

## Parent Corner

**Dianne Gray**  
**President**  
**Hospice and Healthcare Communications**



**HOSPICE & HEALTHCARE**  
**COMMUNICATIONS**

**Phone: 239-595-5583**

**Email: [dgray@hccommunications.com](mailto:dgray@hccommunications.com)**

Little Austin Gray was barely five years old when he received a devastating diagnosis. He had Neurodegenerative Brain Iron Accumulation Disorders, a death sentence for certain, as NBIA (NBIA) Disorders typically strips the patient's ability to walk, talk, eat, and move within months or years. In Austin's case, it would leave him cognitively intact, but would leave him bedbound for the last five years of his 14 year lifespan.

Like most parents would do in a similar situation, I became as educated as I possibly could about the disease process, reading words like dystonia and spasticity in medical textbooks or in online resources. I saw photos of other children with the disease and felt certain there was no way Austin would ever look like those kids, posturing in a way that I clearly did not understand.



What I read also discussed his limited life expectancy and a long list of issues that would most likely be a part of his everyday existence. Though I was stunned and absolutely dazed in the months following his diagnosis, I felt I was capable of handling his care and knew where to turn to when I needed help.

I was wrong. I was sorely lacking in guidance and "know how" needed to navigate his care. Most of all, when it came to pain management, we were all in the dark.

Like many kids with NBIA disorders, Austin was treated symptomatically and our physicians did the best they could to keep the dystonia and spasms at bay. We used baclofen, valium, phenobarbital, and a long list of other drugs in our arsenal against the pain that seemed to pervade his everyday existence.

What we didn't use right away and what I didn't read about early on was morphine.

Looking back, I still lower my head when I think of my son's suffering due to a lack of education and a certain amount of fear on my part and the part of our physicians and other care providers when it came to the topic of opioid use in pediatrics. With that said, we had wonderful physicians and

nurses as part of a complex care team.

They were attentive, well educated, compassionate, and focused doctors, all determined to keep my beautiful son comfortable.

With that said, however, when Austin was hospitalized for 32 days in 2003 for acute pain and a long list of other symptoms, it was only until the last three days of our admittance that the administration of morphine was discussed.

I'll never forget those days as long as I live. My son had a horrible bout of dystonia in which he had chewed the sides of his tongue raw. As well, he had opisthotonos, which meant he would invert his body into a backward "C" posture. The team of specialists in the hospital had commented that they had never seen a case that presented symptoms with this intensity. Together we tried everything we could to ease his pain and his suffering to no avail.

On Day 30 of our hospitalization, I remember the hospital sending in the pain management specialist for a consult. He sat me down to discuss the use of morphine to keep my son's pain at bay.

I recall vividly feeling several things following our conversation:

"Will it kill him?"

"Will it make him stop breathing?"

"Is it addictive?"

"Isn't there anything else to try? It's such a strong drug for such a little boy!"

The specialist assured me there really was nothing else to try and yes, while it was and is a narcotic, it would help Austin to rest comfortably.

Well, it did help him and he did finally rest.

However, here is where I become sick to my stomach. Or is it a hole in my heart that I feel? I think of how long Austin suffered while I as the caregiver, parent and decision maker did not know about morphine and even hesitated when

I did know, as I was not educated on the positive effects of its administration when needed.

Here is what happened: Once the pain management physician left the room, I immediately requested a consult with our longtime pediatric neurologist, who had become my most trusted advisor and guide for Austin's care. He responded immediately to my call and even came by the room to see for himself what Austin was enduring. In the moments that followed I could see he was terribly saddened by Austin's condition. He explained that he felt a huge sense of failure as a doctor and that while he too, was hopeful that morphine would help to relieve Austin's pain, he was nervous about it and didn't feel comfortable prescribing it. Understandable, I thought, but not exactly the booming reinforcement I desperately needed at that time. With that said however, I do understand his feelings and so appreciated then and do now, his honesty and sincerity.

Here's what I did need at the time:

I needed to hear the POSITIVE things morphine (and other opiates) could do for my son:

-That if the morphine worked to relieve Austin's pain, his personality would return. Ever try to laugh when you have a migraine? Impossible!

Once Austin was comfortable, he smiled. You know, the kind of smile that says, "Ahhhh, finally..." with a nice easy breath attached.

-That if the morphine relieved the pain, and the other drugs were then able to help the dystonia as well, Austin would gain weight. Austin's dystonia caused him to lose a significant amount of weight. Hours and hours of spasms burned more calories than we could put in him.

He did eventually gain back all of the weight he had lost and then gained some more so therefore, his skin condition was much improved. Common sense? Yes. Did I realize it before hand? No.

I also needed to hear that yes, while some patients do need morphine for extended periods of time or possibly for the rest of their treatment process, that Austin was suffering. Period. That he needed the morphine and my fear of it being “addictive” was about the last thing I needed to be worrying about at that time. I also needed to hear that morphine can and is removed safely from a pain management protocol when the time is right.

Since Austin’s passing in 2005, I have begun speaking around the country on our case history (the joys and not-so-joyous elements of our experience) and work as an advocate for improved pediatric hospice and palliative care programming where and when I can. As a part of those discussions, I ask care providers in hospices and palliative care centers, “how comfortable do you feel treating pediatric cases in end of life care?” Understandably, I frequently hear, “it breaks my heart.” When these same groups are asked “how do you feel about your knowledge base when it comes to morphine use in pediatric palliative care and/or end of life care cases” the response is sometimes “not so confident.” Again, understandable.

So, what do we do about it? I hope the answer is as simple as this:

Ask, listen and learn. Get comfortable asking your colleagues for information on the topic. Communicate about the positive benefits of opioid use in pediatrics, as well as the negative or fear-based issues that we often hear about.

Learn what parents, as decision makers and caregivers, might perceive when it comes to the topic. Why? Because even if you are not in hospice and palliative care, your patients and fellow community members may just turn to you anyway. I know I sure depended upon our pediatrician as a trusted member of my “trusted advisors.”

I counted on her and I am guessing your patients will count on you.

In closing, I’d like to ask you to ponder the following thought (I wish I had understood this when I was caring for Austin):

Dying is not optional. Suffering is. When we as parents or care providers delay the proper administration of morphine and/or methadone, out of fear or due to a lack of education we allow children to suffer and that, to me, is inexcusable.

