

He and we had 19.75 days.

He had 19.75 days of feeling good. Peaceful. Happy. Joyful. He had 19.75 days of a full life. We had 19.75 days of enjoying him and knowing he had a full life. Eating out. Swimming. Getting to know his new assistant. Starbucks. Trying and loving a new drink. Reconnecting with an old friend. Shopping. Enjoying his food. Volunteer work at Horses Help.... yes, even in the Phoenix summer heat. Walking, walking, walking... lots of exercise. Rising early and being ready for the day before anyone else. Rising to challenges. Participating in as much life as he could. Having a competent role in many little things. All the day to day living we take for granted when we are healthy.

And in the last few hours before the 19.75 days were up, he got to experience Phoenix's relatively new attraction, the Musical Instrument Museum also known as MIM.

They say music is the language of the soul. I know it is certainly the language of Kyle's soul. In fact, in the box that asks you to check primary language on various forms, for Kyle, I would have to say MUSIC. Music gets in there where other things may not. Music really speaks to Kyle. He was in heaven listening to the music samples from all over the world. Tammy and I thoroughly enjoyed observing his reactions to different instruments, beats, sounds, etc. Watching closely, we noticed so many different responses to the varied music. What a delight for all of us.

Though I was really grateful to be able experience MIM with Kyle, I had no idea how precious those last few hours would turn out to be. Just a few hours after being home, Kyle went into another cycle. Again, out of respect for his privacy, I will not go into detail. But if you have been following my blog you know that he has been struggling with this for awhile.

I have to admit I was taken by surprise, though in hindsight there have been subtle clues that something might be brewing for the last few days. But still, I did not expect it. I really thought he might be done with them. He was sitting comfortably in his chair and all of a sudden, he looked different to me. His affect changed. Yes, in an instant, everything appeared to shift. He was experiencing something. He grabbed my hand and held it tight as if to say "please don't let it take me, please don't let this happen to me again." I could see he was frightened, really frightened. "It" was coming and both of us were powerless to do anything about it. He was being taken before my very eyes and all I could do was hold his hand and try to comfort him. He

wanted me to sit with him and hold him and squeeze him tight. So frightened, he did not want me to let him go. I wanted so much to do something, to stop "it", but there was nothing I could do. So I just held on tight and so did he.

Within the next few hours, he would continue to slip away and by this morning, he would be gone and replaced by a different Kyle. I know this sounds kind of dramatic, but this is exactly how it feels and appears to those of us who know him well.

He's resting on and off today, incredibly tired from this thing that has taken him. I hope this one will be milder and shorter than the previous ones. I have more support than I have had in the past and that feels nice. I can be stronger and better when I am there for him. We'll be moving on to Plan B soon. Or is it Plan Y?

19.75 days. Precious.

So if you only knew you had 19.75 days before your life was going to change drastically, would you do anything differently?