

Speaking the silence: **MDMA** in a couple dealing with cancer

What follows are personal accounts of two MDMA sessions shared by a man with terminal cancer (age 25) and his girlfriend (age 28). It's anecdotal reports such as these that demonstrate the importance of initiating clinical trials into this use of MDMA. The MAPS-supported protocol to study the use of MDMA in the treatment of pain and distress in terminal cancer patients was submitted to the FDA in November 1997 by Dr. Charles Grob and Russell Poland, Ph.D., Harbor-UCLA Medical Center.

Sue's account

To summarize my life with a "terminal" cancer patient, I would use the term heart-wrenching. My boyfriend, Shane, was diagnosed in March of 1995 with renal cell cancer. Within three days of diagnosis, they took him in for removal of his right kidney, only to discover that there were innumerable nodules that had already spread to his lungs. We were only casually dating then, but as time wore on, I fell in love with him.

A month after his surgery, they began chemotherapy. Seven different chemo drugs rushed through his body for hours on end. Chemo is the worst *hell* ever created, and Shane would endure one week of every month for the next year in this hell. During his hospitalizations, his personality would completely change for the worse. Pushing me as far away as he possibly could, he made me endure emotionally the suffering that he was also going through. Much to his dismay, I wasn't easily dissuaded. Love does crazy things to your mind.

Chemo

During the final month of the chemotherapy, Shane's oncologist decided that it wasn't of any help, and gave him the option of not doing it, for which we were both grateful. I cannot emphasize enough the pain we were *both* going through with this. His was physical, and mine was mental. He would completely shut me out, and wouldn't talk of his condition with me. It hurt being unable to talk to the man I loved, and I learned to push his condition out of my mind.

After the chemotherapy, we discovered an experimental therapy of *Interferon* and *Accutane*. His doctor decided that he was a good candidate, and we began treatment. This involved taking pills daily that caused him to have to avoid going out in the sun, and shots that made him sick nightly. The pushing away began again. Shane went through terrible mood swings that intensely tested our relationship, and we almost didn't make it through. I kept asking myself "Is this *really* worth it?" During this entire time, we didn't discuss the cancer. The only time it was brought up was after he came home from a checkup and informed me that the nodules in his lungs were growing. I broke down, once

again asking myself "Why am I doing this?"

He hasn't been on any treatment in about nine months, and since then, a new tumor has shown up. This one is where his kidney was removed, and all they can do is monitor him at this point. Our entire relationship has revolved around arguments and stress. I've always believed that the cancer played a big part in that, but never knew for sure... until recently.

A friend brings up the subject

A good friend of mine had been there for me through alot of this, and suggested that maybe the stress in the relationship had to do with his condition. But Shane would always deny that it bothered him. So I was led to believe that it was just poor compatibility. This friend of mine and I began talking of MDMA. He sent me literature; we talked of the potential benefits to "end-stage cancer patients." I was very reluctant to try something I had never heard of, but kept an open mind. The more questions I would ask, the more I would become curious as to whether it would benefit us. Finally, after months of asking every possible question about it, I asked my friend if he thought we would benefit from MDMA. He replied that it would possibly open us up to being able to talk about the issues we were avoiding. He never once pushed Shane and me in any way, shape or form, only guided us into what would be the best thing we have ever done together for our relationship. I agreed to try MDMA and received more information on how to achieve optimal results. When the evening came to have the experience, we cleared our schedules and minds and began what would be the rest of our lives together.

First session

With supplies on hand and a bit of nervousness, we took the recommended dosage of the MDMA (approximately 125 mg) and sat on the couch and waited. The lights were dimmed and we had soft music in the background. I was in a terribly good mood to begin with, and wasn't sure if I was feeling anything. But when the MDMA did begin to affect us, Shane and I moved closer to each other, and just held each other. It was a closeness I hadn't felt in a long time with him. As time wore on, we grew physically closer, and felt a need to touch.

It was in no way sexual, it was almost like a desire to be inside of each other. We talked of many things at this time, work issues, problems with neighbors... different things in our lives. I began to cry for some reason when I would look at him, and he knew what was on my mind. I wasn't ready to talk about such a painful thing, but I truly *did* want to see if it was possible to, like I had been told. The cancer talk had finally come, and we headed into it full speed.

The talk

I finally got the answer I had been seeking for over two years. With the most love I have ever felt, Shane told me that his reasoning behind pushing me as he has is indeed due to his condition. He never wanted for me to get involved with him in the first place, because I will be unable to keep him. ("Push her away, and when she loses me to this, it won't kill her inside...") He told that hurting me is his only fear. Shane had told me this before, but I would always block it out. Once again, "out of sight, out of mind."

But this was different. I *felt* what he was saying, and the tender look in his eyes told me that he would always be there with me. For the first time since this ordeal began, I finally believed that he wouldn't leave me on his own free will, and that his only fear was leaving me, not leaving life in general. He was raised not to fear death, and he isn't afraid to die. But knowing the impact that his death will have on me, it causes him to push me away and make me feel anger towards him. I found myself crying as he was telling me all of this, but for the first time, there was no pain. Just understanding of the feelings and emotions that he felt. Crying has always been emotionally and physically painful; this night, the tears flowed, and I could only feel more and more love towards him. I told him how I feared him leaving and wanted so badly for him not to ever go. He would just look down at me and caress my face, assuring me that he will always be inside of me, and will always be watching over me. It didn't hurt to hear this; if there is ever truly a time to feel your heart smile, I was there at that time. These were things that I had heard before, from both him or his mother, but this night, they finally made sense. I could listen to him without pain, as he was able to do with me. A subject that was previously taboo due to its painful nature was finally confronted with the ease and openness we needed. I had wanted for so long to talk about his cancer with him, but one of us would always get upset (me) or on the defense (him).

Aftereffects

Since doing this together, Shane and I have a whole new perspective and appreciation on things. We have talked much more easily, and felt an openness and closeness that is new and beautiful to us. I can't express how wonderful it was having that talk with him that night. Facing death is about the most painful situation anyone will ever encounter, and with pain comes fear and anger. These two emotions cause many different blocks in communication that make things worse for all involved. Taking these barriers away opens the people involved to more open and caring communication—which is what we experienced. Nobody will be able to predict the length of our future together, but at least we now can face whatever we are dealt as a team. The frequency of hugs, kisses and "I love you's" as a result of this, the openness and understanding... these are things that we have implemented into our everyday time together.

In my opinion, the end result of our doing the MDMA together, is it will bring a peace to our lives together, and to the pending death of our relationship. We won't part with fear and pushing away to make it not hurt as badly. And the greatest benefit I have found is that if the cancer wins this battle, I won't look back on the man that I love and remember so much emotional pain. I will have fond memories of sharing. I'm not in any way insinuating that this is taking away the pain of losing him, but it has brought a closeness to the time we *are* able to share. As our situation progresses, I will admit, I would like to do this again with him. As of now, Shane is not fearing death, but that may change, and having him share his thoughts and fears with me is something from which we would both benefit greatly.

Shane's account

I am a 25 year old male who was diagnosed with renal cell cancer 2 1/2 years ago. I have had my right kidney removed but have numerous nodules spread throughout my lungs and a recently discovered mass where they removed my kidney. I feel great, although I tire rather easily. I have minor aches and pains but to look at me, I look perfectly healthy and normal.

I have been dating a wonderful 28 year old woman, who has stood by me through everything that I have gone through, for about the same amount of time. She's been through all of the misery of chemo and experimental treatments right beside me. Temperamental, but loving and taking care of me. She had refused to

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discuss the whole cancer issue, and would just drop the subject when I would bring it up. She had walked out of my hospital room on a few occasions when we received bad news from my oncologist. I thought that she didn't care.

Our relationship since we met has been great, although strained, and occasional arguments have forced a distance between the two of us that have made it impossible to become truly close. Many times we discussed whether we would ever be truly happy together, whether or not it was truly worth it, this misery I was putting her through.

A friend of hers who was informed of our situation told us about the use of MDMA in therapy sessions and fully explained to us both how it was used in this setting and his own personal experiences with the drug. He also sent us an issue of MAPS that gave me further knowledge and increased our interest in seeking the benefits of MDMA. *Could it help us?*

The MDMA session

A quantity of MDMA was obtained and we made plans together to make time to sit and talk about the problems that we could not seem to get past. Each of us took the recommended dose of MDMA and we sat together on the couch with the radio playing softly and the lights dimmed. We started off talking of inane subjects, giving the drug time to take effect.

After about a half hour we both noticed an extreme calm and relaxation wash over us. We continued to discuss unimportant things but eventually the subject turned to the condition of my health and our relationship. We were both able to talk about the cancer and how it affected us without the pain that was usually associated with such discussions. I discovered that she had been scared to get close to me for fear of losing me. This had caused her to unconsciously push me away. I also was able to tell her that I had tried to push her away to save her the pain of my death if I could not beat this. I am not scared of dying and I consider the cancer as another obstacle in my life to overcome. What it is that bothers me is that I can not control the effect that my health and death has on other people.

We were both able to discuss these things in a totally relaxed and peaceful state without any pain or anxiousness. There were a lot of tears on both ends as we talked about how it will be dealt *with when and if I die* from this, but there was no pain. I think I finally made her *know that it hurt me more than anything* to tear her apart by having this disease, and now I understand her moods and lack of closeness.

These are things that we haven't been able to tell each other before. Either I get defensive and want to hide things from her to protect her, or she breaks down from the pain. This is our first real time ever confronting my cancer. I still hate having to put her through this, but it helps having finally talked about it after all of this time. It was to the point where I would hide my doctor appointments from her, and not tell her the whole truth of how they went when I would go, just so she wouldn't have to hurt any more. This won't happen any more, we are finally in this together.

Afterwards

Since that wonderful evening, both of us have enjoyed a new closeness that we never knew before. Cancer almost killed a terrific relationship, due to lack of communication. It caused us both to put barriers around ourselves to prevent pain and hurting each other. This has changed since we've been able to openly talk about it. As I said, we are much closer. The pain I feel of hurting her will never go away, but it's great to finally be able to feel each others' thoughts and emotions. I now know that her "moods" aren't because of hatred or anger towards me, they are anger and fear towards my condition. And now I can deal with them by making the time that we do have together all the better.

As my condition worsens, I would love to have the opportunity to experience this again so we can openly deal with it. One session changed our relationship for the better, it brought a new found closeness. I know that there will be strain on our relationship, and more pain in how we both feel as my time gets closer. I would love to be able to just sit and talk about this with her, but doing the MDMA helped us to discuss this without the pain so that we could deal with it more openly when *not* under the influence of it. As I said, my dying doesn't hurt me, I do not fear it. I am scared to death of killing her by dying.

Yes, in my opinion, this is about the most wonderful way I could have ever been able to save the rest of our lives together. I don't know when I will lose my fight, but at least now I have someone that is fighting with me, not running the other way out of fear. •

A second MDMA session:

Sue speaks

I wrote before on the experience of taking MDMA with my boyfriend who is a terminal cancer patient, and what we feel the experience brought to us. Our first session was one of eye-



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opening proportions and brought up emotions and feelings that were previously foreign to us because we had closed up to each other as a direct result of the cancer. Since our first experience with MDMA, we have adapted many of the feelings we learned into our everyday lives, and haven't reverted back into the protective shells that we had around us. It taught us to open up to the feelings we had towards each other and to live each day fully and together, not fighting each other as we had been doing out of the fear of our pending loss of each other. Our time together has been fairly wonderful, minus a few minor arguments that are normal in everyday life.

Since our friend had sent us four doses to use, we picked another night to do MDMA again. We were expecting this time to be somewhat similar to the first experience. I talked in detail to a therapist knowledgeable about MDMA before doing it because I experienced a lot of stomach upset and vomited at the "coming down" of the first experience. He suggested putting it in capsules to ingest and told me to expect it to hit us at a different time interval.

We once again picked a night when there were no children around and got our "setting" perfect, thinking that it would be like the first time. I was worried about how Shane had so many things on his mind the first time... but our knowledgeable friend assured me that we would be all right. Without the nervousness that I had felt the first time (*I thought I knew what was going to hit us...*) we took the capsules and waited. It was almost 45 minutes before we noticed any effect of the drug. I was slightly concerned about this, but not enough to call either of my "consultants."

Powerful but different

Once it hit, it started off with the same feelings as before, the need to be close to each other. We sat on the couch and just touched each other and felt the overpowering feeling of love. But then things changed. We both felt the need to move and decided to go for a walk. We ended up on the field at the end of our street and lay on the grass and watched the stars, in each others arms. Not talking. It was like we had no need to communicate, and that we already knew what the other felt inside. Before taking the MDMA, I had told the therapist and my friend about some upcoming decisions that Shane and I had to make concerning some things that Shane's oncologist had posed to us. These were things that I wanted to discuss

during the MDMA session, while we were able to talk so freely. But for some reason, lying there, I felt no need. It was like I already knew the answers in his mind, as he did mine. We lay there, just holding each other, and I honestly felt like I was inside of him and could feel his emotions.

The issue

Shane's doctor had told us that there was a big possibility that a tumor was growing where they had removed his kidney, and that she thought the cancer had spread. She talked to us about the possibility of trying chemotherapy. I was afraid of telling Shane what I felt about it, for fear of altering his decisions on it. The decision is ultimately his, and I didn't want him to do as I wanted instead of following his own mind. These are some of the things that I wanted to talk to him about, but I couldn't bring myself to start the conversation. And it's not like I didn't think of it, it was right there in my mind. But when I would think of approaching the subject, I would then have this voice inside of me telling me, "No, don't bring it up, just lay here and feel this way, feel this good and this close."

Realization

I now realize in my heart, that no matter what we do, nothing is going to change the fact that he is going to die from cancer. Telling him that I want to keep him around no matter what the cost is just going to reduce the quality of life that we have left. I'm going to enjoy what we have. Shane is adamant that he doesn't want to go through any more treatments unless the doctors can tell him that things will get better, and my telling him that I want him to be with me forever would cause him to go through the hell of chemo just for me. I knew this all along, but couldn't admit it to myself. It's like that night, just lying there with him showed me what we *do* have ahead of us. Serenity and happiness is ours for the taking if we work together, and I think that deep in my mind, I knew this. I knew that life isn't about quantity but quality, and if I had been able to tell him the things on my mind that night, it would have reduced the quality left in order to give us a three percent chance at a bit more quantity. I am far from a quiet person, but that night, I couldn't for the life of me bring myself to tell him what I felt about treatments, and my own selfish desire to keep him forever.

Disappointment

We lay there for about an hour, just watching the stars, then got up and slowly

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walked down the path of the field. We were just holding hands and walking at a snail's pace, but feeling closer than ever, closer than the previous time doing MDMA. But what we both found odd is that we never, throughout the course of the night, felt like talking or sharing. Everything we experienced was internal. It was almost like we were inside of each other, knowing what the other felt. I honestly felt that this whole journey was a "flop" because we confronted *nothing* concerning his cancer that night. But after giving it much thought, yeah, the first time it was great that we *were* able to confront the main problem we had in our relationship—my fear of losing him. But this time brought us even closer.

Knowing what the other felt

We weren't able to share with words, but it went so much deeper than that this time. It was like every time I would think of something I wanted to talk about, I wouldn't bring it up because past discussions we have had gave me the answers and I already knew. They may have come late, but the answers came to me that night. We have talked about it since that night, and it's weird, because the way I was feeling is the same as Shane was. Just like the first experience. We both wanted to confront so much the first night and we did. This night was just about being there inside of each other. Shane told me that he also had issues he wanted to talk about, but he knew what I would say. We both felt like we could read each others minds and souls.

I told the therapist afterwards that I felt like I had let him down because me and Shane's story should be an example of MDMA as used in a cancer situation, and that we resolved nothing that night except feeling like we were inside of each other. He told me that we may have made more ground than I thought. I didn't believe him that next day, but now is a totally different story. Granted, we were able to get more out in the open and discuss more that first night, but the second time in essence was actually better, because our subconscious told us that we already had our answers and were dealing with things better than we had thought. I am still in a serious case of denial about losing the man that I love, but I'm able to deal with it so much better. I will never get over the pain I feel inside when I think of the day that the cancer wins, but I know that Shane and I *are* on the same level now. Having the opportunity to once again express my thoughts and feelings about the cancer, and instead just laying there enjoying what we *do* have, tells me that I'm stronger than I thought. We've confronted everything about it. There is nothing left except to ensure that the quality of life we have left together is the best we can possibly make it. If it weren't for the first night doing the MDMA, we wouldn't be where we are right now—the second night sealed what the first night had prepared us for.

Comparing the two sessions

Shane and I no longer feel anger towards each other. We *still* fall back on our first MDMA session together when one of us feels like we are closing down emotionally on the other. If you wanted my honest interpretation of the second MDMA experience, it is that we reached a level where it's a moot point discussing the cancer, and that we *are* indeed dealing with it to the best of our abilities. The pain is there, but I now feel that I can open up to Shane, and he no longer feels that he has to hide from me about it

anymore. I was finally able to open up to him and let him know how I feel, and he respects my fears. The second night taught us that we already know what the other feels inside, and that we just need to do the best with what we have left.

We have hit a new plateau of our relationship, and love what we have together. If you were to ask either of us if we would be interested in doing the MDMA again, we would both say yes. It's not fair at all that my 25-year-old boyfriend may die before the turn of the century, but what MDMA has given him is something that a lot of people will *never* find. It's almost like we can take one night together, and turn it into a couple of years worth of closeness.

Is it wrong?

I know it's wrong to say that we are trying to live our full life together in a hurry, but that's kind of what it is. We took one night to open up completely to each other, and solve problems that would have killed the rest of our life together. The second night, we felt so close and so in tune, it was like time stood still and we lay there for an eternity and just felt like we were inside of each other. Our eternity is going to be cut short by cancer, this we know... we should be able to feel as if we *are* living our lives together, growing old together, making the most of what we *do* have. Maybe we *are* making our life together in one or two nights, but that is more than I can say for many people who essentially *have* a lifetime to enjoy each other. We don't, and we know this. It's as if time stood still that night and gave us a lifetime worth of feeling. A lifetime worth of love.

Summary

Do I regret taking an "illegal drug" these two nights? I consider myself to be a law-abiding citizen who has respect for the law. What I *do* regret is that we *did* have to break the law to be able to share with each other. To be able to have what others *can* take a lifetime to achieve. We don't have that proverbial lifetime together... guaranteed. But by having "broken the law" and done MDMA together, we have the chance to bring a lifetime of love and understanding into our short time together. Now, tell me, which part of this should be illegal... •

Letters can be sent to Sue and Shane care of MAPS.