

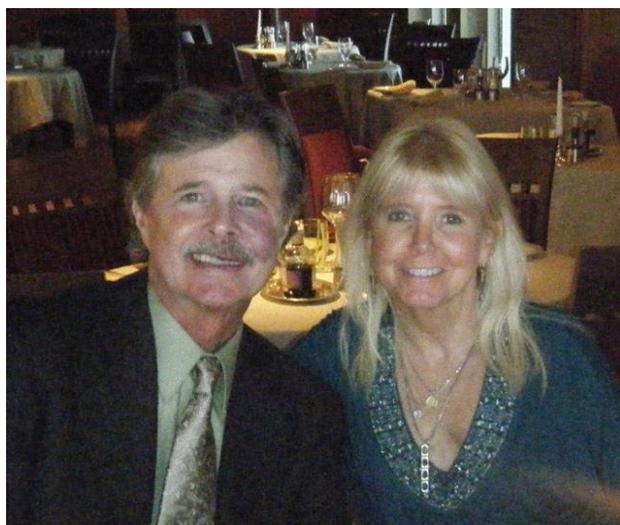
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Loved Ones GRASPing for Help: An Interview with Denise and Gary Cullen

William L. White

Introduction

In the latest year for which data is available, more than 37,000 people died of drug overdoses and other drug-related causes in the United States, and another 25,440 deaths were attributed to alcohol (Center for Disease Control, 2012). These numbers reveal only a glimmer of the devastation and losses that alcohol and other drug addictions wreak on families and friends. Until recently, few mutual support resources existed for those who had lost loved ones from addiction. Today, groups like Grief Recovery After a Substance Passing (GRASP) are filling that void. The history of GRASP begins with Pat and Russ Wittberger, whose young daughter Jennifer died of a heroin overdose. (Pat and Russ' story is presented in the book [When a Child Dies from Drugs](#)). Pat and Russ founded GRASP to create a platform of mutual support for people who had lost loved ones in similar circumstances. Leadership of GRASP later passed to Denise and Gary Cullen, who lost their son Jeff in 2008.



I had the opportunity in August 2013 to interview Denise and Gary Cullen about the history and future of GRASP. Please join us in this conversation.

Bill White: Denise and Gary Cullen, thank you for your willingness to take a Sunday afternoon to talk with me. Let me start with a really basic question: What is GRASP?

Denise Cullen: GRASP is Grief Recovery After a Substance Passing. It was started by Pat and Russ Wittberger to provide a grieving outlet for people who have lost someone to addiction. We have both face-to-face meetings and online support and groups have recently been formed outside the United States. The Facebook closed GRASP group is used by people who don't have

a group close to them, as well as face-to-face group facilitators and members. GRASP groups currently meet in thirty states, and we are for loved ones, not just for parents. We're for anyone who's lost someone they love to a substance use disorder. The deaths usually result from overdose, but sometimes it's a health issue or a suicide related to their addiction.

Bill White: Could you share the story of your personal involvement in GRASP?

Denise Cullen: At the time of our son Jeff's death in 2008, there was really nothing in our area that addressed this kind of loss. We just don't fit in with regular grieving groups. There's so much stigma and shame attached to drug-related deaths; it just doesn't work to go to a generic grief group. There were no GRASP groups in California at the time, but being a social worker, I felt that it would be pretty easy for me to just start my own with the help of Pat and Russ Wittberger. So, I started my own chapter, and we had seventeen people on our first night. Shortly after that, the Wittbergers decided they needed to move out of their leadership roles. Gary and I ended up taking over leadership to assure that GRASP would continue. This happened January 1, 2010. The Facebook group began in March 2010. We were already in the process of filing for non-profit status for Broken No More, which is the activism arm of GRASP.

Bill White: Gary, I'm wondering if you could add any additional details on the early history of GRASP.

Gary Cullen: Well, my function within Broken No More and GRASP is mostly managing the marketing and financial duties. When Pat and Russ first put up the GRASP website, it was never linked to Google or other search engines, so very few people could find it. So when we took it over, the first thing we did was completely build a new website and links to it. That's where much of our growth has come from, along with a lot of word of mouth communication.

Bill White: What is the relationship between GRASP and Broken No More?

Gary Cullen: GRASP is not a stand-alone 501c3. It is part of Broken No More. Broken No More is the organization through which we do advocacy and GRASP is for grief support. We try to be as transparent as possible that we are the owners of both sites; however, we do keep them separate because they have very different functions. There are people in GRASP who may not agree with the advocacy positions taken on the Broken No More site, so we do try to carefully separate these functions. Broken No More's primary goals are to provide support and education for those who have lost a loved one through substance misuse and addiction and to provide public health advocacy to reform the criminalizing and stigmatizing drug policies in the United States that create barriers to effective addiction treatment. The support we offer is with GRASP, a nationwide network of bereavement support groups for those who have lost a loved one due to drug overdose.

Our efforts so far have mostly focused on staying on top of the exploding growth of the need for GRASP groups around the country. We are working hard to have our Broken No More advocacy efforts catch up with the support and healing efforts of GRASP. Denise has led our advocacy efforts by working to affect legislation in California and other states, and by doing media outreach to educate the public, including many interviews, articles, speaking engagements, and an appearance on Bill O'Reilly's television show. Barry Lessin, our Clinical

Director, sees Broken No More and GRASP eventually becoming part of the larger national movement in policy change. And Bill, we recognize that your work in giving validity and a voice to the growing recovery movement is vital to those efforts, and we very much appreciate your including Broken No More as a small part of your efforts.

Bill White: What kind of support does GRASP offer?

Denise Cullen: We have close to 50 groups in 30 states that meet once or twice a month. We have more requests to start chapters in new areas all the time. These are peer support groups, always facilitated by someone who has suffered this loss. The online/Facebook support group is an ongoing, closed group now. We changed that late last year. If you go to the site today, somebody will post a bit of their story such as “It’s my son’s birthday, he died in 2010” and then, many, many people will respond supportively and maybe tell a little of their story. Or people will ask questions: How do you cope with this? How do you answer the question from a new friend or acquaintance who wants to know how many children you have? I can’t look at my child’s pictures—how do you all deal with that? I need to go through his clothes but I just can’t, what do I do? And then there are some advocacy things that I’ll post that we’re working on or that we know someone is working on—such things as overdose prevention programs or harm reduction initiatives. Nobody who has lost a child is going to argue with the need for such programs.

Bill White: You mentioned towards the end of last year that you moved towards a closed group. Does that mean that people must sign up to become members of that closed online discussion?

Denise Cullen: Yes, we really didn’t want to do that because we feel really strongly on both of our sites that stigma is not going to be reduced by keeping our experience private, but a lot of people have issues, such as concerns about access to their grandkids, or just wanting their most intimate thoughts kept among those who truly understand. They don’t feel free to share all their feelings if everybody in the world can read them. We finally caved in and moved to a closed format. We still have an open group that we have more than 1,800 people on, but the closed group remains an option for people and has the most activity.

Gary Cullen: We actually have a lady—one of our GRASP people—who about three years ago started a list of names of people who had died from drugs within our group. It’s a list of what we call ‘Casualties of the War on Drugs’. It includes the name, age at death, date of birth, and date of death. We post the list on Facebook and it’s also posted on the Broken No More website. We also have this list on a vinyl banner that we take to events. It is a memorial wall of the loved ones lost. One of our members, Margaret Alexander, who’s like an ‘ambassador,’ solicits stories of loss from people and posts their faces and stories on our websites. She makes up banners with our logos and these photographs. She is working on the 3rd banner. These are powerful images. People reach us from around the country requesting that their loved one’s name or face be added.

Bill White: How many names are now on that list?

Denise Cullen: There are 391 on the names banner, with close to 50 more waiting for the next printing. These names come to GRASP as requests. People want their loved ones remembered. We don't use names from any other source.

Bill White: What are some of the most beneficial aspects of participation in GRASP?

Denise Cullen: Well, definitely being in a safe place where the person that you're talking to completely understands what you've been through—not just the death but often the years of struggle that preceded it. In our case, Jeff battled for twelve years with periods of recovery followed by relapse and on and on. We were always waiting for the shoe to drop. It was a roller coaster from hell, and it's very common that many of our people have been through that before their loved one died. So many rehabs, so much effort, and still their loved one died. It's a unique type of stigmatized loss that is best helped by others who have been through it. So many people have said that GRASP saved their life. When you lose a child, you don't want to go on. It's that devastating.

Bill White: Gary, anything that you would add to that?

Gary Cullen: It's like Denise said. So many people have said that GRASP literally saved their life and that they wouldn't have been able to make it without GRASP. It's just that connection of like people, people that support each other. And GRASP is always evolving. We have a certain core group of people who have been with us from the beginning and they are always there to welcome new people, to help others, but unfortunately there's a constant new influx of people that are coming in to the site who've just lost their son or daughter, sister, brother, spouse, or friend. When they post, within a few hours, there will be 25-30 comments from others who have lived through this.

Denise Cullen: We all know that when you help someone else, it helps you. That's part of the healing process within GRASP. It empowers people in the process of their grief when they're able to reach out to someone else. And that help extends to the advocacy work with GRASP people moving over to Broken No More to become involved in the movement to change the policies we have. We have to prevent this epidemic from continuing, and we have to have sentencing reform. Working to get these changes is healing too. And people come to that point when they're ready.

Bill White: What do you think local communities least understand about alcohol and other drug problems and their consequences?

Denise Cullen: Unless it's affected you, people still don't understand that addiction is a disease and not a moral failing or a character flaw and that people can't just snap out of it. It's not a matter of will once you become addicted. We all experiment as young people and who knows who's going to be the one who doesn't get to move through it and go on with their life, as most people do, and who is going to be part of that small percentage of people who become severely addicted. And many suffer from other disorders as well like Jeff, who had a co-occurring

disorder that prevented him from being able to maintain lengthy periods of sobriety. Too many people still think those who are addicted are just bad people who need punishment and incarceration. Well, that's not the answer at all.

Bill White: You referenced earlier people experiencing their loved ones going through rehab after rehab. I'm wondering if you have thoughts about the current design of addiction treatment and ways it might have been improved that could have made a difference for Jeff and others like him.

Denise Cullen: I definitely do. I'm for whatever works for people. AA is the standard, but it did not work for our son. That's the only option Jeff was given in treatment, though I know that is starting to change, but not fast enough. Jeff died the day he signed up for six months of court-ordered treatment. He was 27 years old and they were finally going to allow him to be on medication if that was what came out of the assessment. He'd been diagnosed with attention deficit disorder when he was very, very young and he had the impulsivity and the judgment issues common in ADD. Most rehabs, at least the one's Jeff was in, were in my view money-driven. They want their money and they do a little bit of counseling, but it's not enough. And this forced AA is a real problem for me, too. Jeff was always willing to go, but he didn't believe in a higher power and so he had a real problem with it and it didn't help him. It did more damage. He told me that sitting in those meetings was extremely difficult for him. If he was in a treatment facility, hearing those stories triggered his cravings and interfered with his treatment. If he was court ordered to go, or the few times he tried to go on his own, he couldn't wait to get out of the meeting so he could use. A psychiatrist we worked with said that is quite common. Jeff spent his fifteenth birthday in his first adolescent inpatient treatment center and it was solely 12-step based. They even convinced us to allow Jeff to smoke cigarettes as a reward/incentive tool in treatment! Of the nine programs he was in—all entered willingly—every single one was 12-step focused.

Bill White: Gary, any additional thoughts on what we're talking about?

Gary Cullen: Denise and I went to a town hall meeting about six weeks ago that was put on here in Orange County. It consisted of two main speakers and then a panel with four people including Denise and then a question and answer session about addiction. The problem with the meeting was that the two main speakers were both recovering addicts who talked primarily about their drug use years. I just think the whole thing is still really, really screwed up. The people out there just don't understand what addiction really is. You would not take a child that had cancer and treat them the way we treat addicts in this country.

Bill White: Gary and Denise, how do communities respond to the kind of losses that GRASP's members have experienced?

Gary Cullen: I think it varies greatly by community. Here in Orange County, they do their best to bury and hide it. They want to blame it on pill-pushers. They want to blame it on some doctor that wrote prescriptions. They don't seem to really want to address the real issue of addiction. It's very frustrating right here in our own little backyard because of the conservative nature of where we live. But I'm not sure any community as a whole grasps the whole issue very well.

Bill White: Denise, what are your thoughts?

Denise Cullen: The people that are affected at GRASP, they get it, but the community that has not been affected yet is not open to offering support. There is the blind belief that “This is never going to happen to my child.” We all once thought that. The stigma and shame are so pervasive.

Gary Cullen: Denise and her sister went to a Compassionate Friends meeting.

Denise Cullen: We did. When you walk in, they have an intake form that you have to sign that had a line to fill out the cause of death of your loved one. I was never ashamed of my son through his addiction, and when he died, I never lied about it and neither did Gary. We were very open. But I just didn’t feel like walking into a roomful of strangers and writing down the cause of my son’s death and neither did my sister, who was very close to Jeff. So we left that line blank and then we sat down. There were about 20 people in the room and the facilitator came over, kind of crouched down in front of us and asked again how Jeff had died. And finally, I said something like “Why do you need to know?” And she later kept saying “Well, let’s give the new people a chance to talk.” You don’t pressure people to talk like that. This was five months after Jeff died. After the meeting, the facilitator came over to me and apologized, and the woman who talked me into going to the meeting also apologized because it was just a very unpleasant experience. GRASP provides a forum of safety where everyone there shares such similar experiences. And there, we don’t have to face the unspoken judgment that this would not have happened if we had been good parents—if our children (or other loved one) was a good person.

Bill White: I’m very interested in your thoughts about what you think local communities can do to prevent drug-related deaths.

Denise Cullen: There’s so much. The panel Gary mentioned that I went to speak on was supposed to address prevention. All the potential speakers were asked in advance: “What would you say to young people to convince them not to experiment with drugs?” And so I answered the question honestly. I said, “You can’t. Adolescent development includes curiosity and experimentation. Kids do risky things and most survive and move on with their lives.” This issue was not addressed at all at the mini-conference. So my approach is one of harm reduction—to be as honest as you can with kids rather than “just say no” and use of scare tactics. They don’t believe us anymore and they don’t trust us anymore to share what they’re doing. That must change. Kids need a safety net. They need to know what to do if they try these things and things go wrong—simple things that are so important, like “Don’t ever do this alone. Don’t ever combine this with that if you’re going to use these things.” And it’s always prefaced with, “Of course, your brain is still developing. We don’t want you to use any drugs but if you do, keep these things always in mind.” And we need to teach people who take opiates for whatever reason, prescribed or illegally, to have naloxone and naloxone training for overdose prevention. We need Good Samaritan laws in every state that allow people to intervene when an overdose occurs without risk of arrest. Those are the main things I can think of.

Bill White: Let me ask a final question. What really is the best way for people to reach GRASP and Broken No More for information about face-to-face or online meetings or to get information or literature?

Gary Cullen: The websites are www.grasphelp.org and www.broken-no-more.org

Bill White: Denise and Gary, thank you for taking this time to share your experiences and to inform us about GRASP and Broken No More.

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