

MDMA and a couple struggling with cancer: Sue's final letter

Hello,

I recently lost my fiancée, Shane, to cancer after a long battle. It has been trying on those who were close to him. It has also been a very fulfilling event, due in part to MDMA sessions we went through to seek to accept his death and relieve the emotional pain and hardships we encountered as the result of his terminal illness. While we had only three sessions with MDMA, they were life-changing. Our story has been published for all to read in the MAPS Bulletin since the first experience three years ago.

TAKING MDMA TOGETHER was the best decision we could have ever made in regards to the cancer. We discussed this many times before his death last week. Shane's very long obituary concluded with a request at the end; in his memory, in lieu of flowers, we asked that people support the MDMA research going on for people facing cancer. Unfortunately, not many people knew of what we had done to be able to deal with his cancer in such a positive way, nor had they ever heard of MDMA. We were lucky enough to have a beautiful friend who designed pamphlets to distribute at the service that outlined the research and why we both support it so strongly. Through this, over 100 people were made aware of the research, the need for research and how it helped us in less than a one hour time span. Grandparents, aunts, uncles, people who had never even heard that marijuana could aid a cancer patient... all were made aware of crucial MDMA research going on to help others.

There is such a need for recognition of this wonderful research and its potential to change the lives of those facing terminal illness. The spectacular people fighting the cause need the help of all of us out there to bring it to a positive light. Among people who read Shane's obituary, some have sent

checks who had no clue what we were asking, but donated out of respect, others donated out of love, while others donated out of genuine care for the program and the help it could bring. There are enough of us out there that can help bring awareness. Nobody knows if someday they could be facing all that we did. Hopefully they never will, but in the event they do, it should be feasible that they have this readily available to them, unlike how we had to "break the law" to help our anguish.

I plead to you now. Please, bring light to the research going on in a positive way. Make others aware of the importance of helping terminal patients and their loved ones with acceptance and love... despite what they are facing. Please help fight for the rights of those who are scared and hurting. If you lose a loved one, or someone whom maybe you didn't even know personally... instead of flowers make a donation in their name—out of love for them and love for your own life and that of your loved ones—to a program that helps cure the pain.

Please, don't let Shane's death go in vain. We benefitted so much from this, you may have a day when you need this also.

Thank you and warm hugs to all.

October 10, 1999

IT HAS BEEN the longest week of my life. Shane passed away on October 2, 1999 at 2:50 PM in the comfort and love of his own home. He was surrounded by me and my children who were holding his hands, touching his face tenderly and telling him that while we would miss him horribly that it was OK that he was leaving. I knew that this day would rip my insides out and while it did do just that, I feel that it was a beautiful experience. That morning Shane woke rather incoherent and kept telling me, "I gotta pee," so I would hold the urinal for him. By

She's final letter... our last journey

this time, the cancer in his abdomen had grown and was pressing on his spine, making him unable to walk at all. He was confined to a wheelchair. Upper body strength had also given in to weakness and inability to move much, hence he used a urinal exclusively. This had begun about a week before our last MDMA session (which occurred September 4). After a few hours of his drifting in and out of consciousness, I realized that it just may not be the medication that he was on. Something was severely wrong. I contacted our Hospice nurse, who came out to put a catheter in him. He was moaning while drifting in and out, a horrible painful moan that broke my heart. I thank God deeply that the catheter alleviated the pain he was feeling; immediately after she drained his bladder the moaning stopped and I knew that he was peaceful. Unfortunately, this was accompanied by the dreaded news that they felt he would be passing that day. Shane's breathing had slowed and he fell unconscious at this point. The nurse took his blood pressure and a reading of 80/0 confirmed this.

The phone calls to his family began, telling them to please hurry to be by his side to love him into whatever eternity awaited him. What seemed like hours, but in reality was less than an hour and half later, he physically left us while I held him tightly and kissed him into peace. The hardest event of my life was kissing him as I told him to "please go," but "never leave my heart and soul." While it was the hardest time for me, it oddly was the most fulfilling. I can't put that into words, so I won't even attempt it. Shockingly, my tears flowed with minimal pain. Repeatedly telling him how much I loved him and wanted his happiness came so naturally. I was ready. I hated being ready, but I was. May he forever rest in peace and eternally in my heart. Our last MDMA session together is on videotape, although I don't know when I will have the strength to watch it. We decided to tape it so we would have it to enjoy together; seven to eight hours of pure love that read more naturally than the best written script for any Holly-wood movie.

The night that we decided to do this, concerned that there might be a cross reaction with the MDMA, we opted for Shane not to take his medications. We were told this was an unfounded fear, but being overly careful as we are, we didn't want to risk marrying a beautiful night. At approximately 7:20 PM we opted for a rectal administration to avoid any stomach upset. Shortly after this, the video begins. When I decide to watch it, it will show the two of us sitting on the couch, and you can visibly see Shane's physical pain. He had been off any pain killers for approximately 12 hours at this point, a great feat for him. He was shifting himself on the couch, trying to get comfortable. When he would get up to walk to the bathroom or kitchen for a drink, the pain was apparent, with much wobbling as he moved due to the tumor pushing on his spine. Still, there was a very jovial mood between the two of us. We joked that our "feature film" would be for all to see... Michelle Pfeiffer would play me, and we opted for Scott Baio, of all people, to play him! We were in a light-hearted mood as we waited for the effects of the MDMA to begin, sharing many smiles and hugs. But shadowing this mood was an evident tension of fear and mental pain. Within an hour we felt the effects. The thought of this brings the largest smile to my face in remembrance. It was an unbelievable night that I wish every government official could view. Every person who is sceptical of the legalization of MDMA to help people with cancer pain needs to view the miraculous events that began to unfold. As the effects of the MDMA were felt our mood really lightened. The love we have for each other became more evident and we moved physically closer to each other. We began talking, not of the cancer like we had hoped to do, but of our life together. We reassessed each other's faces, arms, legs, backs and souls. We thanked each other for the years of love we shared, holding each other's hand like it was the most precious of gems and looking into each other's eyes like the Heavens were unfolding before us. Beautiful, that's the only way to phrase it. But this is not the only wonderful thing that occurred that night.

Since our second MDMA session, Shane's discomfort had intensified, and with it the need to increase his pain medication. Since the multitudes of drugs had begun to surge through his system, he became a bit distant on more than an occasional basis. This was from the physical pain, the medications and a bit of fear thrown in. He had repeatedly expressed to me recently that he was terrified of my not being "ok" when he passed. We shared this fear equally. A wedge is the only way to describe recent distancing. During this third session, the wedge was removed and we felt nothing but closeness. The talking with each other flowed freely and non-stop, something that we hadn't had in a long time due to the pain he had been in and the closed up feeling that accompanied it. Gone—no more shell around him, and no more treading lightly on my part—just closeness and communication.

A miracle of pain relief

Shane's health had deteriorated drastically, as I said. Walking had become a chore for him. Sitting comfortably was a thing of the past. This video of our session shows what we deem a miracle. In the first two hours, Shane is clearly physically uncomfortable. That diminishes as time passes until suddenly he is pain-free. I'm not talking the mental/emotional pain that we knew would be gone; physically he had zero pain. We didn't expect this at all. He would be up and walking around with no wobble, no holding his back, and no wincing as pain hit. He even "hammed it up" for the camera as he virtually jogged towards the kitchen, leaning into the lens of the camcorder telling the world that he didn't hurt. No amount of morphine had been able to accomplish this and he had been living for a long time hurting to a harsh degree. I can't even begin to express our happiness at this. This night allowed him one night of normalcy that

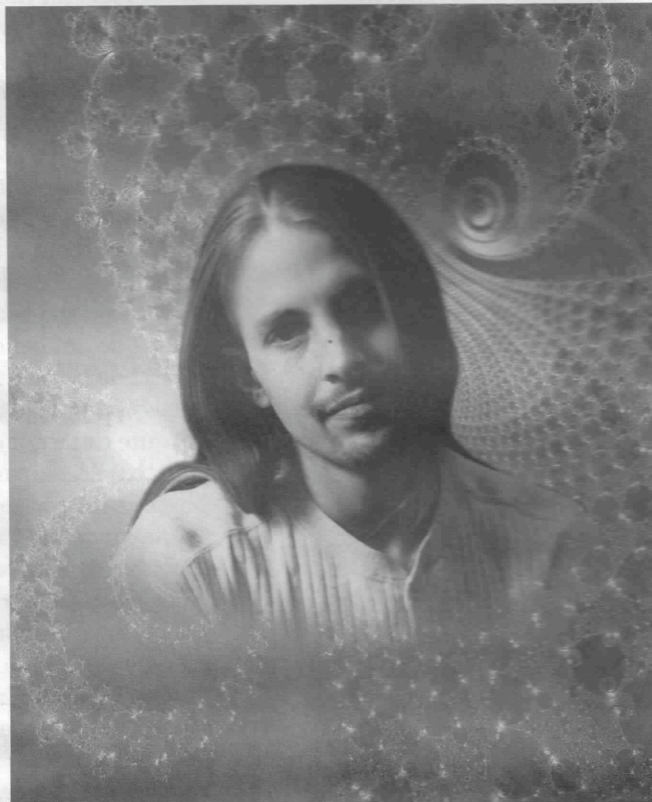
neither of us had felt in a long time. Tears come to my eyes as I write that because I had watched this strong man crumble physically over the past months and suddenly it was a step back in time for us. The cancer was gone, the pain... de-

stroyed. We questioned this for a few days after the session, but, "Why ask why?"

We enjoyed approximately 5-6 hours free of physical and mental pain. We joked, we loved fully, we talked like we hadn't seen each other in years and had much catching up to do. We would suddenly stop talking just to look at each other and feel... cancer free. We had attempted to make this a session about the cancer, and sought to videotape a learning experience for not

only us, but for everyone that we would honor by allowing them to view our night together on this tape. But how can you address a disease that felt eradicated? MDMA allowed us that night to do what our oncologist hadn't been able to do. To kill the disease entirely... if only for a night.

Eventually we allowed the tape to stop and as the drug wore off we opted for privacy and intimacy that we would rather not share with anyone on video. We thought it may be our last night of it. Normally a private person, I'm not afraid to share that while we had gone almost a year with no physical intimacy due to pain and medications... we were almost able to achieve it that night. More than physical love, what the camera missed was the



Shane 1972-1999

emotional and mental love that we were able to achieve with a bit of chemical assistance. Mere words cannot describe the warmth in my heart as I write about this. Cancer took my soul-mate from me physically for the remainder of my life. Cancer robbed us mentally and emotionally. We were able to fight back and "kill" the cancer not only for the last night we took MDMA together, but for the next five weeks that followed before Shane's passing last week. I have no doubt that this wouldn't be the statement I would be making if it were not for the MDMA sessions that we shared over the past three years. Some people swear by it as a "recreational" drug... we wouldn't know about that. It has only been

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used as a tool for us, as one would use a hammer to aid in building a house. It helped us build our life despite the odds we faced.

Since Shane's passing, I have not yet broken down. I can't assure that this won't happen but I was able to accept his physical absence hours after it happened. I have cried semi-openly, but am able to do so without pain. This is not saying I don't miss him. I can never express the emptiness I feel by not having him by my side. I have had emotional stress and physical stress such as drastic weight loss and lack of sleep. But accompanying this emptiness is a fulfilling feeling that I also cannot express.

Shane's service was on October 7th and I woke up that morning with a smile. I felt that morning as if it were not the finale of the life of my soul-mate, but as if it were our wedding day. I made it through the entire service with no tears and a genuine smile on my face as we gazed again into each others eyes for an hour of pure love. The only unfortunate thing of that was one of us was in a photo and one of us was a living breathing soul. That doesn't matter. He lives on in my heart and mind as if he is not gone.

The only downfall of these sessions: Shane's family is not happy with me for I am not playing the part of a desolate grieving widow. I didn't become a blubbering mess at the service as a large percentage of people did. I smiled, I laughed and I loved. This would not have happened if it were not for the exploration we did over

the past three years. I'm the lucky one and unless they experience what we had. Our physical relationship was cut violently short, but our spiritual relationship had been solidified beyond imagination. Our acceptance soared over the past three years, something that they do not understand. I feel for them that they were not able to share this with him, for if that were the case, then they also would be "ok."

While my heart goes out to anyone who is facing what we have dealt with over the past years since Shane's diagnosis, I would like nothing more than to hold each and every one of them close and tell them that there is hope and acceptance out there. I wish I could say I believe a cure for cancer is in the near future, but I would be lying. I do not believe this, unfortunately. What I do believe fully and have seen and lived first hand is that while MDMA will not cure cancer, it can cure the emotional pain that accompanies it if used correctly. This entire fight makes me cry more than Shane's passing. I am appalled that it is not available to those who need it.

I ask of those reading this to please, pass along information about MDMA therapy research to those facing a terminal illness. The more of us who fight for the cause, the better the chance that recognition will surface. There are wonderful people out there who are fighting for those of us who need/needed it, but they cannot do it alone. No-one should have to face the road Shane and I were heading down before we were made aware of MDMA. In the same token, everyone facing terminal cancer should have the feelings of acceptance brought on by MDMA made available to them when it is so desperately needed.

I would like to thank everyone out there who has taken the time to read about our situation and has wished us well. I can laughingly say "All's well that ends well." I thank MAPS for allowing me to tell our experience. I hope that it will make someone ponder options that could be made available and in essence, I am immortalizing Shane and our life together. My warmest thoughts and love go out to all... please make the best of life while you can.

Shane

MAPS Annual Report

Fiscal Year 98-99, June 1, 1998 – May 31, 1999

Rick Doblin

Fiscal Year June 1, 1998 — May 31, 1999 (FY 98-99) was another year of significant accomplishments. More than twice as much money was devoted to educational projects than to research projects, due in part to continued struggles to obtain permission for research. Staff time was more evenly divided between educational and research efforts, primarily because working to resolve and overcome bureaucratic obstacles to research requires more time and effort than money.

MAPS' efforts on behalf of research bore fruit this summer—after the close of MAPS' FY 98-99—with three FDA decisions which we reported in the last *Bulletin* (Vol. IX No. 3). First, the FDA approved MAPS' application to have marijuana designated an Orphan Drug for AIDS wasting. Second, the FDA approved Dr. Ethan Russo's MAPS-supported marijuana/migraine protocol. Finally, the FDA decided to permit Dr. Charles Grob to move forward with a MAPS-supported study of MDMA in cancer patients, with the exact protocol design still to be negotiated.

Financially, total expenditures of \$280,194 in MAPS' FY 98-99 were essentially the same as the \$288,548 spent in FY 97-98, permitting MAPS to continue to support a wide variety of projects. Income was substantially greater in FY 98-99, rising to \$308,743 from \$227,637, primarily due to an increase in large grants restricted to specific projects. MAPS' membership still continues to grow gradually and reached 1850 with our target of 2500 members still to be obtained.

MAPS' net assets were \$351,701 as of May 31, 1999. Of this amount, \$80,000 is restricted to specific research and educational projects. These sums need to be subtracted from net assets when considering MAPS' unrestricted funds available for new projects or organizational expenses.

MAPS' goal as a non-profit organization is not to increase its net assets, but to advance its mission. Nevertheless, having some net assets gives MAPS the ability to commit to support high-priority projects and gives a measure of stability in the face of fluctuating contributions from its membership.

As in previous years, MAPS' statement of income and expenses is published in the *Bulletin* along with a detailed explanation of the individual expense items. In this way, MAPS members can review exactly how their donations were allocated and what expenses were incurred. This report is an invitation for dialogue; MAPS members are encouraged to review it and share with the staff any comments, suggestions or questions that they would like to offer. MAPS will continue to