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From Private Grief to Public Advocacy: An Interview with Jim Contopulos

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Introduction

There are few experiences more devastating and isolating than losing a son or a daughter or brother or sister in an addiction-related death. For decades, the pain of these family members has been experienced in silence with only occasional breakthroughs in public consciousness of their existence (e.g. the late Senator George McGovern's publication of *Terry: My Daughter's Life and Death Struggle with Alcoholism*.) One of the things the new recovery advocacy movement in the United States has attempted to do is to mobilize these family members for mutual

support and public advocacy. In June of 2013, I had the opportunity to interview Jim Contopulos, one such family advocate about his loss and a film he has created to help change how this country views and responds to its addicted citizens. Please join us in this deeply moving discussion.

Bill White: Jim, first, thank you for agreeing to share your experiences in this interview. Could you begin by sharing the story behind the film, *Beautiful Boy .. More Than An Addict?*

Jim Contopulos: Absolutely, and thank you. The film is about my son Nick, who died on May 29th, 2010, at the age of 26. In the film, I take you on a walk as I look back and lament the loss of our beautiful boy. Nick began experimenting with drugs somewhere around the age of 13. Like so many, he started with alcohol and then on to marijuana. Soon, Nick became enamored with drugs and their affect on him. He once told me that he loved being high and wanted to try every drug that was out there. While I appreciated his honesty, I knew that the drugs available to him such as methamphetamines and heroin were

extremely potent and readily available. I was terrified and had absolutely no idea what to do or where to turn for help.

Looking back now, we estimate that Nick was in over 20 residential treatment programs and was admitted to our County's emergency mental health facility over 70 times. He had become addicted to drugs as well as someone who carried a mental health disorder of bi-polar with extreme anxiety. We call that a dual diagnosis or someone with a co-occurring disorder and we would soon find out that navigating our society's haphazard, fragmented "system of care", left Nick and those of us who loved Nick, despairing and without hope.

But Nick was more than an addict. He was my son and my beautiful boy. He was extremely bright and quick witted, with a love of friends, family and animals. The late Irish poet, John O'Donohue once said "All of us, even our ill, are much greater than our biographies". And so it was with Nick and with the many "other Nicks" who crowd our shadows. The title for the film came, in part, from David Sheff's remarkable book, *Beautiful Boy* which was his own desperate journey from following his son into the world of addiction and mental illness. Nick had read both this book and the one by David Sheff's son, and mentioned to me many times "Dad, you know, you and I could have written these books." How true that became.

Finding long term, affordable, quality, multi-dimensional, recovery and care grounded in evidenced based, "best" practices left Nick and those of us who loved him, with, in the words of Father Greg Boyle, "a fatal absence of hope". So many times, we witnessed Nick's courageous and honorable work of recovery only to relapse and experience the tears of self-loathing. For 13 years Nick experienced this as well as the stigmatization, loneliness and misunderstanding of his disease.

Towards the end, Nick would say to me, "Dad, I don't use heroin anymore to get high; I just use heroin to feel normal". And my heart would break. At the beginning, in a desire to feel "at peace" in his own head and skin, Nick chose to use drugs. What he didn't know, nor did any of us, is that he opened a door he

alone, could not close, no matter how hard he and we tried. While he made the choice to use drugs at the beginning, he never chose to become addicted. No one does.

Bill White: I'm assuming from what you said, Jim, that Nick experienced a variety of treatments over those years and exposure to various support groups. Is that correct?

Jim Contopoulos: Yes. At the age of 15 we placed Nick in his first of many, long term residential treatment centers. This was the beginning of many years of cycling 'in and out' of residential treatment centers throughout the country. In the beginning, we felt, perhaps, that we could "buy" recovery. We were desperate to save his life and have our son return to us. Like many desperate and 'well meaning' loved ones, we fell prey to what I call the 30/60/90-day false promises.

It took us and Nick, many years and many efforts to realize that recovery cannot be purchased. Many times, we witnessed Nick's hard work of recovery and recovery's reward of self-respect, only to experience the devastation of this relentless, chronic, terminal disease. Once we realized that "recovery could not be purchased" we continued to support Nick in his own efforts to find recovery at the many free recovery locations such as Salvation Army. In nearly all these recovery locations, the prevailing wisdom was that before the mental illness could be addressed, Nick had to be clean and sober for a significant period of time, which became increasingly difficult.

It is my understanding now that if one has a co-occurring disorder such as Nick's that the disorders need to be treated concurrently. That is a change that needs to continue. Without exception, Nick would begin the hard work of recovery without any help for his mental condition, and then relapse back to drugs and be kicked out to the street. I now know of facilities that we are beginning to see relapse as a symptom of the disease and are beginning to respond to relapse differently. I only wish that had occurred for Nick. In the end, the only place where Nick truly found relief from his mental

state was with heroin, which, in time, became his own “ball and chain”.

Bill White: Do you have a sense that addiction treatment helped but at the same time also failed Nick and your family?

Jim Contopulos: Absolutely. Because we loved him so much, and felt extremely desperate and hopeless for him and with him, we fell prey to our current “system of care”. I do believe there was help for Nick to begin recovery, but what lacking were quality help, support and structure to sustain his recovery. Nick participated in several short term cognitive behavioral therapy recovery programs, but was unable to sustain the recovery due to either the cost or the availability of the residential “bed”. Eventually, both our resources for Nick and the public resources were drained, as he would wait weeks for any available bed.

The irony of all of this, is that Nick was incarcerated a total of approximately 3 years between prison and jail. If only a small portion of the amount spent on incarcerating Nick, would have been spent on long term recovery, everyone, the taxpayer and Nick, would have been much better served. However, there was no long term “culture” of recovery that was available to Nick that would address both disorders. Despite this, Nick would begin the hard work of recovery again and again, and would sustain recovery for weeks or months and would love it.

He loved recovery, being in recovery meetings and its reward of self-respect. I know how odd that may sound since Nick died as a result of a relapse and a failed effort to “detox” himself. But it is true. What he and we came to realize and respect was the power of this disease to destroy both his life and those of us who loved him. In recovery, they call this illness a “cunning, powerful, and baffling disease” and both we and Nick experienced this reality many times.

Bill White: With your references to Nick’s heroin addiction, some of our readers will wonder if Nick had access to the major medications used to treat heroin addiction; methadone, buprenorphine, or naltrexone.

Jim Contopulos: Yes he did. Like many addicts, Nick cycled in and out of the criminal justice system. Because he, himself, had no resources, he asked for my help in paying for daily Methadone treatments so he wouldn’t relapse and be placed back into prison. With conditions, we did this for him at a cost of \$280 per month. During this time, Nick continued with his 12-step meetings and to live in a sober environment. In time, he was released from parole and felt extremely proud of this accomplishment.

Regretfully, rather than stay on Methadone and with the conditions we established, Nick chose to detox himself from Methadone. The State of California allows a Methadone facility to detox a client, regardless of the current dosage of Methadone, in as little as 15 days. Witnessing Nick’s detox from Methadone was horrific. I can’t help but think that we wouldn’t allow this type of inhumane treatment for an animal, much less somebody as vulnerable as Nick.

Some time after the work with Methadone, Nick went under the care of a doctor who subscribed Suboxone (buprenorphine) for his opiate addiction and Xanax for his anxiety. The Suboxone helped with the opiate cravings, but regretfully, the doctor supplied large amounts of Xanax and allowed Nick to oversee his own medication. It wasn’t long before Nick began to abuse the Xanax and had to go through a painful detox once again. He was an addict, a terrible addict and needed long term, structured care and oversight.

While he was being prescribed the medications which he desperately needed, there became a resentment and fear of Nick within the 12-step community because of the medications. This created a distance between Nick and those who felt that if you are using any type of mind-altering medications, then you are not truly considered sober. Finding the right conditions to administer these drugs is essential for long term success. Regretfully for Nick this was not the case.

Bill White: Jim, I’m wondering through your experience with Nick and your family, if you’ve

come to any conclusions that you could share with the “other Nicks” and their families.

Jim Contopulos: Despite the fact that, initially, we had no idea about addiction and miscalculated it’s power to destroy, we made many attempts to help Nick find his own recovery and stayed very close to him throughout his life, as difficult as that became. With that said, looking back, I believe that the very best thing we ever did for Nick was for my wife and I to find our own way into our own recovery.

Becoming involved with Nar-Anon, and with Celebrate Recovery for the two of us, oddly enough became the very best thing we could have done for Nick and, of course, for ourselves. We began to gain understanding of the disease and to change ourselves. We began to take the focus off of Nick and began to look deeply at ourselves, because addiction affects the entire family and we had become sick as well, desperately sick. This, in time, helped Nick to take on greater responsibility for his own recovery.

While I say there may be no “formula” for recovery, I do believe there are common “ingredients” that lead to a successful recovery, such as responsibility, honesty, transparency, humility, and community. Finding those communities of long-term support and care is extremely difficult. In my opinion, recovery teaches us that we are not meant to do this work alone, neither for the co-dependent or the addicted. Rather than building more jails and prisons to house our sick, it is my hope that we can find ways to build communities where care never quits, for those afflicted with these unrelenting diseases.

Bill White: Jim, how did you come to the decision to turn your grief over the loss of Nick into advocacy by making a film about his life?

Jim Contopulos: Bill, Nick had overdosed multiple times, and we always wondered, “when are we going to get the call”. I held on to a hope that said “keep him alive until 25”. I felt that if Nick could sustain his recovery until then, perhaps it would continue to build.

Regretfully, it did not. We imagined that we could “fortress” ourselves against the dreadful possibility of his death. Now, I know that nothing could have prepared us for the death of Nick. All deaths are hard, but the loss of a child is the hardest death of all.

After Nick died, I recalled a conversation that I had heard months before on CNN. In the wake of the devastation of Hurricane Katrina, I remembered a conversation on CNN with a survivor of the hurricane that was now moving on to help herself and to help others. In the interview, this lady who had suffered enormous loss, when asked how she was able to move forward, said, “At some point, I stopped asking “why me” and began asking “what now”. That simple statement lodged into my heart and brain and I began asking “what now” for the “other Nicks” who will open doors that they, alone, can never close.

That is why I decided to tell Nicks “story”, because I believe, his and our story is sadly not unique. I believe when people see Nick’s story in the film, they will see their own loved ones story and their own family’s journey into these desperate places they never knew existed. That’s also why I was part of a team that conducted our 1st Annual Seams of Gold Conference to address the issues of mental illness and addiction in our local community. I can’t over emphasize how unprepared most families are to confront these issues. For years, I didn’t even know about the existence of NAMI (National Alliance on Mental Illness) and its work with family members. I did not understand the complexities of our county’s services and how to navigate this dysfunctional system. I am now convinced, after having lived in this personal hell that we are not meant to face this alone. There are communities that surround us that will hold us up and support our path.

Regretfully, because addiction and mental illness are both stigmatized in our society, we are isolated from those who would normally care for us. Because of our societal attitudes of fear and misunderstanding, we have allowed the L.A. County Jail to now become our nation’s largest in patient mental health facility. This should never happen. We

are better than this, and we must find a way to redirect our resources, our understanding and our energies to better care for those who are sick, desperately sick.

Bill White: I know the film is about to be released. What do you see as your next steps after the film?

Jim Contopulos: Honestly Bill, many times, I have no idea. I wanted to tell Nick's story because I wanted to honor what I witnessed in his effort to find recovery. I know the film and his story is the story of so many others who have lost their lives to this unrelenting disease. About the same time that I lost Nick, I also lost my job which gave me a great deal of time to work on the film and work through my grief.

If just one thing was to arise from this film, it is that I would like to see a national conversation begin to emerge around this societal plague. How we have found our way into this present situation and what we, as a civilized and caring society could do better for those among us who are sick.

A friend of mine, who lost her son to a prescription drug, is involved with GRASP (Grief Recovery After Substance Passing). At the recent conference we held, she supplied two 4' x 10' vinyl banners with the faces of 177 young men and women who have lost their lives to a drug overdose. Nearly all of the individuals on these banners were in their early- to mid-twenties. This is unacceptable and is why I consider this to be an epidemic that must be addressed on a national level.

Bill White: Jim, are there any final words that you would like to share with any other families who've lost a family member to addiction?

Jim Contopulos: Yes. Let me begin by thanking you for this opportunity to speak to your audience. Bill. What I would say is that addiction is very much a family disease. By that I mean that each member of the family will become sick in their own way and it is imperative that each member of the family, not only the addict, find their own way into those rooms of recovery where experience, strength and hope can be shared.

We desperately need the shared wisdom, understanding and love that can take place in those rooms where we will find a "well worn path" of recovery. I only wished I had cracked the door earlier. Rooms where your secrets and your fears can be revealed. As I said earlier, I am more convinced than ever, that both the addicted and we who love the addict are not meant to "go alone". Recovery has the ability to teach our society a very important lesson if we will simply listen.

In closing, let me relate a story that took place during a very difficult period with Nick. Before he was 18, we began to understand that his use of Methamphetamines was out of control and we had to intervene. One particular evening, we decided to take aggressive action in order to save his life. I was filled with overwhelming fear and grief. I recall telling a close friend of mine that my grief was so great, I could hardly stand up. What he said has stayed with me all these years. In response to my statement, he said "then let me be your legs". I needed that, we need each other and when we find those moments of fear, grief and hopelessness; then we need someone to be "our legs".

Bill White: I only want to ask you one more question, Jim, and that's how our readers can get information on how to view or obtain a copy of the film.

Jim Contopulos: Bill, the film is posted on YouTube at <http://www.youtube.com/watch?v=VGZ1ESOlvbM>

The film is also available at no cost for organizations that are supporting recovery and will be available at www.seamsofgold.org as well as www.morethananaddict.com. We are just now in the early stage of getting both of these websites up and moving.

Bill White: Jim, thank you so much for taking this time to share your story with us. This has been a very moving interview for me.

Jim Contopulos: Bill, thank you. It's been my honor to speak with you and your audience.