Article 2 for SOFT Newsletter about Sadie Collins 10/10/10

Losing Sadie

Today, as I write this, is exactly a month since Sadie died. It is very painful still, no less so than the day she died. The feelings have changed over the month and some days feel easier than others, but it remains intensely painful. Drew and I just miss Sadie so badly. It feels so empty to know there is no going back - she is gone forever.

Over this past month we’ve been surprised to find we have been able to do some normal things. To the outside world, we probably appear fine. Everyone says we are being so strong. Every day we have to draw huge strength and push all our emotions way down deep as they are so intense. We prefer not to allow them to bubble out in public. So we carry our emotions way down in our hearts each day. Family and friends have been wonderful and they do so much to help us. They truly care and we are so hugely grateful to them. Many friends sit and listen as I talk about Sadie and how we feel, but we struggle to let the true intensity of our feelings show as it is very painful for us.

The simplest of tasks can be so tough. When Sadie was here, she gave us her strength. We knew we had to do these things because she needed us to be strong. Now things like going to the supermarket, visiting friends and going out to public places are all really tough. It takes a lot of energy to manage it and leaves us so tired and low afterwards. We just ache for Sadie.

Who knows how long we’ll feel this way? We know it won’t be forever as we move through the grieving process, but I expect it will be a long time before the pain starts to ease. Meanwhile we will just keep trying our hardest every day and keep pushing ourselves to do more.

Last time I wrote, Sadie was 6 months old and seemed to be thriving. Sadie died on 10/09/10 aged 8 months. She had deteriorated steadily over a few weeks. We were so lucky to be Sadie’s parents and to have her for such a long time. For a couple of months she was so well that I thought she could make it past a year old as she was robust, happy and learning. I used to look at Sadie and wonder how on earth she could die. I used to ask “what will happen to make her die?”

In the end it became apparent that Sadie’s body couldn’t do what she needed it to do and she became more and more uncomfortable in it, as if it were holding her back. Sadly discomfort turned to pain and we worked with the hospital and Francis House Children’s Hospital to manage her pain. This became more and more difficult as weeks went on, because the pain increased rapidly. It was made harder because there was no clear indication of the cause of Sadie’s pain. In between episodes of her screaming and writhing, she would be happy and would seem her normal self, so it was also hard to explain what we were witnessing. We knew our daughter and I knew in my gut that something was dreadfully wrong. I knew she was dying.

Over a period of a month we were in and out of the hospice. Initially we’d stay over too, in the parents’ flat but often we’d go home (if Sadie was settled) knowing we were only minutes away and that we had to get used to being home without her. I don’t know how we’d have managed without the wonderful team at Francis House.

We always logged Sadie’s feeds and in the last couple of months, we saw her feeding slowly reduce until her intake had halved. Eventually, Sadie was given an NGT to ensure she was not going hungry and to enable us to get pain relief into her. A couple of weeks before she died, Sadie started vomiting. Not all the time, but it was unusual for Sadie.

In the last week, she became restless and also began to have frequent apnoeas. Again, this was unusual for Sadie, as she’d had them early on in life but they had subsided. I was mostly focussed on Sadie’s pain. It terrified me wondering when she would next have an episode as they could start so quickly. All I wanted to do was help her and to soothe her and I just couldn’t any more. The morphine would take so long to kick in that eventually we kept her on a regular dose.

Two days before she died, Sadie had a terrible night where we could not settle her with morphine or midazolam and we didn’t want to put her in the car. It took us a long time to get things under control. Something happened that night as she was barely conscious again. I didn’t know it at the time. I thought she was just so exhausted and that the morphine was making her a little blue around her mouth. It wasn’t until a friend, Jane, who lost her daughter to Edwards several years ago visited and pointed out her erratic breathing that we realised her apnoeas were worsening. I am so thankful to Jane because she insisted I called Drew at work and speak to Francis House. Drew came home around 3pm and we took Sadie over to Francis House for the last time.

Sadie’s condition worsened that evening. She was comfortable, but her breathing was not good. As Drew and I put Sadie in her sleep-suit she opened her eyes to look at her Daddy, then she turned her head and held my gaze for a long moment. That is the last time she seemed truly alert. We put her to bed and stayed close by. At 10.30pm we brought Sadie into the parents’ flat with us and cuddled her on the sofa until 1am. The staff took her whilst we got some rest, but brought her back to us at 1.30am. She had deteriorated and we then just sat and held her. It became clear she would die very soon. It was so indescribably sad, but surprisingly we felt calm and peaceful. We watched her in our arms as her breathing became less and less and she slipped away at 3am.

We received so many cards and letters. Many from people we didn’t even know. People had heard of Sadie and were inspired by her, so they took time to write and express how they felt. We couldn’t be more proud of our brave little girl. Sadie’s funeral followed a week later and we were glad to see that so many friends came (although I couldn’t see faces – it was such a blur). The church was full. Drew was so strong and he got me through it.

Sadie was buried in the church cemetery in our village, so it’s a comfort to know she’s close. Visiting her grave is still very hard and we try to keep visits to twice a week.

It was an honour being Sadie’s parents. We miss her deeply as she has left a huge void in our home and hearts, which will always be there. I believe in my heart that Sadie’s spirit is in heaven and I hold on to the belief that we will be reunited again one day.

We are so grateful to everyone for all the support we have had. Our friends and family have been amazing and they give us so much strength.