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November, 2015

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Dear

"He's a really good guy", the nurse from the clinic told our referral specialist, begging us to visit and admit him to hospice. She acknowledged that his care might be challenging. She let us know that he had been discharged by a pain clinic the week before for his lack of cooperation and had been turned down by another hospice due to a problem with his insurance coverage. He also hadn't shown up for his appointment that day at the clinic. "He really needs some help," she pleaded. "I know you guys can do it."

The photo on the coffee table looked almost nothing like the man propped up by three pillows on his couch. It had been taken during a rare moment of critical acclaim for an artist who felt his life's work had mostly gone unnoticed. The flash of a smile celebrating that instant of triumph could not have been further from the affect of the man currently on the couch.

Dustin's affect wasn't the only thing that had changed since the photo was taken. The left side of his face, from his forehead to his chin was covered in a dressing that should have been changed a week earlier and the other side of his face showed that he had lost about 30 years of fat padding in the two years since the photo had been taken.

Our nurse, John, knelt between the coffee table and the couch. Dustin turned toward him. "You're gonna tell me how I should have gone to my clinic appointment yesterday, right?" There was nothing but defiance in his voice.

"No," John told him. "The first thing I'd like to know is whether or not it hurts when this dressing gets changed."

"Oh, well, yes... it hurts almost all the time but, yes, its worse when I change the dressing."

John talked to him about his pain and the medication he used for it and encouraged him to take some. "We'll wait for that to kick in before I change it. Okay?" Dustin agreed. "While we wait, would you mind telling me a little more about your illness and what you'd like to get from hospice care?"

"I'll tell you what I don't want. I don't want any more people telling me what I should do and telling me what I can and can't have. I've been through enough shit and it looks like I've got nothing but shit to look forward to in the little time I have left. So I really don't need anybody adding to it."

"Okay," John responded. "We'll do our best to respect that. Do you think you can tell me something about what you do want?"

Dustin was silent. John took a seat and waited. The large living room was cluttered with some of the most haunting works of art he'd ever seen. Most of it unframed, some were on the walls and much of it leaned at odd angles against the walls or perched atop the five or six easels around the room. They were various sizes with beautifully crafted images of desolation, anguish, and even brutality, brushed on with intricately disparate variations of black, dark blue and gray but with small splashes of color on each canvass. To John, those small splashes represented a tiny sense of hope. Not much, but just enough to leave him feeling more curiosity than despair.

"I don't know yet," Dustin finally admitted. Can I get back to you on that?"

"Sure," John replied. He went through the necessary admission paperwork and changed Dustin's dressing.

Sometimes building trust takes time, sometimes it takes having no other choice. For Dustin it was a sudden pain crisis. "I almost didn't call you. I didn't think you'd be able to do anything but it was so sharp and so excruciating. I just couldn't stand it."

Our on call nurse went out to visit as soon as she got the call. The medications we usually use didn't work well enough so we got orders for IV medications and had nurse stay with Dustin around the clock for a few days until he was comfortable, yet alert enough to manage the equipment himself.

With trust established, Dustin began to open up to our team. He spoke of a life devoted to his art. He spoke of himself as a man who had allowed, even forced himself to neglect everything else in his life with an inner certainty that his art was his life and that someday the world would appreciate his legacy. The comfort he had once taken in a tragic view of himself was now falling apart as an ultimate reality drew near. He chastised himself for spending so much of his life romanticizing rather than enriching what he referred to as "the poverty of my spirit." He referred to the works scattered about his home/studio as "ghosts of the future"- finished but not really existent. He lamented a life's work whose potential for ever actually existing was uncertain.

The verbal abuse he directed at himself was as brutal as his paintings.

No one on our team is an art dealer or critic. We could provide no comforting affirmations to Dustin that his art would someday be recognized, that his life had been worthwhile, that he was not the failure he felt himself to be. What we could do was be there with him, listen to him, and wait with him.

But we learned some things that might help. We learned that he had a daughter, Emily, who he had not seen in over seven years and who was now about 14 years old. "My biggest failure," according to Dustin. "I've given her nothing."

It took some convincing, as Dustin did not initially see what good might come of letting his daughter see "the freak show I've become," but a few weeks later Dustin's ex-wife and daughter flew in from across the country. Her mom could only take a week off of work so our Social Worker wanted to help Emily make the most of her time. She prepared Emily for her dad's appearance as well as his prognosis. As scared as she was, Emily was also excited. She hadn't understood what happened between her parents and why she had lost contact with him, but she wanted her dad back.

Emily's mom was supportive. We could tell that despite whatever pain she had been through with Dustin, she still had feelings for him. "He's a good guy," she told us, "his own worst enemy, but a good guy." Emily was determined not to let even the slightest sign of shock or disgust show on her face at her first meeting with her dad and our team helped Dustin look as presentable as possible.

The first visit was a little awkward and superficial. The second was more emotional as Dustin did his best to share his feelings with Emily without overwhelming her. By the third visit their connection could be felt from across the room. Emily had her own artistic talents and Dustin was able to both praise her work and teach her a bit about the craft as well.

Dustin told us that saying goodbye to Emily was the hardest thing he'd ever done. But there was something very different about him. He smiled more often and readily trusted various treatments we advised. He spoke only about Emily with our Social Worker and Chaplain. The self-loathing was gone and a man more closely resembling the one in the photo on the coffee table emerged.

A few short weeks later, Dustin could no longer get out of bed. He asked our team to hang the painting Emily had made for him on the wall directly in front of him. The last couple of days of Dustin's life were calm. He wasn't awake too often, but when he was he would simply stare up at that painting and smile. The painting was a simple still life. A vase filled with daisies atop a table. Much more sunlight than you'd find in any of Dustin's work. In the lower right hand corner, just above Emily's signature (in a bright, gaudy shade of pink that Dustin would have never been caught dead using) were the words, "Love you Dad!"

At Good Shepherd Community Care we are honored to care for our patients and their loved ones. It is the reason we exist. From a financial perspective it has been getting more difficult for us over the past couple of years. We appreciate your past support and ask that you do what you can to help us continue our mission again this year.

Sincerely,

A handwritten signature in black ink, appearing to read 'Timothy Boon', with a large, sweeping flourish extending upwards and to the right.

Timothy Boon
President & CEO

