

Enduring Love, gay couple copes with Alzheimer's



by **Gretchen Rachel Hammond**

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Michael Horvich, left, and Gregory Maire. Photo courtesy of Michael Horvich



Gregory Maire, left, and Michael Horvich. Photo courtesy of Michael

On Oct. 19, 2000 Michael A. Horvich and Gregory Lee Maire stood before a Justice of the Peace against the stunning backdrop of Stowe, Vermont, for their civil union ceremony.

Surrounded by the magnificence of the Green Mountains and Worcester Range, they expressed their love for each other in words and in the unspoken, peaceful elation unique to the moment when two souls who have searched alone for each other through time and circumstance are finally united.

Maire tried to read something to Horvich on that day. But he was so overcome with emotion, he couldn't get through it.

The verse was taken from Hymn to Serenity by German Poet Friedrich Holderlin.

"Behold! The lovelier blue of heaven is gathered in my friend's eye and from his unclouded brow beams highborn fidelity. More brightly it is written there than in gold upon our door; Where good men love one another; joy dwells ever and evermore!"

It was a cold, rainy April 2016 morning when Horvich invited Windy City Times into his and Maire's downtown Evanston condominium.

There was an immediate and temperate sense of welcome to the rooms, each filled with an extraordinary array of plants, books, art and photography neatly ordered amidst items of deep personal significance to their owners but easily understood to the stranger as intimate expressions of two inseparable lives.

Anyone who has known love, even for a moment, can recognize them.

"I'm nervous," Horvich admitted as he gently shooed one of the home's two cats out of a chair and sat down. "You look back at over 40 years of both of us growing up and becoming who we are and it's our story. I want to make sure I get it right. I want to make sure I remember all of the important parts—some of them

soundbites, some of them beautiful concepts. I might cry, but I don't mind crying."

Horvich describes himself as a Renaissance Man. He is an actor, writer, photographer and the curator of Michael's Museum—an exhibit of the miniature treasures and toys which Maire encouraged Horvich to collect over the years.

It is now on permanent display as part of the Chicago Children's Museum at Navy Pier— something generations of kids can enjoy courtesy of a 70-year-old man whose long, white beard and playful eyes ensure that, when Horvich dons a Santa Claus costume as he did during the 2015 holidays, no child ever imagines he is anything but.

When he and Maire met in 1976, there hadn't been many positive role models for either of them growing up. Horvich was a teacher at the time and closeted.

"People weren't ready to discuss who they were," he said. "I couldn't even talk in the teacher's lounge with my fellow colleagues about being gay."

Instead, Horvich attended a Monday night Lakeview meet-up called The Men's Gathering.

"The purpose of the group was to be supportive," he recalled. "It was a place you could talk about feelings and emotions."

At the time, Horvich was coming to the end of a 13-year relationship with a man. Maire was married to a woman.

"Greg's wife was the education director of a forest preserve and he was a stay-at-home-husband trying to become a published author," Horvich said. "He loved his wife but he needed male company so he would go to the Monday night meetings and have friends and deal with his awareness and his emotional issues."

Both Horvich and Maire would both tell the same story of how they met: "Michael was there first, Greg came in. Michael saw him from across the room. Greg was wearing a Lacoste shirt, a pair of khakis with a big brown belt and Docksidiers without socks. He had short hair with streaks of blonde. Greg looked back at him at the other end of the room in a pair of tight blue jeans, a flannel shirt and tennis shoes. It was lust at first sight."

"Even though we were instantly in lust, we did not consummate the relationship for a year," Horvich said. "We courted. Although it was a time where everybody else was hopping into bed at a moment's notice, Greg and I instead went out to dinners and got to know each other. He was one of the most intellectual men I had ever met—an artist and close to a concert pianist on his grand piano. He was gentle, kind, funny. Everything about him was just wonderful."

After going out together for a year, Maire went over to Horvich's home for dinner.

"We decided it was time," Horvich said. "We wanted to get to know each other intimately. So we called up and told the guys we weren't coming to the meeting. We don't know for sure but they probably all applauded and said 'it's about time those two got together.' Greg spent the night and it was lovely. I had got to know him emotionally and intellectually. Up until that night, I'd just lie under the piano while he played Chopin or we would exchange backrubs. There was an easy equality to it."

Aware of his bisexuality, Maire's wife had been initially tolerant of his relationship with Horvich. That began to change as the men grew closer.

"She became more possessive and didn't want to share him," Horvich said. "I was trying to be understanding and supportive but, at one point, I said 'Greg we can't live like this anymore' and we broke up."

Maire left his wife in order to sort out his feelings and moved in with a friend.

"After two weeks he decided that he needed the love of a man more than he needed the love of a woman," Horvich said. "He would explain to me that it wasn't so much I [Michael] had won and she lost but that he had decided in his own favor."

Yet, even at a time when co-habitation was more of an instant relationship prerequisite, neither of them rushed into anything. Horvich continued teaching. Maire began to work for the Chicago-based mental illness advocacy nonprofit Thresholds.

While serving more in a managerial capacity, Maire held a degree in architecture and helped the organization design some of their halfway houses. It inspired him to go back to school, complete his exams as an architect and, eventually, start his own business.

"We both wanted to be sure we had learned from our previous relationships," Horvich said. "At first we lived across the street from each other in Boystown. After seven years together, we bought a house in Evanston."

Their lives combined into a rare harmony through the rise of gay liberation and HIV/AIDS the fight against the Defense of Marriage Act (DOMA) and the struggle for equality. While they stayed involved in social services and as advocates at organizations like Gay Horizons (now Center on Halsted), as a couple they were undamaged. Despite the world which raged around them like a violent typhoon, they remained insulated by perfect love.

There were always arguments, some of them caused by each man wanting to assume the position of head of the household, but there was nothing that was outside the realm of compromise.

"He was very stick-like with his emotions, with his behavior and how he lived his life," Horvich explained. "I was very sponge-like. Over time, he became more of the sponge, and I became more of the stick. He was always calm. He would never allow himself to worry unnecessarily. We grew in parallel with respect, discussion, communication and negotiation. It was just a beautiful blending. We would always say that our roles changed at a moment's notice. He loved to cook. I liked to shop. At a certain point, we would negotiate and he would do the shopping."

"We talked all the time," Horvich added. "We never assumed anything. We learned how to apologize more quickly. Having a relationship means giving up a part of yourself and holding the other person's feelings in mind in almost everything you do. You can't always win."

One day, Maire was just beginning to play Chopin Ballade Number One Opus 23 on his piano.

"He called me in to say 'Michael I want you to hear this.' He played several bars and it was gorgeous."

Horvich suggested that Maire try to learn it in its entirety. "He proceeded to learn the piece from beginning to end over a period of five years," Horvich said. "I would lay on the sofa while he was practicing. To me the sound of piano music cannot speak to me anymore on what home was about."

Horvich does not think the word "soulmates" is adequate enough to describe them. "We lived many lives together in different forms," he said. "We were always demonstrative of our love. Everyone who came into our home recognized it. People who would come and visit us would say how comfortable it was, how quiet. That's just how our relationship was."

After Horvich retired from teaching, the couple went on a fall trip to Vermont. It was there that they held their civil union.

Horvich handed Windy City Times a photograph of Maire. It was taken backstage when the two were volunteering at the Lyric Opera. One could tell that Gregory was an instantly likeable man. He was wearing a black shirt, a pair of gracefully sympathetic eyes and a modest smile. On the back of the portrait was the Holderlin poem.

"Behold! The lovelier blue of heaven is gathered in my friend's eye and from his unclouded brow beams highborn fidelity. More brightly it is Where good men love one another, joy dwells ever and ..."

Horvich took a deep breath and steadied himself to relive the past 12 years.

"We had our second home in Evanston and Greg's firm was doing really well," he said. "He was designing homes in Lake Forest, Glencoe and Highland Park—even as far as Saudi Arabia. He was playing his piano and loving life. I was retired so I was running his business. One night, I came home from a rehearsal at the Lyric and Greg had taken a nap. He woke up very confused. He didn't know what year it was. He didn't know his parents had passed away. I asked him who the president was and he replied 'Bush!' He hated Bush so much that I guess the feeling was strong enough for him to remember."

Concerned that Maire had suffered a stroke, Horvich took him straight to an emergency room.

The following day, Maire was diagnosed with Transient Global Amnesia—a sudden but temporary memory loss.

"Usually you get over it 100 percent," Horvich said. "But I was keeping a closer eye on things. I noticed that, all of a sudden, things in the firm weren't going so well. Greg is very confident, always on time, always dressed impeccably but then he started to forget an appointment, or he'd go to a meeting not dressed appropriately for it. There was enough going on that I decided we needed to take a total look."

After a full battery of tests, Maire was told that he had Alzheimer's dementia.

He was 55 years old.

“The gut reaction was that both of us started crying,” Horvich said. “In some ways we were relieved by the diagnosis because now we understood what was going on, but I mean you are just dumbfounded. We didn’t know what to do and we were worried about the future. At that point in time, not a lot was known about the disease. So we went home, did some thinking and research on how we were going to deal with this. I don’t think we knew how rocky the road would get but we never had any doubt that we would be able to survive it together.”

At first, they reorganized the business and took steps to protect themselves legally. “For instance Greg couldn’t stamp the [architectural] drawings anymore,” Horvich explained. “Then he would be responsible if there was a problem with the building. What we really wanted to do was close the business and spend what time we had left with each other.”

Characteristic of both men, they ensured that their employees all landed on their feet and that none of the clients were left hanging in the middle of a project.

The couple moved into the Evanston condominium and set about travelling the world as much as they could. They relished each moment together as if they were enjoying a divine banquet for the first and only time.

The piano was sold. It was Greg’s decision.

“He really couldn’t play the piano the way he wanted to,” Horvich recalled. “So he had all these albums and he said ‘I can always listen to CDs and enjoy my music that way.’ It was such a centered decision. But as decisions like this had to continue, I grieved for 12 years. Every little loss. It was OK though because we had each other.”

“Behold! Heaven ... friend’s eye ... beam ... written there ... good men love one another, ever and. ...”

“For some people, one of the things that happens with Alzheimer’s is that it puts up a buffer so that the person who has it doesn’t realize the changes that are happening,” Horvich explained. “At a certain level, Greg did understand the changes. We’d get together with friends and he’d tell them ‘I’m fine. This Alzheimer’s just isn’t as bad as I thought it would be’. But I was dying inside.”

Horvich and Maire changed their expectations as Alzheimer’s progressed. As Maire began to lose his ability to communicate—something which had been the foundation of their lives together—Horvich took to writing. He put together an almost 30-page essay entitled “Our Story” and started a blog which he called “Michael Horvich Cares about Alzheimer’s.”

“I wasn’t able to sit down with Greg anymore and process and talk, so I started talking to my computer,” he said. “Alzheimer’s is not just a memory problem. That is the least of the worries. What starts to happen is all cognitive processes start to slow down, disappear, come and go at will.”

As an example of its progression, Horvich recalled Greg’s preternatural and adored ability to cook intricate, multi-course meals.

“He could do that less and less,” Horvich said. “So slowly I started helping him. I became more of the chef and he became more of the sous chef. Slowly, he couldn’t do that anymore either. So he would just sit at the counter while I prepared dinner and then he would clean up afterwards. He would get frustrated and angry that he couldn’t cook but he also realized that at least I was there and we would do the best we could together. Whatever he felt was always appropriately tempered.”

Seven years into Alzheimer’s and Maire could no longer clean up or even empty the dishwasher. “The whole thought process was too confusing and frustrating,” Horvich said. “So I said ‘why don’t I do it? That’s OK’.”

It was the same situation with the breakfast trays. Maire always took great pride in putting together a complicated morning meal.

“He wasn’t able to do that anymore,” Horvich said. “So I would lay out the tray for him and he would fill in the details. When he wasn’t able to do that, I would put breakfast together for him. When he couldn’t navigate on the computer to a news page, we ordered a newspaper to be delivered. The goal was always to be as creative as I could to compensate. To keep Greg at a place where he was happy and safe and felt good, needed and part of the relationship.”

During those rare moments when Maire lost his even-keel attitude, the couple would cry together and rock themselves to sleep.

Horvich stressed that he never wanted to simply assume that Maire had lost abilities on any given day. He created a graph in the air to demonstrate the progression of the disease to Windy City Times.

“The losses are like this,” he said moving his finger up and down in peaks and valleys. “I was constantly monitoring his abilities in relation to the knowledge that one day he could do something, the next day, he could approach it but not get it done well. The next day it would be OK. Then the next day it would be worse and then maybe it would disappear. Then it would come back and be OK again. But then it would get worse and then extinguish itself. I was always aware of this trajectory.”

As careful as he was, there were still moments when Horvich lost his patience. “Greg would look at a knife and fork and not know how to use it,” he said. “I was frustrated at first but I learned quickly and I started making finger food.”

When Maire could no longer recognize the signs of needing to go to the bathroom, Horvich would gently remind him every couple of hours to try. “Then it would get to the point where he would take a dump and he didn’t know whether he was finished or not,” he said. “Sometimes I would have to wipe for him. That’s what happens when you love someone.”

Horvich tried to prepare himself for every eventuality, every loss except one—that Maire might lose the ability to express his love. For the first time during the interview with Windy City Times, Horvich lost his composure and began to sob.

“What was hardest was thinking that he would forget my name,” he said. “Once I got really angry at him and said ‘do you even know my name?’ The nature of Alzheimer’s is that it presents itself in ways that are so crazy, that when you’re experiencing it, you don’t even know how to think about what’s happening. I helped myself through therapy, through friends, I learned how to cry myself to sleep silently so I would not wake Greg up.”

Eventually, Horvich began to hire companions from Northwestern University. He developed the application form, an explanation of their responsibilities and a questionnaire.

Although Horvich and Maire tried to maintain their old lives, enjoying restaurants or nights at the Lyric, eventually the challenges surmounted the joys.

Horvich compensated where he could. Thanks to a neighbor in their building, Maire was able to express himself through engaging in painting.

As 2014 began, Alzheimer’s progression intensified.

“I was getting him dressed and he got angry with me,” Horvich said. “It was escalating quickly and I was really frightened. I had to call 911. Two paramedics, two firemen and policemen arrived. When Greg saw them all, he relaxed because he knew they were there to help. I had turned into the devil. Greg was terrified of me. He didn’t want to be near me. While this was painful, I knew it was Alzheimer’s talking, not Greg.”

Horvich also realized that Maire could not stay at home anymore. He contacted the Lieberman Center—a senior health care facility in Skokie, Illinois.

“Greg never once asked why I was sending him there,” Horvich said. “But it was so hard to leave him.”

For the first time in decades of living an inseparable life, Horvich returned to an empty house.

“Behold! Heaven.”

“Greg was happy to be at the Lieberman Center,” Horvich said. “He became very comfortable in his new, small environment where I was no longer putting expectations on him like going to the opera or trying to function normally in our life. For the last couple of years, he didn’t communicate at all sentence-wise.”

Still, Horvich transformed Maire’s room at Lieberman into one of the best decorated and most welcoming in the center.

“All of a sudden I had this whole team helping me with Greg’s medical and safety needs,” Horvich said. “Greg started having seizures and had to go to hospital. By the time he got back to Lieberman he was no longer ambulatory. He had to be fed. He had to have a machine to lift him up and out of bed. I found a guy named Manny to be Greg’s caregiver. He and Greg developed a beautiful relationship. Manny was a gift from heaven. He was there seven days a week.”

“You know Greg was still there emotionally even though there were few communication skills,” Horvich added. “I would come in and he would know who I was. He was so happy to see me. I’d say ‘you know what? I love you’. I would tell him that 12 times in an hour. He would reply simply, ‘I know’.”

“It was a good life even though it was greatly diminished,” Horvich added. “I got him a teddy bear and he would carry it around. Everyone knew Greg and his bear. He was named ‘Peaceful’ and Greg would use the bear to tantrum when he was upset. He would cry into it. He would laugh and get silly with it. Out of everything I tried, I felt the bear was the best thing I ever did for him.”

On Oct. 1, 2015 Horvich received a call from the hospice care nurse. “She said that he was non-responsive all day and ‘I think he may be preparing to leave us’.”

As he remembered, Horvich’s voice cracked. He hunched over slightly and tears fell down his cheeks. “So I ... I’m sorry. I haven’t been through this for a while.”

“I didn’t want Greg to be in pain through an elongated process,” Horvich said. “But, in his inimitable style, he slowed his dying down to make it easier on me and everybody who came to say goodbye.”

Maire was in a coma for three days.

“On the third day I crawled into bed with him,” Horvich recalled. “I put my head on his shoulder and told him how much I loved him and how much I would miss him. I apologized, again, for those times I was mean or inconsiderate. I gave him permission to leave when he was ready with the assurance that I would be OK. Then I got out of bed and kissed him on his open, non-responsive mouth three times. The third time, he closed his mouth and kissed me back. He was able to muster enough strength through his coma to kiss me goodbye.”

On Oct. 4, Horvich was preparing to go back to the hospital when he decided to light a candle for Maire. “The phone rings,” he said. “As I was lighting the candle, Greg was leaving us.”

Maire’s body was cremated. His ashes were placed in a sewing box that once belonged to his “favorite grandma” Carrie.

“I brought him back and, as I came over the threshold, I said ‘welcome home’,” Horvich remembered with a smile. “It felt good rather than leaving him in a concrete vault in a cemetery.”

Horvich described grief as coming in rolling waves. “I relived the times I was mean,” he said. “I was afraid to give into emotions. But I continued meditating and I learned how to sit with my emotions, how to live with suffering and grief. I learned that everything isn’t permanent. It is constantly changing. So it is with life and death.”

Horvich and Maire’s story has been told in a documentary short film entitled Alzheimer’s: A Love Story which is receiving awards at film festivals across the world.

Before Maire died, he and Horvich had a conversation about helping others. It was something that had played a significant role in their life together. Despite each of the trials Alzheimer’s presented, their outreach to those in need only cemented the fact that they loved each other more than ever.

Thus the “More Than Ever Education Fund” which Horvich and Maire established, is a fitting title for the educational opportunities which will be afforded to youth confronting homelessness in the Chicago area. Administered by the homeless-advocacy organization La Casa Norte, the fund will provide scholarships and educational initiatives for those homeless youth who are a part of the organization.

Regardless of the changes life still has in store for him, Horvich feels that his beloved Greg is constantly at his side as a conqueror and hero of Alzheimer’s. Never a victim of it.

“The minute that he died, the Alzheimer’s disappeared,” Horvich said. “All of his problems were gone and he was free and could fly again. The Alzheimer’s became a non-issue. He comes to me in dreams. He says that he is OK and doing well.”

The poem Horvich and Maire read at their civil union still echoes as testament to the kind of love that is as real as two men who met across a crowded room, forged a life together, laughed and fought together and overcame the worst of times to remain, forever and a day, together.

“Behold! The lovelier blue of heaven is gathered in my friend’s eye and from his unclouded brow beams highborn fidelity. More brightly it is written there than in gold upon our door; Where good men love one another, joy dwells ever and evermore!”

For more information visit: mhorvichcares.blogspot.com and mhorvich.blogspot.com .

