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### A bereaved mom's story

Monday, May 11th, 2009

By: **Taunya English**  
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Parents of gravely ill children say Pennsylvania's health system has little to offer when a family decides to focus on quality of life, instead of life-extending treatment that

could also prolong suffering. A Chester Springs mom says her biggest battle came after she grasped that her son's disease could not be defeated. (Photo: Katey Lawson with son Liam)

#### Listen:



Katey Lawson's son wasn't two and a half yet, and he was dying. Born with a brain disorder, Liam had always had seizures, but now his body was racked with spasms the doctors couldn't control. He was in pain, and he couldn't sleep. Lawson says suffering was Liam's life.

**Lawson:** I mean I wasn't afraid of hearing the word 'hospice.' At that point I was looking for anybody that would just want Liam to be comfortable.

Liam had the "smooth brain" disorder called lissencephaly. He never developed the folds that give the brain its wrinkled look, and that caused neurological problems. Early on doctors explained that Liam's brain wouldn't be able to keep up with the needs of his growing body. They said eventually lissencephaly would take his life. In the summer of 2003, it was happening.

**Lawson:** We were literally sitting here with a dying child and didn't know what to do.

Lawson says, despite Liam's terminal illness, his doctors seemed stuck in cure mode.



Liam Lawson in 2002

**Lawson:** We didn't have any plan for end-of-life pain management. They didn't really tell us what we could expect because they didn't want to talk about it. And I think it's difficult for the hospital community, and everybody, to accept that, you know, these children are gonna die, there's nothing we can do for them, other than keep them comfortable.

Katey and her husband Bill wanted a way to care for Liam at home. The Lawsons didn't know the name for it then, but they were looking for palliative care.

**Lawson:** Who's gonna to say: 'Let's make Liam comfortable, he only has a few more weeks to live, let's enjoy our time with him?'

Many agree with Katey Lawson. And this month a Pennsylvania task force is rolling out [its recommendations](#) for better hospice options for children. The Children's Hospital of Philadelphia, where Liam was treated, has a [palliative care program](#) today, but in 2003 it was just starting.

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That year when Liam stopped eating, a specialist suggested a feeding tube. Katey Lawson, who's a registered nurse, saw that as a painful and futile choice. But she felt pressured to agree to the feeding tube. And one doctor warned: if the Lawsons said "no" they might be accused of starving their child to death.

**Lawson:** She said: 'Well, I don't have a problem with it, but some people might call that child abuse.'

Unwilling to risk losing custody of their son, the Lawsons agreed to the feeding tube. But Liam's body couldn't absorb the nutrients and he became dangerously overloaded with fluid.

**Lawson:** The hospital is cure, cure, cure, and if we can't cure, 'Well, we don't really have any other options.' It's just not true, there are other options.

Lawson knows some families might have welcomed the continued treatment - and extra time with Liam — but says her son's unrelenting pain dictated the right choice for her family.

**Lawson:** As if dying is the worst thing in the world, suffering is worst than dying.

There are no pediatric hospices in Pennsylvania, and many end-of-life providers aren't equipped, or willing to care for children.

The help came late, but the Lawsons eventually found a hospice nurse to guide Liam's care and a pediatrician who prescribed liquid morphine to ease his pain.

**Lawson:** Finally after two and a half years, somebody is hearing me, after so long, it was relief to know that somebody was finally going to help us keep Liam comfortable, when we weren't quite sure what was going to happen at the end.

Liam Robert Lawson died on October 2nd, 2003. His mother says he slept comfortably in the 24 hours before.

**Lawson:** He was very quiet, he was with us, we held him the whole time, I had my hand right on his chest, he was, he was quiet.

Lawson says a good death is possible, and with the right help, you can plan for it.

#### More information:

[The Pennsylvania Children's Hospice and Palliative Care Coalition \(PA-CHaPCC\)](#)

[The Liam Lawson Foundation](#)

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### 3 Responses to *A bereaved mom's story*

**Kim Carolan**

May 12th, 2009 at 1:35 pm

Wow, the story just made me cry and I am not prone to crying! Poor little Liam! I am glad that he was comfortable in the end, but ... truly, there are no words to say. Thank you for sharing!

**Lourdes Crohare**

May 12th, 2009 at 7:20 pm

I am doubly saddened by little Liam's story. First, what a tragic and sad story for the Lawson family. Katey and Bill, my pareyers are with you and Liam. Just to see Liam's beautiful, cute angelic face. And second, because I have a one year old grandson , Charles Anthony, who was also born with lissencephaly and each day we thank God for him, and each day we worry about his future. Like the Lawson's we just pray he never has to suffer and we pray that we get to enjoy him as much as possible, he truly is such a joy in our lives. God bless little Liam and all his family.

**Jennifer slax**

July 21st, 2009 at 2:31 am

I work for a hospice company called VITAS hospice and we do not turn down pediatric patients. We serve Montgomery, Phila. And many other

surrounding areas. I am not a representative but a nurse aid that works for the company. I am so sorry for your loss. If anyone is having a hard time finding a hospice that is geared towards children, we do accept kids. Nobody should have to have pain at the end of their life. May God bless you and again I am truly sorry for your loss.

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