# Learning to Cope, Together: How My Son's Experience with Addiction Inspired Me to Launch a Family Support Network

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**Editor's note:** This month's <u>Special Series on Community Approaches to Addiction</u> focuses on ways to bring addiction prevention and recovery beyond medical settings and into communities. Today, we feature the second in a series of interviews with inspiring people who have led efforts to reduce the impact of addiction on their own communities. In 2004, Joanne Peterson founded <u>Learn to Cope</u>, a non-profit support network that offers "education, resources, peer support and hope" for family members coping with a loved one's addiction. Learn to Cope, which includes over 11,000 members, is a nationally recognized model for peer support and prevention programming. Here, Ms. Peterson discusses her efforts to launch and sustain Learn to Cope with Heather Gray, Senior Editor of The BASIS.

# Dr. Gray: What inspired you to start your organization?

Ms. Peterson:

To be completely honest, I never had a plan to start an organization. My son graduated high school in 2001 and the following summer he made the fateful decision to try prescription pain pills. During that time, young people were experimenting with OxyContin and Percocet. In a short period of time, his life and our life changed drastically. By 2002, we discovered he was using heroin. My husband and I struggled to learn how to get our son into treatment. We learned the first admission to detox would be one of many. We had

to figure out on our own the continuum of care. Ultimately, we learned that this was going to be a long road and challenge to our marriage, our other children's lives, and our family.

Living with a child with a substance use disorder is very similar to living with a child with a potentially fatal illness like cancer. The difference is there is stigma attached. You lose friends and family because they are not sure what to say or do for you.

Finally, in 2003, after many relapses and detox visits, our son ended up in trouble with the law. The entire scenario landed in the newspaper. We were outed; the cat was out of the bag. Our family had suffered silently for a long time. Once the newspaper article was printed, the stigma began and the emotional toll on our family grew larger.

I felt that since the newspaper further stigmatized my son and our family's situation, it was time to tell the story behind the story. I did this to get our family and our son's dignity back. I didn't want people to remember him for the trouble he got into. And yes, the stigmatizing word "addict" was the description used in print.

I wanted people to know this was happening all over town and it was not being addressed. I wanted people to know that many young people were trying this pill and eventually turning to heroin. I wanted people to know he was suffering at the hands of a drug that was widely available in the form of a pill. The warning bells need to be sounded. I had no idea the enormity of this across Massachusetts and all of New England.

In the spring of 2004, I came out by speaking publicly at a town forum in Stoughton, Massachusetts. A district attorney was warning the public about OxyContin infiltrating the communities. Many young people were getting prescribed OxyContin for sports injuries or wisdom teeth extractions or were just making the terrible decision to try it. Overdose deaths and crime rates were rising. Pharmacy robberies were a common story in the papers and on the evening news.

I stood in front of a crowd of about 200 people and told our story. At this point, I felt there was nothing left to lose. My son was now in jail and people needed to know the story behind the story. I stood there and cried. My tears dripped on the

ink and smudged all I had prepared on paper to say. So, I just spoke from my heart. I felt my son's life was going to be a life in and out of jail now, game over, the drug won. An article was printed about the forum in a local newspaper. The one condition I had for the reporter was to print my email address so I could hear from others in the same situation. My email address contained "learn2cope" because that's what I was doing.

I heard from family members from all over the south shore of Massachusetts. I decided to start meeting once a week with other families in May of 2004. I could not keep up with all the emails and phone calls from people looking for resources. I called our group "Learn 2 Cope" and it grew immensely in a short period of time. We had to periodically move the meetings to larger locations. It was not unusual to see standing room only, 60 to 80 people all with the same look of desperation and fear. Fathers and mothers in tears explaining the same scenarios everyone else in the room was experiencing. Many of them parents of children as young as 17 using OxyContin and heroin.

"My inspiration to start meeting with parents came to me from my own healing. As soon as I started meeting and talking to other families going through the same thing, I started to heal. I no longer internalized and blamed myself; I started to understand that no matter how well you parent your child and try to keep them safe from making these decisions, it can still happen."

I also knew that it was time to start getting educated on substance use disorder, or what we called it back then, "addiction." Gone were the days to just sit in a circle and talk about what we were going through. I wanted to learn about this disease. The science behind it, why it was so hard to stop. My inspiration was now two-fold. One, I needed to help myself and my family. And two, I wanted to arm myself and others with education about it.

# Dr. Gray: How did you learn to start and run an organization like Learn to Cope?

Ms. Peterson: Well, starting Learn to Cope was indeed baptism by fire. I didn't know this is what I was doing. I just needed to help myself and I wanted to connect with other families who were living day-to-day with this.

In September of 2007, after three years as a volunteer running these groups, I

received a letter in the mail from a state representative congratulating me on a \$100,000 earmark to run my program. I had no idea what an earmark was, and I didn't think I had a program. However, I found I had networking and community organizing skills. I took a risk and left my full-time job in September of 2007 and began working for Learn to Cope, Inc. as its Executive Director.

I had an old dial-up computer in a spare room in my home. I drove all over the state speaking, organizing community members, starting groups, and speaking at the state level on treatment availability. I became a known advocate. I created a "buddy system," teaching other parents how to facilitate meetings as the growth continued. I created family packets full of information I would have liked to have received when I needed it, and a website with a private online forum. My philosophy is and has always been, "People need to feel better after leaving a meeting than they had walking in." Today we have over 200 facilitators and have developed a training model. Each meeting has speakers at least once a month to educate, train on overdose prevention, give out Narcan, and offer hope and support.

I noticed over time that others were finding their voice and becoming strong advocates. We are judges, law enforcement professionals, nurses, doctors, teachers, or stay-at-home parents. We are rich or poor, married or single. We come from all communities but collectively we were becoming a powerful voice and we were finding our voices together.

Over the course of time I was learning how to manage and run a non-profit. Family members formed fundraising teams and planned events to ensure we continued to have funding to grow Learn to Cope, create materials for meetings, and afford to travel around the state speaking and educating. People were traveling to our south shore meeting from all over the state. I was asked to bring a similar chapter to Salem, on the north shore of Massachusetts, and I agreed—the second chapter of Learn to Cope was formed. It was then I learned how to network in communities and duplicate what I had done on the south shore.

I decided to visit all the places a desperate family member might go to find help as I had in years previous: police stations, court clinicians, emergency rooms, detox's, counseling agencies, and churches. I told them a new support chapter would start later that summer. Offering education was a huge component, as people were hungry to learn about treatment options, overdose symptoms and

prevention, Hepatitis C, HIV, trauma, criminal justice issues, the continuum of care, and other issues. I would invite experts to come and speak and folks in recovery to offer hope. The second chapter quickly grew into another room with standing room only. Still today, 13 years later, the room in Salem is full. After training and support, more and more chapters started and were run by experienced facilitators. Many who originally had to travel a long distance to attend were now bringing it back to their own communities.

I have come to realize over the years that because I was a child who lived with addiction and mental illness in my home for many years, and then later became the parent of a child living with addiction, I knew from my own life experience what families need. That includes siblings. I had a brother who battled cocaine addiction, HIV, and depression, and a sister with alcohol addiction and schizophrenia. I learned at a young age that there was not any help for them, or support for my mother. In the 70's, people didn't share what was going on in the home. Reaching out for help was not the norm. When this happened to my son, I did not want to go it alone. I wanted to learn how I could help without becoming a part of the problem. I didn't want a repeat of what happened to my brother's life and I didn't want to be afraid to speak up.

Starting Learn to Cope saved my life, and I know today it also helped my son find long-term recovery. My brother lost his battle in September of 2011. My sister is now in a nursing home at the age of 58. It continues to hit my family. I lost my beloved niece to a fentanyl overdose on July 28th, 2018. I have learned how to take the painful situations that plague my family and use what I know, my life experience, and my resilience and just keep going.

Today Learn to Cope has 25 chapters across Massachusetts. We are in 11 out of 14 counties in Massachusetts and we have a chapter in Florida. We are looking at Connecticut next. Our first bilingual group will be starting in Western Massachusetts in the summer of 2020.

I am proud of our training model, building a network that fills a need for families with education, support, resources, and hope. I am proud that we continue to sustain and grow it. Many people from outside Massachusetts call us asking for a Learn to Cope chapter in their state. We have begun creating an expansion plan for Learn to Cope to train other communities nationally. The story will continue, as there are and always have been families in need—especially in underserved

populations and rural towns.

### Dr. Gray: What challenges have you experienced?

Ms. Peterson: There have been many challenges over the years, and all have been part of the learning process. It's been quite a journey. I think one of the hardest challenges is that in doing this work, you get to know many people who lose their loved ones to overdose. It's heartbreaking. It's never going to be easy taking that call from a grieving parent. I have attended more funerals that I could ever count over the last 15 years.

I had to learn how to run a nonprofit and I am proud to say I do that well and I now have an amazing staff. I don't do this alone. It's always a challenge to keep up with the amount of people in need. We are a team; we could not do this alone. I am so grateful for the altruism of volunteers who are always willing to help. Our schedules can be grueling at times, taking crisis calls any day of the week at any time. It's an effort to take time for yourself but I have gotten much better at self care and I do my best to make sure our staff and volunteers do too.

#### Dr. Gray: What are you most proud of?

Ms. Peterson: I would say that I am most proud of Learn to Cope in itself. I am proud of what it stands for and that I was able to build it and grow it to what it is and what it does today. I am proud that it helps so many people. I hear people say it saved their life or the life of their child over and over.

We are the first parent-run network to train and give out nasal naloxone (Narcan, an overdose reversal antidote) and we have over 150 overdose reversals-meaning families have a tool to save a life at home while waiting for an ambulance. Learn to Cope is also funded by the Massachusetts Department of Public Health's Bureau of Addiction Services, another milestone for a parent-run network.

I am proud that is was built with "boots on the ground" work, not just creating a page on social media. Our website has a private and confidential family forum that is available 7 days a week. I am proud of the many family members who have become advocates and the Learn to Cope team which is a group of amazing people.

I am proud that we are a respected and worthy entity in Massachusetts. I am proud that I have been able to use my voice to help others, whether it's been at

the State House, the White House, or just in general.

I am mostly proud of my son, who today lives a wonderful life with a wonderful wife and family. I am fortunate to see him live a healthy life.

#### Dr. Gray: What do you see for the future of Learn to Cope?

Ms. Peterson: I wish I could say an organization such as Learn to Cope will no longer be needed someday. The fact is, there will always be addiction and mental health issues. Our website has over 11,000 members and we get new registrations every day. I hope to see this organization and others future organizations continue to give voice to those who need to be heard. A place without stigma and judgement. A place to heal and a place to feel hope. I feel we will spread our model in more areas in the Northeast of the country and perhaps further. I have many ideas.

"I see more conversation on taking the shame off the shoulders of families so they will not be afraid to come forward."

This organization has not stopped growing since it started, and there are many thousands in the world who need help. I hope in some way I have helped to change the conversation and to show its importance and relevance. My wish is that the deaths will stop. I am sad to say we still have too many. We still have a lot of work ahead.

# — Joanne Peterson and Heather Gray

What do you think? Please use the comment link below to provide feedback on this article.

#### **Author bio:**

Joanne Peterson is the Founder and Executive Director of Learn to Cope (LTC), a non-profit, peer-led support network which began in 2004. She designed LTC to offer families the support, education, resources and hope that her family would have benefited from. LTC has grown to have a full staff who collaborate with communities across the state to spread messages of prevention, education, awareness and advocacy.

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