical part of the body such as nutrition, sleep, and exercise also aids in managing grief." Keeping up with self-care routines plays a crucial role in maintaining both physical and mental health during tough times — this is true for any grieving person but exponentially more so for autistic people who can feel untethered without our routines.

Graham links routine to cognitive function: "Adjusting to new strategies is linked to difficulty with executive functioning [...] Maintaining routine helps in managing the grief process by providing some structure and familiarity during a time of change." This familiarity can be comforting, providing a framework that helps lessen the chaos brought on by grief.

Hudgins provides a heartfelt example from her own life: "After the initial shock, the cat got fed, my fish got fed, and my snakes always had water." Even amidst her grief, maintaining care for her pets brought a semblance of normalcy and responsibility that kept her grounded. She further shares a touching moment with her fish, Max: "Some of my animals became sick in the spring... I swear, Max held on for as long as he could, until he knew I was strong enough to say goodbye. And so I held on for him, because I knew he was relying on me. I will love him forever for that. I honestly think he saved my life." This story vividly illustrates how caring for others, even pets, can anchor someone during the grieving process.

I relate so much: I have a cat who has seen me through some very difficult times. There have been points in my life when the only reason I remembered to feed myself was because my cat demanded to be fed.

Wheeler offers a straightforward piece of advice: "Maintaining daily routines should be kept the same when possible. This predictability and consistency will go a long way to comfort the individual." This advice underlines the importance of stability in helping autistic individuals feel more secure when everything else feels uncertain.

Mair and Nimbley's literature review points out a fundamental aspect of autistic experiences of grief: "Autistic individuals... tend to prefer stable routines and this preference can make it challenging to adjust to the changes that come with a significant loss." The disruption of a loved one's death can be doubly difficult due to the simultaneous disruption of daily life.

My survey analysis for TPGA touched on a poignant element of grief when I quoted Sara Luterman's response: "Accommodate the fact that an intrinsic part of loss is change. Especially for an autistic person. Death can be upsetting not only because someone they love is gone, but because that means their world is disturbingly different."

This insight sheds light on the broader impact of loss beyond emotional pain—the disorientation of a changed daily life.

In essence, for autistic individuals, maintaining routines isn't just helpful; it can be crucial. It's about more than just keeping a schedule—it's about holding onto a piece of stability when the whole world seems to be shifting under our feet.

The Importance of Including Autistic Individuals in Grief Rituals

Involving individuals with autism in funeral processes and mourning rituals isn't just about inclusion; it's crucial for helping us understand and cope with loss. Autistic individuals often benefit greatly from being part of these rituals, provided we're given clear explanations of what to expect and why these traditions are meaningful.

Graham points out a common issue at funerals: the use of metaphors and comforting phrases that can actually be quite confusing. "At funerals, metaphors are often used to soften the discussion of death, but these can be confusing for someone on the autism spectrum who might take these metaphors literally." Comments like "It was for the best" or "They are in a better place now" are meant to comfort, but for someone who interprets language very literally, these phrases can be puzzling or even feel dismissive.

My brother died at age nine and a half, when I was almost seven. Some things from that time period are seared in my memory, while others have been lost. My mother told me a story I had forgotten: some well-meaning adult told me that my brother had died because God needed him. Mom says I replied, "well I hate God, then, because I needed Michael more!" If you want blunt honesty, you can't find blunter or more honest than you'll get from an autistic child who hasn't learned social filters and masks yet.

Wheeler emphasizes the value of preparation and involvement: "Provide the opportunity for participation in the viewing, funeral, burial, and other bereavement rituals, if appropriate. Be sure to prepare ahead and explain what will happen." This not only helps autistic individuals prepare for what might otherwise be an overwhelming experience but also aids in their emotional processing. (I've included several resources in a list below that might help you provide those explanations.)

Mair and Nimby share an affecting quote from an autistic individual: "It's important for me, it's important for me because, he's, he is a good guy to me." This statement underscores the emotional connection and personal importance of being involved in funeral rituals, which can provide a sense of closure and personal peace.

Practical support is also key. According to Mair and Nimby, helping autistic individuals with logistics, such as attending events or creating meaningful objects to remember the deceased, can be particularly helpful. This kind of support acknowledges their need for concrete actions and tangible connections to the person they have lost.

My grief survey analysis quotes a participant, BGP, discussing how typical adult rituals may not resonate with autistic adults or children: "Rituals that are created for adults often aren't meaningful to autistic adults, much less kids... I think kids need some concrete ways of saying goodbye, some action that is meaningful to them." This insight highlights the need for personalized rituals that resonate on a personal level, helping to bridge the gap between traditional practices and individual needs.

Moreover, I wrote that respondents mentioned challenges and difficulties when not included in rituals or when rituals are not adapted to be meaningful from their perspective. Conversely, respondents mentioned positive experiences often occurred when autistic individuals could engage in actions or create personal rituals that hold significance for them.

In essence, the inclusion of autistic individuals in grieving rituals, with appropriate adaptations and clear explanations, is not just about fairness; it's about providing a pathway through grief that acknowledges and respects our unique ways of processing the world.

Coping Mechanisms for Grieving Autistic Individuals

Crafting Personalized Emotional Support for Autistic Individuals During Grief

Grieving is hard for everyone, but autistic individuals often face unique challenges that call for personalized emotional support. Understanding and respecting these unique needs can make all the difference in helping us navigate our grief effectively.

Fisher makes an important point: "Tailored support should recognize autistic ways of grieving; not crying at a funeral does not make them a monster." This highlights the need for sensitivity to different emotional expressions. Fisher also advises to "Allow more time for them to process information and keep concepts/data minimal," acknowledging that processing grief can be slower and more complex. (And many of us autistic folks already need extra time to process even simple input from others.)

Graham notes the importance of alternative expression outlets, especially for non-speaking individuals: "It's vital to find some means through which they may express their grief... especially for non-verbal individuals who may need to express feelings through other means, such as art therapy or online support groups." This approach can provide vital emotional release where traditional methods might fall short. Graham, herself, said she found solace and felt less alone by engaging in online support groups and reading about grief and bereavement.

Hudgins shares her personal struggle with finding appropriate support, mentioning, "I eventually got into therapy but I'm not sure how much it helped. It would have helped more earlier on, like right after my dad died. I feel sad that I had to go through so much

of this alone." Her experience underscores the need for timely and effective support tailored to individual needs.

The benefits of early and adequate intervention are clear. Hudgins felt that "earlier therapeutic interventions might have been more beneficial," pointing out the pitfalls of delayed or inappropriate support. The difficulties she faced in seeking help, such as fear of misrepresentation by mental health professionals and police intervention, highlight systemic barriers that can prevent autistic individuals from receiving the care they need.

On the other hand, Hudgins found crucial support from friends: "The practical and emotional support from a close friend who helped manage immediate life needs like contacting her workplace for leave was crucial." This kind of support can be invaluable in managing the day-to-day realities of life while grieving.

Wheeler suggests, "It might also be appropriate to find a grief counselor who is knowledgeable about providing support for persons on the autism spectrum." Specialized understanding from professionals can help navigate the complex terrain of grief in autism more effectively.

Mair and Nimble expand on the importance of recognizing and supporting neurodivergent grief: "Supported and Included centres on how neurodivergent individuals are understood and recognized in their grief, supported in navigating the loss, and included in both events related to the loss and the broader intra-personal grief experiences." This comprehensive approach ensures that support extends beyond immediate needs to include long-term emotional care and inclusion.

Creative and expressive activities, such as making memory books or participating in puppet theatre interventions, have also proven beneficial. These activities provide autistic individuals with a way to process their feelings in a format that resonates with their unique experiences, as highlighted by Mair and Nimble.

Lastly, I'd like to quote myself quoting myself (I was both a survey participant and analyst) reminding us of the patience required in supporting autistic individuals through grief: "A child may need information repeated multiple times while they process the permanence of death. Be patient and strive to keep the child from feeling judged for needing to go over the same ground repeatedly." This patience and understanding are crucial in creating a supportive environment that acknowledges and accommodates the unique ways autistic individuals process grief.

Personalized emotional support for autistic individuals during grief isn't just helpful; it's necessary. It should be flexible, understanding, and tailored to meet the diverse ways in which autistic individuals experience and express their grief. This tailored approach not only alleviates the burden of grief but also affirms the individual's experiences and feelings as valid and important.

Leveraging Tools and Resources to Help Autistic Individuals Understand Grief

Understanding and processing the complex concepts of death and loss can be particularly challenging for autistic individuals. Fortunately, visual tools, books, targeted therapies, and more can play a critical role in making these abstract concepts more comprehensible and manageable.

Fisher emphasizes the utility of visual tools: "Visual aids and increased alone time can help in processing feelings," suggesting that these tools can provide a visual context that makes it easier for autistic individuals to grasp emotional concepts. Fisher also notes the importance of "Learning about ASD traits and how to manage symptoms rather than focusing solely on emotional expression," which highlights the need for educational resources that cater specifically to autistic ways of experiencing and expressing emotions.

Graham points out the effectiveness of structured therapeutic methods: "The use of visual aids, social stories, and structured therapeutic activities like art therapy can provide the support needed to help individuals with autism spectrum disorder process and express their grief." These resources offer alternative ways to articulate feelings and thoughts that might be too difficult to express verbally.

Hudgins shares a personal anecdote illustrating the use of digital resources for coping with anxiety, a common companion to grief: "I was having another panic attack—or I thought I was having a panic attack, I had panic attacks all the time. I sat up in bed to look for those deep breathing Gifs on my phone. I sat up and realized I couldn't sit up." This example shows how digital tools that are designed to provide support can become inaccessible in moments of distress.

Wheeler suggests practical ways to make the concept of death more tangible: "Use many concrete examples of death and what it means, like comparing a live fish with a dead one, and view videos and books about when someone dies to make the concept more concrete and understandable." These resources help clarify the finality and reality of death in terms that are direct and literal, which can be easier for autistic individuals to understand.

Moreover, Wheeler advises on the use of narrative aids: "Access and use social narratives and visual aids to explain and follow the new routines after a loss." Establishing new routines can be a significant challenge after a loss, and these tools can help ease the transition by providing a clear guide to the new normal.

Mair and Nimble document the therapeutic benefits of creative activities: "Making family trees and memory books" and the use of "creative writing and poetry" are noted as effective tools for autistic individuals to express and process grief. These activities not only provide a medium for emotional expression but also create lasting memorabilia that commemorate the loved ones they have lost.

In my TPGA survey analysis, I highlighted the importance of vocabulary and factual understanding by sharing this quote from Trixie: "Vocabulary building using social stories, videos, pictures of death, burials, and mourning people (given that the child is aware of the concept of emotions)." Providing factual, straightforward explanations can demystify the abstract aspects of death and mourning, making them more relatable and less intimidating.

Integrating visual aids, social stories, and structured activities into the support process can significantly aid autistic individuals in navigating the complexities of grief. These tools not only enhance understanding but also offer meaningful ways for us to express and cope with the profound emotions associated with loss.

A List of Helpful Books and Other Resources

Books:

Brown, L. (1996). *When dinosaurs die: A guide to understanding death*. Boston: Little, Brown and Company.

Faherty, C. (2008). *Understanding death and illness and what they teach us about life*. Arlington, TX: Future Horizons.

Gaines, A. and Polsky, M. (2017). *I have a question about death: Clear answers for all kids, including children with autism spectrum disorder or other special needs*. Philadelphia: Jessica Kingsley Publishers.

Lipsky, D. (2013). *How people with autism grieve and how to help*. Philadelphia: Jessica Kingsley Publishers.

Communication scripts:

(Note: the phrase "Social Stories" is copyright Carol Gray and should not be used to describe visual narratives that were not made by Gray or those licensed to use the phrase. Be careful not to violate copyright of Gray's term, especially in publication.)

Carol Gray's guide to loss, learning and children with ASD. *Jenison Autism Journal*, (15)1, 2-42. Available at: <https://carolgraysocialstories.com/wp-content/uploads/2015/10/Spring-2003-ISSUE.pdf> Social Stories on the Autism Alliance website: <https://autismalliance.org/social-stories>

Visual Narratives around death and grief from the Indiana Resource Center for Autism:

- My Special Person Died:
<https://www.iidc.indiana.edu/irca/articles/assets/myspecialpersondied.pdf>
- When a Person Dies:
<https://www.iidc.indiana.edu/irca/articles/assets/whenapersondies.pdf>

- When Someone Dies:
<https://www.iidc.indiana.edu/irca/articles/assets/whensomeonedies.pdf>
- Going to a Visitation:
<https://www.iidc.indiana.edu/irca/articles/assets/goingtoavisitation.pdf>
- Going to a Funeral:
<https://www.iidc.indiana.edu/irca/articles/assets/goingtoafuneral.pdf>
- Going to the Cemetery:
<https://www.iidc.indiana.edu/irca/articles/assets/goingtothecemetery.pdf>

Other Resources:

HeartPlay <https://www.heartplayprogram.org> is a program in the Boston area that provides grief support for participants of all abilities. The site offers book lists and downloadable resources, many aimed at autistic children. HeartPlay also maintains a list of certified Autism Welcoming™ funeral homes. Autism and Grief Project: <https://www.autismandgrief.org> is an online platform to help autistic adults cope with grief.

Conclusion

In this article, I've explored the multifaceted nature of grief as experienced by autistic adults, highlighting the unique challenges and effective strategies for support. Recognizing that grief does not manifest in a one-size-fits-all pattern, especially for those on the autism spectrum, is fundamental to providing empathetic and effective support. I discussed the importance of maintaining routines, involving individuals in mourning rituals, and employing personalized tools and resources to aid understanding and processing of loss.

As we continue to advance our understanding of autism and grief, it is imperative that ongoing research and education adapt to include these and similar insights. Such efforts will not only improve support mechanisms but also foster a deeper appreciation of the diverse ways in which autistic children and adults experience and cope with grief. Let this article serve as a call to action for all involved—caregivers, professionals, and autistic individuals themselves—to advocate for and implement more inclusive and understanding approaches to grief support. Together, we can build a community that truly recognizes and respects the grieving process in all its forms.

*Maxfield Sparrow is an Autistic writer, scholar-activist, peer facilitator, and direct support professional assisting fellow autistic clients with activities of daily living. Additionally, Sparrow teaches astrologically-inspired contemplative writing through their business, Mercury Muse. Max holds bachelor of science degrees in political science and applied economics from Idaho State University, and studied for two years in the creative writing MFA program at Naropa University's Jack Kerouac School. They are the author of *The ABCs of Autism Acceptance* from Autonomous Press and the editor of the anthology *Spectrums: Autistic Transgender People in**

Their Own Words from Jessica Kingsley Publishers. Sparrow lives in Silicon Valley with Mister Kitty (a.k.a. Fermat the Wondercat).

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Sue Rubin on Rosemary Crossley

Rosemary Crossley, thank you for your dedication to providing techniques and resources of communication to people with non-verbal disabilities. Your advocacy gave a community and their families the ability to live in an inclusive world. You will be sadly missed.



In Memoriam -- Anne Donnellan, Ph.D. 1943 - 2024

Anne Donnellan's professional life was devoted to humanizing people with disabilities who had routinely been dehumanized and then "treated" with punishment in an attempt to change them.

What many do not know is that Anne's professional career began as a behaviorist. When she saw Rosemary Crossley offer a communication option to two non-speaking autistics in Madison, Wisconsin, she became that rare professional who said, "I was wrong. There is a better way." From then on, she advocated for inclusion and presuming competence.

She was a prolific writer. A sample of her work that helped change the field are these:

- *Alternatives to Punishment and Progress without Punishment* (both with Gary LaVigna)
- "The Least Dangerous Assumption" which offered a different approach to supporting vulnerable people.
- *Autism: Sensory-Movement Differences and Diversity* (with Martha Leary)
- "Autism and the Concept of Neurodiversity" (*Disability Studies Quarterly*)

Anne joined AutCom soon after its founding and presented at some of our conferences. We are grateful for her leadership in helping autistics be better understood and lead a better life.

A memory of Anne by Martha R Leary May 2024 Halifax, Nova Scotia, Canada



The night before we met Andre, Anne and I sat in our rented suite, files and papers strewn around us, piecing together bits from descriptions of his life.

What we read told us that although Andre was supported by kind and knowledgeable people, things had gone horribly wrong for him. People were afraid of him and he of them. As a result, he was living in extremely restrictive circumstances. Many interactions with his support people were on closed circuit tv broadcast from his garage where staff generally stayed.

Anne joked with me that evening with the famous quip from Laurel and Hardy, "Well, here's another nice mess you've gotten us into!" Was it likely that we as total strangers would have any useful advice to offer in this consultation? Anne led the way - plan to focus on one thing only - to discover Andre's competencies – what can he do right?

We told Andre that we were there that day to get to know him, to understand what he liked, what was important to him and what would make his life better. We intended to help him explain this to his Team. Andre showed us around his home, taught us how to use his exercise equipment and told us what to draw on the poster we made for his Team Meeting at the end of the day.

Through our time together we learned that Andre tended to echo our postures, gestures, emotions and affect. When we laughed, he laughed. Ah! A competency that could lead to some good relationship building. We also learned that when we scowled or showed disapproval over the smallest thing such as not liking green beans, Andre became fearful, scowled, avoided eye contact and left the room. All day we smiled and laughed. If anything went wrong, we sloughed it off, and said, "No worries!"

The Team Meeting was in a conference room at a local hotel. Anne started the meeting standing beside Andre up front with a mic in her hand. She spoke in her jolly way, introducing Andre and the poster. She handed the mic to Andre who spoke to his amazed staff about the drawings on the poster, revealed that he was bilingual, afraid of his dark episodes that he called thunder storms and that he wanted to dance. The Team Meeting turned into an enthusiastic celebration of Andre.

Andre's challenges are complex and they did not all live happily ever after. However, the plans that grew out of our time there produced some dramatic life changes for Andre and his supporters. And there were powerful lessons for Anne and me too. I don't think we ever again questioned the notion that when you truly 'see' people with the intention of finding the good, the curtain rises on a changed world.

This lovely photo of Anne was taken by Andre. The smile on her face reflects her gratitude to him for reminding her to always look for the best in people. Although she had known this all of her life, Andre was able to make sure she would never forget.

Great News!

You may now become an AutCom member or renew your membership--including paying membership fees--on our website! Visit www.autcom.org and click on "Become a Member." We also welcome donations on our website. Thanks for supporting our work!

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 SATURDAY, APRIL 6, 2024**

Register now.
 Registration in Advance is Required

11:00am – 1:00pm ET | 10:00am – 12:00pm CT |
 9:00am – 11:00am MT | 8:00am – 10:00am PT

Moderated by
 Maxfield Sparrow,
 Autistic self-advocate,
 peer support group
 facilitator, author

Raesin
 Caine

Sujit
 Kurup

Margaux
 Wosk

James
 Burke

John
 Marble

Visit www.autcom.org to learn more about Autism National Committee

Image: announcement flyer for the webinar, with webinar title, date, time, and names and photos of the moderator, Maxfield Sparrow, and panelists, Rasin Caine, Sujit Kurup, Margaux Wosk, James Burke, John Marble

This year, we are continuing our series of webinars, which began in 2023. On April 6, we presented our first webinar for 2024: “Is Work Working for Us? Autists’ Own Experiences Seeking, Finding, and Continuing Work.” We had an exciting panel of five Autistic people today who told attendees about their lived experiences. This diverse group of people, with their varied journeys into and through the world of work, responded to individualized questions in order to, as moderator Maxfield Sparrow put it, “create a space where their individual thoughts and experiences can truly shine.” We hope you were able to attend the webinar and to ask questions of the panel. We are pleased to announce that the webinar recording is now ready for viewing either on the AutCom website or on YouTube. A link to the captioned recording on YouTube is below, along with a link to the transcript.

Link to YouTube recording: <https://youtu.be/NQNODJvTE-Q>

Link to transcript: <https://autcom.org/assets/Conferences/autcom-2024-webinar-transcript.txt>

Principles of the Autism National Committee

As a member of the Autism National Committee I endorse for all people with autism, pervasive developmental disorders, and related disabilities the development of high-quality community services, including education, residences, jobs/job training programs, and of individualized support services in all locations for both individuals and their family members; of state-of-the-art communication options for all individuals with unique communicative and social needs; of adequate supports to every family to assist them in maintaining their family member with a disability in their home at least throughout the childhood and adolescent years; and the dissemination of available knowledge of those aspects of the disability requiring special support and understanding; the promotion of research to provide parents and professionals with greater insight into the unique needs of individuals with autism and related disabilities; and the use, development, and promotion of positive, respectful approaches for teaching every aspect of life.

Moreover, I oppose the use of institutions to separate people from their communities, and deprive them of dignity, freedom and the level of independence they can achieve in supportive community living; the use of procedures involving pain, humiliation, deprivation, and dangerous drugs as a means to alter and control individuals' behavior; the increasing use of bizarre technology to control self-injurious and aggressive behavior; the widespread ignorance of the basic social and communicative needs of people with autism; and the widespread disregard for the individual's unique, basic and human needs. I object to programs which disregard the skills, preferences and basic human needs of the people they serve, and I believe that there is no longer need or any justification for using painful and abusive procedures.



Autism National Committee

www.autcom.org

The first autism advocacy organization dedicated to "Social Justice for All Autistics" through a shared vision and a commitment to positive approaches



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Membership form on Page 23



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