

The Maine Trust Project

“We need people in our lives with whom we can be as open as possible. To have real conversations with people may seem like such a simple, obvious suggestion, but it involves courage and risk,” wrote 18th-century Irish poet, singer and songwriter Thomas Moore.

In this mistrust-filled world full of political contention and both fake and devastating news, mustering such courage is challenging. Finding common ground and engaging in civil conversations about important issues facing our communities, our state, our country and our world can seem elusive, if not sadly impossible.

This concerning state of affairs prompted Pine Tree Watch to examine the concept of trust. And thus, we’re launching a new series called “The Maine Trust Project.” Each month, we’ll sit down with a Maine resident to discuss this precious commodity. We’ll see which people and institutions Mainers trust and how the concept of trust drives their thought processes and actions.

<https://pinetreewatch.org/the-maine-trust-project-deon-lyons/>

Digging through adversity to the opportunities beyond

Deon Lyons hasn’t let a lifetime of health issues keep him from trusting in himself and in those who put him at ease

By Stephanie Bouchard

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Get to know Deon Lyons

Age: 58

Residence: Clinton

Religious affiliation: I was raised Roman Catholic, but I stopped going when I was probably 10 or 11. I don't appreciate people telling me how I need to worship God. I have a good relationship with God myself, which I use when I need to. We have an understanding. Sometimes it's a love-hate relationship, but I realize that the only thing that I'm hating in that relationship is myself for not trusting.

Political affiliation: I am a conservative, but I don't like what the Republican party has turned into. I don't like politics. I don't trust most of the politicians. I do love what (former governor) Paul LePage has done. I just wish he would learn when to keep his mouth shut. The state Legislature – some days, they're no more than an accumulation of spoiled brats – as is the Congress in Washington.

How he describes himself: Lots of days I'm frightened. I'm forgetful. I am anxious. I am vulnerable. I am stubborn. But I'm also trusting. I'm funny. I'm loyal. I'm a quick learner and I am eager to learn new things. I am intuitive. I am a lover of family. I've learned to move away

from material things. The only thing that is going to be there when your time is nearing the end is going to be family.

How he defines trust: I'm a very trusting soul, and I'm very gullible, so trust for me is to be put at ease. Not to have to worry about being misled or being lied to or conned or manipulated.

CLINTON – Deon Lyons has cancer. It's advanced and the outlook is anything but cheery. But he's not letting that get him down. His attitude is not surprising given one of his favorite words is "opportunity."

"Opportunity" is a much better way of looking at what life has handed you than, say, "challenging," which is the word most people would use to describe what he has faced over the course of his life.

In late summer 1960, Deon was the fourth child born to his parents in Lubec. He was born with retinoblastoma, a rare form of retinal cancer commonly affecting children under age 5. Today, depending on what part of the world you live in, the prognosis is good – 9 out of 10 children live into adulthood. But in the early 1960s, treatment for eye cancer wasn't as developed as it is today.

The Lyons' doctor in Bangor, though, had heard of a new radiation treatment which was just making its way into U.S. medical centers. The treatment wasn't available in Maine, let alone the tiny coastal community of Lubec, but it was in New York City.

So, at just 5 months old, Deon traveled with his mother by train to what was then called Columbia-Presbyterian Medical Center (now New York-Presbyterian/Columbia University Medical Center). His medical team had to remove his left eye, which cancer had already destroyed, but was able to save his right eye by using radiation.

The radiation caused some facial disfigurement. Beginning at 17, Deon had numerous cranial-facial reconstructive surgeries in Boston, but otherwise, he lived a "normal" life.

"I was blessed," he says, "because a lot of the kids that had this type of cancer were losing both eyes, dying, or being severely burned by the radiation because it was just so new, they didn't know how to regulate the strength of it back then."

Deon married Lyn LiPuma in 1982, and they bought a house in Clinton, where they raised their son Matt, who is 36 and has a son of his own. Deon cultivated a huge garden that includes blackberries, raspberries, blueberries and more than a dozen apple trees of different varieties, and spent 25 years on the road all over Maine as a regional sale representative for several tire companies.

But things took a downward turn starting in 2010, when the effects of the long-ago radiation caused near-total blindness in his right eye. And a series of strokes between 2010 and 2016 left him completely blind.

"That was the beginning of my new chapter," he said. With the encouragement of his family, he says he seized the opportunity.

He got hooked up with a local vision rehabilitation counselor and was able to enroll at Carroll Center for the Blind, a Massachusetts-based facility that teaches blind and visually impaired people how to live independently.

After learning how to touch-type and use a screen-reader program so he could use a computer, Deon began a blog detailing his vision-loss journey. He also self-published “Sully Street,” a fiction novel about five teenage boys growing up in a small Maine town in the 1970s, and started taking liberal arts classes at Kennebec Valley Community College.

Fall 2018 was supposed to be his final semester at KVCC, but he landed in the hospital instead. And though he was a semester shy of finishing, the school awarded him an associates degree at his home in early February.

Among the many severe health issues discovered last fall, cancer was found at multiple sites in his body. He spent several months in the hospital stabilizing. Today, he is home with his family and a team of visiting hospice workers and is figuring out this latest “opportunity.”

“No matter what you do or where you go, no matter whether it's good or bad, there's always an opportunity in there somewhere,” he says. “Sometimes it's right on the surface. Sometimes you got to go and dig it out.”

Q&A:

Pine Tree Watch: Who meets your definition of trust and how do they meet it?

Deon: I guess anyone that when you first hear their story, you don't walk away with an uneasy feeling. I've learned how to hear different things in people's voices since I lost my vision, and sometimes it's like, ‘I don't believe a word of that’ just by the way they're saying it.

Other people are those that are willing to help me out of the goodness of their heart. My wife and I have experienced a lot of that these last eight years. And I trust people within the blind community with all my heart and soul can muster. I know a lot of them have been through the same experiences that I've been through. These are some of the most inspirational people I've ever met in my life. Although they're working from a handicap, they don't see it that way.

I trust my wife with every fiber of my body, and I trust my son, all my family. I don't think I trusted anybody more than my father. He was there for me throughout my whole life, but I don't know what I would've done without him in 2010. He was one of those people who kept prodding me along. He'd say ‘Don't sit there. You need to get up and do this. This is what you were handed. Make the best of it.’ He made me trust myself – that I was able to do it. If he could trust me, then I should be able to trust myself.

PTW: Who doesn't meet your definition and how do they fail to meet it?

Deon: People that say one thing and do another. People that make promises they don't follow through with. I have learned the last decade, probably the people I trust least are politicians. They'll tell you one thing and then do completely different things just to gain your trust when they're campaigning. It's amazing.

PTW: What breaks trust for you?

Deon: Being lied to. Being stood up. Being taken advantage of. Seeing how other people are being mistreated by others.

PTW: Can broken trust be healed?

Deon: It's one of the worst feelings in the world to have your trust thrown out the window, so, depending on what transpires afterward, sometimes. If it's ever built back up again, it takes a long time. And effort. It takes effort to amend, to show me that you're willing to understand how to build my trust and to understand what my trust in you should mean to you.

PTW: Has your definition of trust changed over the years, and if so, how?

Deon: Yeah. Back in the day, it was more about me trusting other people. My trust now, I guess, I focus that on myself: how I perceive that other people might trust me. That's more important to me now – how I can earn someone's trust. You don't get a second chance to make a first impression.

PTW: What worries you?

Deon: Probably the main thing that worries me now is how a lot of people want to turn the United States into an organization of the world. I believe we need to keep our independence from the world. That's why people are still flocking to the United States – to get away from the rest of the world. We are still the greatest nation that's ever been formed in the history of humanity, in my opinion. People come here to gain an opportunity.

PTW: What inspires you?

Deon: I'm more inspired by sports now than I ever have been. I've always loved sports. I played sports throughout my whole youth. I loved the camaraderie and I learned a lot of things. I wish politics would take a few lessons from sports, like learning how to build trust so they can figure out what works and what doesn't.

PTW: What issues on the state or local or national or international level do you think are really important?

Deon: Here in the state, it's the jobs, which have so much to do with so many different areas – the economy, the infrastructure, roads, bridges, schools. I think Paul LePage did a very good job at trying to bring better jobs here to the state, to give companies a reason to come here. He was met with a lot of roadblocks, but he went at it. I think we're in better shape now than we were eight years ago, but we're a far cry from being where we need to be for the future.

PTW: Please share a memorable trust moment in your life.

Deon: I would have to say it would be the day my wife said 'I do' when she married me. The day we got married, she made that commitment to me to love and honor, to have and to hold, 'til death do us part. These last eight years have really proved to me that that commitment means something to her. Some days we have a love-hate relationship, where she loves to hate me, and I

hate to love her. It's hard work to keep a marriage going. The rewards at the end of the day, though – you can't put a price on that.

Deon's family has started a GoFundMe page to help with medical bills. Go to <https://www.gofundme.com/deonlyons> to donate.