

This is a letter to my only daughter, my beautiful Alexa Rose Cioffi, who died on April 9, 2016, following her struggle with opioid addiction, leaving behind her son, Frankie—the joy and purpose of my life.

Dear Alexa Rose,

This month marks the 10th anniversary of your death. As I write I am listening to playlists that I made for you on several special occasions in your life. I write to bring peace to you, to celebrate your life and all you loved, and with the hope that your story will shine a light on the devastating reach of opioid addiction, and the urgent need for lifelong care and community for people like your son, Frankie, who was diagnosed with autism shortly after your death.

For those who are suffering from addiction and depression, and their families, I hope you find something warm in this. For those who are stunned and destabilized by grief, I pray you find comfort and peace in the lives of your loved ones.

For families who are trying to navigate life with autism spectrum disorder (ASD) and Down syndrome, you are not alone. May these wonderful angels from the heavens who live here amongst us be met with the people, money and resources to help them. May laws be changed to help educate and care for these amazing Vermonters for their entire life. May people understand that it is our obligation as a society to care forever for the innocent souls amongst us who are disabled with special needs. The gifts that we receive from them are immense and profound.

The day you died.

I asked if you could watch Frankie while I went to the store to get diapers and baby food, but you were too sick to get out of bed. I asked if you needed to go to the hospital and you said, “No, I just need to sleep.” I brought you some Tylenol and a ginger ale and Frankie and I went to the grocery store.

When we came back home an hour later, the house was quiet. I changed Frankie’s diaper, gave him a snack and then put him on the kitchen floor to play with some toys. Then I went into the first-floor bedroom and saw you. You were near lifeless. My heart stopped. I screamed, and then screamed your name. You didn’t move. I took out my phone, called 911, and started CPR. Frankie didn’t come into the room, and he didn’t see you, but he heard me scream. He went into the dining room and then into his playroom where he sat on the floor for 11 minutes until the EMTs arrived. To this day if Frankie hears me sneeze he says, “Papa” because it brings back his memory of my scream that day.

The horror of losing you is forever embedded in Frankie, Mom, your brother, and me. When the EMTs came, I feared that you were passing. I went into the playroom and picked up Frankie and brought him upstairs, held and comforted him. I called Mom and then Aunt Carol to come to be with Frankie until Mom and I could make sense of all that was happening. As parents Mom and I felt the deep hollow and dull ache of nothingness looking at your body. When you passed grief came quickly without an invitation and settled in like a shroud.

In Memoriam: Alexa Rose Cioffi, All Our Hearts

Are you at peace?

Since your passing, the question that haunts me is: Are you at peace? I can only pray that you are and pledge to help to finish your work here. If you are not at peace, then may this letter be helpful in carrying you to eternal peace and love.

Over the past ten years I've thought of you every day, many times a day. I see you in the places and people you loved and most especially in the deep blue eyes, mannerisms, reactions, and expressions of your beautiful son, Frankie. How blessed we are for that gift.

This morning, as spring in Vermont nudges its prospects for the gentle months of summer in the offing, I remembered the look in your eyes on that summer day when you and I were sitting on the jumping bridge between Edgartown and Oak Bluffs in Martha's Vineyard. We were watching other children gleefully and repeatedly jump into the water, then climb up on the bridge and hoist themselves to the top of the rail, gaze at the exhilarating flow of the sea merging into the salt pond below and jump again. As you summoned the courage to jump, you took my hand and smiled. An instant later, you became one of the thrilled veterans of the jumping bridge brigade who assembled there every day in the summer months. With intense love and deep gratitude, I think of our many, many experiences together over your years—some funny, and some that held learning for both of us.

After your third car accident, you said to me, "Dad, it wasn't my fault." I looked at you and said, "Honey, when you drive into the rear end of another car it is your fault. You didn't mean to do it—that's why they call it an accident." We both laughed and after your broken hands were casted, we went in search of a new car to give you a goal to get better soon.

What neither of us knew that day was that the prescription you were given would open the door to opiates slinking their way into your life. Those years were so excruciatingly painful for you and for all of us who loved you. I wish there had been a road map for you—for all of us—to find the pathway to change. We didn't find it then, but your passing has blazed a trail of hope:

for those suffering from addiction, and for families working together to build lifelong homes for adults living with Intellectual and Developmental Disabilities (ID/DD).

What I believe about dying: Love is all that matters.

Alexa, please take comfort in the warmth of eternal love from your family. When you were a teenager, I shared with you that I had drowned in the Bolton potholes before you and your brother were born. That experience taught me how hard some of us will fight to live and what happens when we finally surrender at the end. What followed for me in the minutes after my dying was very peaceful. I was so keenly aware of my loved ones and beloved places and then suddenly I came to the light and was abruptly returned to this life.

What I learned from that was that death isn't so bad for those who die, life is a gift for the living, and love is all that matters.

The author, Morrie Schwartz, taught me that death is natural. Everything that is born, dies. What we are looking for is a certain peace with the idea of dying. Before we can find that peace we must do the really hard thing: make peace with living. As Morrie teaches, "as long as we can love each other and remember the one feeling of love we had, then you can die without ever going away...for you live in the hearts of all that you have touched when you were here."

Alexa, you live on. If peace has not yet found you, my prayer is that what follows—all that your life set in motion—will be the thing that finally brings it home to you.

What your life began.

In the ten years since you passed a lot has—and is—happening.

A trail of hope for those struggling with addiction.

A year after you died Paula Routly, Cathy Resmer and the team at *Seven Days* created a yearlong in-depth series titled "Hooked" about the scourge of opiates in Vermont. They were inspired by the rivetingly truthful obituary of Madelyn Linsenmeir, written by her sister Kate O'Neill. It had an amazing impact and gave so many of us the courage to take action.

Just when it felt we might be making some progress on opioids, Covid hit. Since then, opiate addiction in our state and country has only gotten worse. The drugs are stronger and the way government and health insurance companies offer help is not keeping pace with the crushing weight of need. Treatment needs to be offered more rapidly and for longer periods of time. Pathways to recovery and new life opportunities must be supported. Those who are committing crimes need to be held accountable and, if possible, given the opportunity to rehabilitate and

become happy and productive members of our communities. Vermont is trying and we must, can, and will do better.

Three years after you died, a wonderful young woman, Jenna Rae Tatro, from Johnson Vermont died from an opiate related overdose. A week after Jenna passed, I was introduced to her parents, Dawn and Greg. We bonded together in grief and understanding and have become the closest of friends. Hauntingly, Jenna's experience was almost a carbon copy of your struggle and circumstances. Dawn and Greg invested Jenna's life insurance policy as well as their own significant personal contributions to create Jenna's Promise, a recovery center for women suffering from addiction in Johnson, VT. What they have done and are doing is absolutely life changing for so many women in our state.

While raising Frankie doesn't allow me much time to devote to working in recovery, I try to help them find money and resources whenever possible. The Tatros are amazing people, and I hope that people reading this will make a donation to Jenna's Promise. Jennaspromise.org

You live on in the people you loved.

Your daring lust for life carries on in your children and in all that you loved.

A child yourself when your first child was born, you worked with the Lund Center to lovingly and carefully select an adoptive family to raise your child as their own. I hear that your child is talented and an amazing young person. I know the permanent separation from you the day after birth drove you into deep depression and created feelings of guilt and immense loss but, honey, you should be so proud of the gift that you gave to your child. The love that you thought you had lost is forever beautiful and about to set sail into the amazing waters of possibility.

You mom, Jovana Guarino, is strong and healthy, and she is the best surrogate mother to Frankie. She loves him and passionately cares for him as she did you.

Your brother, Michael, and sister-in-law, Alaina, are doing so well. They are the greatest parents to Bennett and Jack. Michael is the best dad I know. You would be just as proud of him as I am. He is amazing.

Your greatest gift: Frankie

The apple of your eye, your beautiful son Frankie, has led me and Mom to find the pathway from grief to the providence of joy and the rebirth of purpose. Frankie is now 12 years old.

On the day you died, and from the minute I walked away from your lifeless body, I picked up Frankie, held him close and knew that our lives were forever changed. I've adopted Frankie and your mom and I are doing all that we can do to be his loving parents.

Two months after you died, doctors confirmed that Frankie is autistic. We didn't even know what that meant but we are learning about autism, with him, every day. Frankie is so beautiful. He looks exactly like you, and his facial expressions and reactions sometime stun me. I see and feel so much of you in him. It is so beautiful. Being Frankie's dad is the most joyful privilege.

The gift, privilege and awesome responsibility of autism.

Frankie makes me smile and laugh internally every day. But autism is so perplexing to try to understand and it is the most formidable challenge that I have ever attempted to navigate.

Frankie is like a person sitting at a computer screen with 50 windows open at the same time. He is actively engaged in every window, but he rarely can attend to just one simple thing in the way neurotypical people can. He is verbal, but he is not conversational. He memorizes everything he sees and hears—people, places, sounds, everything. He can't tell you what he does during a day, but since he was three years old, he has been reciting PBS commercials and scripts from books, movies and signs. It is amazing and sometimes so very funny.

He was finishing brunch at one of his favorite places and when he sat back and smiled, I said to him, "You are so lucky to have such a good ____." I stopped hoping he would finish the sentence and thinking that he would say "Nona or Papa." Without hesitation he said, "college savings fund." I almost choked on the water I was drinking and did everything possible not to laugh out loud. I have no idea where that came from.

Like so many others who are autistic Frankie has a gift of hyper-awareness and intelligence. However, he is incapable of performing almost all the activities of daily living. He must have one-on-one help toileting and dressing. He doesn't understand running hot water could burn you. He is spatially unaware and doesn't understand the dangers of traffic, heights, poisons, people, and all the many dangers encountered in life. Frankie will never be independent, and he must be forever lovingly cared for. So, we must work hard and smart to build and attract resources and make options for Frankie's lifetime care.

Autism is a social and communication disorder. Living with autism is a minute-to-minute, day-by-day lifelong journey. Learning to raise an autistic child is the most immense responsibility and the most exhausting thing Mom and I have ever pursued.

Very few people understand autism. Even fewer enter professional areas of education and development, and then even fewer pursue being loving and patient caregivers to people who are autistic. The school system and special education is just pathetically incapable and insufficient. While every teacher, provider and principal we know is so lovingly committed and passionate about helping all students, they are just overwhelmed and overworked in a system that lays everything upon them.

The curriculum, programming and services for special needs students is direly in need of total structural, system, programmatic, and delivery redesign. The focus for special needs students should be upon the specific needs of each student, and specialty services like Speech Language Pathology, Occupational Therapy, Physical Therapy, and social engagement must be vastly expanded.

Currently, just to hold off developmental regression, the parents, grandparents and loved ones of children with special needs must do everything that they can 24/7 to advocate, and fight, for the services, education, rights, well-being, and dignity of their loved ones with special needs. That is exhausting, expensive and at times overwhelming. But we are committed to doing all that is possible, in any way we can, to make a positive contribution.

We have found that, for us, it is a gift and privilege to work with Frankie and these amazingly special people. Frankie's Autism Team is like having a Board of Directors and we are so lucky to have the help of Vermont Family Network, the Howard Center, Sarah Curran and the UVM Luse Center, Dr. Jeremiah Dickerson and UVM Health Children's Autism Psychiatry Center, Dr. Joe Hagan, Dr. Nick Bonenfant, Jordan Palker and the Team at Lakeside Pediatrics, SD Associates Behavioral Services, UVM Colleges of Nursing and Education, and a broad array of medical and clinical specialists and providers. It takes a massive village, and we are so deeply grateful.

What we are building.

I am now 70 and I know that time is not my friend. I must value and squeeze the most out of every day. I must earn as much money as possible and invest it for Frankie's lifelong care, which for him could be 90 years.

One day, about four years ago I talked with a friend whose daughter has special needs, and he told me what he and his wife were doing to plan for her future. Then he looked at me and asked, "What's your plan?" That night I tossed and turned unable to sleep. I woke up sweating with immense anxiety about Frankie's future. We had to create a plan for Frankie's future and perpetual care in a world without me and Mom, and we had to move on it as quickly as possible.

I came into my office and talked with my friend and colleague, Alex Demoly, about my ideas and we started researching.

Discovering the Camphill Movement.

We scoured the Northeast for housing and community living models. We didn't think that the primary and current Vermont model of "share living providers" (whereby Vermont adults with ID/DD live with a family who gets paid for their care) should be the only model possible. The vast majority of Vermont families who do this service are absolutely wonderful souls but, as you must know through your son, change and transitions for most autistic people are very difficult and, while the need for loving care grows, the population of caregivers in Vermont is aging.

We need to create more options for permanent residences for adults with ID/DD in our state. I think we looked at and traveled to six places in Vermont, Massachusetts and New Hampshire. My schedule didn't allow me to go to a place called Heartbeat in Hardwick, Vermont on the day that visit was scheduled, so Alex went. That visit led us to Hannah Schwartz, the founder of Heartbeat. She had come to Burlington to run Mansfield Hall, a dormitory like residential complex on College Street in Burlington that is home, during the academic year, to students with ID/DD who attend the University of Vermont, St. Michael's College, Champlain College, and the Community College of Vermont. I asked Hannah how she came to do this work, and she told me that her parents had devoted their lives to helping people with ID/DD, helping to create Camphill in Kimberton, Pennsylvania.

We had seen a number of unique residential communities by that time, but I was concerned that they might stumble once the founding parents had moved on or died. I asked Hannah if she would take me to Camphill Kimberton. I went with Hannah in December of 2023 and was absolutely blown away with delight and wonder with the four Camphill Communities that we saw. The care, dignity, love, and respect embedded in the Camphill model is exactly what I hope for Frankie. There are over 100 Camphill Intentional Living Communities worldwide. They opened their first community in the US in the 1960s and there are now over 40 locations. I went to see the adult intentional living communities not knowing that I would also see a school for grades 1-12 and a school for 18- to 20-year-olds. Those two schools amazed me.

A home with heart: Riverflow Community

Hannah was working with a group of parents who wanted to start an intentional living community somewhere in or near Northwest Vermont, so I offered to help. Later that month a property poked its head our way and we began our quest to build the nonprofit Riverflow Community, modeled after Camphill.

In January of 2024, we were able to purchase the property and commence raising money to renovate the home. Just ten months later, in October, Riverflow Community opened welcoming four "Friends"—Vermont adults with autism and Down syndrome—to their permanent home. Riverflow is and will be a forever home for Vermonters with ID/DD. While caregivers can change

over time, the Friends will live there forever. Life there is totally centered on their lives and needs.

We are moving through the permitting process to build four more homes on the property, and we hope to earn affiliation with the Camphill Movement, which requires us to continue fundraisings to accomplish our goals. The build-out could take ten years—or it could be sooner if we can change laws, create more state funding, and raise more money from people and philanthropies.

What we are doing is very exciting and life-changing for the people who live there.

riverflowcommunity.org

But, one home is not enough.

Even as we expand the Riverflow Community, I am beginning to work on a project in St. Albans that will serve as the forever home to more Vermonters with disabilities, and working with an incredible group of parents who have formed the Developmental Disabilities Housing Initiative (DDHI) in Vermont to advocate for people with ID/DD.

All this so Frankie and others will have lifelong living options when they become 22 years old and are considered permanently disabled and no longer eligible to receive support through the public school system.

The goal of DDHI is to create hundreds of lifetime permanent housing options for adult Vermonters with ID/DD throughout our state. The task is significant but not insurmountable. Governor Scott, Vermont legislators, the Vermont Housing Conservation Board, and wonderful non-profits like Champlain Housing Trust, the Howard Center, and others are helping us seek and find pathways to solutions, funding and resources. The Greater Burlington Industrial Corporation (GBIC) and Cynosure have made significant donations to building and supporting this great network of Vermonters dedicated to this important endeavor.

Alex and I have enlisted Patti Komline and her government affairs team at Downs Rachlin Martin, as well as special needs Attorney Jim Caffry to help, and we continue to support the efforts of DDHI. Our coalition of volunteers has helped secure \$2.8 million in the FY26 state budget that begins this July. That money will go to the Champlain Housing Trust for housing in Burlington for adults with ID/DD. We want the state to support multiple styles and models of housing for people and have hope and trust that many good Vermonters will join the cause.

What you and Frankie have taught me.

When I was a boy my incredible mother and the nuns who taught me in school told me the greatest virtues to work and aspire to in life were patience and humility. Finally, in the last quarter of my life, with your passing and the gift of raising your beautiful son, you have instilled deep enlightenment into the meaning of these valued aspirations.

Alexa, your life continues to teach me, give me purpose, and provide me with joy that fuels and inspires me to try to practice and earn those qualities. You've taught me:

- Patience is one of the most important quests in a meaningful life. The gift of living with Frankie and working with people with ID/DD teaches me every day the awesome value of seeking to earn the virtue of patience.
- Humility must be earned. It is the foundation on which I have built my life since you passed.
- Passion and purpose are the only things worth striving for, and the most one can ever hope to attain.
- Health is the only wealth of worth.
- Time is the only possession of value.
- Kindness and respect should be practiced and lived again and again.
- Obligation is sacred. Look beyond your reflection and into your soul and give. If you have been blessed with talent, or gifted with means or money then pass it out and pay it forward. Give until it hurts to those who cannot provide for themselves.
- **Love is the only thing that is forever.**

Making peace with grief through purpose.

Any of us who, without warning, have been brought to our knees and left breathless with the sudden experience of the loss of a child have awakened to an unforeseen overwhelming power that knocks us down: grief. It is tremendous and destabilizing. It smothers our will and shatters our understanding of balance and order. It causes us to question our beliefs, our trust, and the meaning of whatever we came to understand as our base and navigation system. It lays slaughter to our goals and annihilates our plans.

Yet, it can also provide the opportunity to build character and redefine us in a positive way.

I recently heard Ken Burns talk about grief. He articulated what I had come to understand finding my own way forward. Grief is an overpowering destiny force. However, it also can be a fuel that provides the sustenance and energy to propel us to another purpose.

As foreign as it may seem, in retrospect, we are often made by the tragedies and loss that we suffer. The part of tragedy and of loss that upends us can also be part that makes us and redefines our sense of purpose. Grief can become a new internal operating system—one that recalibrates our purpose and renews our ability to focus on what matters most. The horror of grief can fuel a recommitment to our life mission and redefine our sense of purpose. And, if we

are lucky, we find a passion that provides the eternal fuel to sustain our ability to execute our purpose.

The bounty of our work, if we are successful, will sustain and last for a long time after we have passed on to the light forever.

One Love. One Heart.

Alexa Rose, inscribed on your gravestone are the words: One Love, One Heart, Rest in Peace. Your life continues to create profound purpose, you brought incredible lives into the world and your soul created the means for enlightenment and love to live on forever.

May those suffering with grief find hope, promise and purpose.

Love,

Dad