

WHOSE LIFE IS IT ANYWAYS?

AFTER YEARS OF SHATTERING CANCER THERAPY

This little girl says she's had enough and so does her mother. But doctors refuse to stop treating her. So who's right?

As Leah BETH Richards lay sobbing in her bed, her mother Kathryn could hardly bear to look at the pitiful little scrap that her once lively happy daughter had become. The eight old had been the picture of health dashing about on her quad bike, enjoying horse riding and playing with the other children in the close knit Welsh community of Beddau, north of Cardiff. She loved school, her terrier Charlie and following her older sisters around. But after seven months of gruelling cancer treatment following surgery to remove a massive stomach tumour (the third in her short life), Leah Beth was at breaking point. The side effects of the highest grade chemotherapy and radiotherapy her body could tolerate, plus the after effects of traumatic surgery had left her shattered. Her weight had dropped by 9lb, her hair was gone and her skin was cracked and black around the right side of her stomach from the side effects of five times of week radiotherapy. Leah Beth was being fed through a gastric nasal tube and couldn't walk more than two steps without keeling over with exhaustion, says her mother Kathryn, 36 a housewife. Five weeks earlier she had been discharged after 24 weeks in hospital. Because of the strength of the chemotherapy, she had been nursed in isolation, says Kathryn. She had become doubly incontinent and was often too weak to lift her head to vomit. Passing faeces was painful and she had constant mouth sores. I remember her asking us if she was going to die and when we said "no of course not" she would say "I feel better now" pick herself up and get on with having the next painful treatment .

But now with three radiation treatments left to go, even Leah Beth was cracked. I known my daughter and realise she would not give up the fight lightly says Kathryn. So where she looked me in the eyes and begged me in the eyes and begged me with tears flooding down her face, to end her treatment and give her some peace. I knew I had to abide by her decision. She knew by giving up treatment would mean her life expectancy would be much shorter, but she had got to the point where she didn't think it was worth carrying on. We had to make a choice between quality and quantity of life and if we had few special months rather than a couple of miserable years then that was what she wanted. I made her a promise she would not have to go back to hospital. But having made that impossible choice Kathryn discovered she was not able to honour her promise. She called the hospital and asked to speak to Leah Beth's paediatric oncologist. I explained that she suffered enough and as her mother I was determined to support her. I wanted to halt the last few treatments of radiotherapy, says Kathryn. I don't know what I expected, perhaps attempts to try to make me change my mind or agreement to a postponement of the treatment. But instead the consultant said if that's your attitude, we will get child protection services involved.

Kathryn says I burst into tears shaking with anger and fear .I had nursed my child through three bouts of cancer I sad by her bed night and days for seven months doing the job of the nurses. The doctors used to check with me her drug dosages and they trusted us to be in charge of her isolation unit. Leah Beth was capable of making up her own mind about her treatment. She known all about her illness, she used to correct the nurses if the got they got her drugs muddled up and knew all the medical jargon. But as her mother I had no real rights over my daughter's treatment. And as the child Leah Beth had no right at all.

Medical guidelines say this is not quite the case. Although traditionally children under 16 have not been considered competent to make their own medical decisions, their parents acting for them have the right to withdraw consent for treatment any time.

But if doctors feel the treatment is in the child's best interest, no matter what the child or parent wants, they can simply as Leah Beth consultant so abruptly said involve child protection services and instigate court proceedings.

As an adult you have the absolute right to refuse consent to any treatment says Michael Keegan policy advisor of the General Medical Council.

The Richard's nightmare began in December 2000 when Leah Beth suddenly developed a swollen tummy within a week she looked like a famine victim says her father Marks 51, a security consultant.

On December 21 we took her to our GP who send us straight to the hospital for a scan. We were told to take her to the oncology unit at the university hospital. It was not until we walked into the ward and saw all the photos of former patients with bald heads that I realised we were in trouble. Showing the scan the oncologist explained that our little girl was suffering from a very rare form of childhood kidney cancer called Wills tumour. Fewer than 70 children a year in Britain are diagnosed with it. The cause is unknown and the survival rate for the first episode is around 85 per cent. We were told Leah Beth would need chemotherapy to shrink it before it was surgically removed. Leah Beth had the first of her fortnightly doses of two chemotherapy drugs. Within days our once lively toddler lay there sick and wizened like an old woman. She had to wear nappies again and unable to eat, was fitted with a gastric tube.

In April the tumour was successfully removed .The surgeon had to remove Leah Beth left kidney but said he was confident that the tumour had no spread. Three weeks later she was home. She went back to the hospital for ultrasound scans and blood tests but as she became stronger we dared to hope she was truly in remission.

Ten months after her discharge Kathryn put Leah Beth in the bath and noticed her stomach was swelling again. Within a few hours the little girl was lying in the ultrasound department's hospital. The tell tale signs of the tumour came into view of the screen. This time it was more aggressive and her prognosis was no so good.

The chemotherapy dosage was much higher and Leah Beth was very sick. And while the second operation was a success this time as follow up chemotherapy she was given four weeks of radiotherapy .It had to be focused on an area which included her ovaries and womb which means she will never be able to conceive a child. Doctors said it had also damaged a section of her heart. But the treatment seemed to have worked .For three years and nine months she was in remission. She put weight back on and her hair grew back. With the permission of the hospital Mark felt confident about taking his family on holiday.

The first week in Spain was idyllic he say but on the middle Sunday Kathryn and I were sitting watching the children Leah Beth was wearing a bikini and suddenly Kathryn turned to me with panic in her eyes , Mark look in her stomach, she said.

One of the characteristics of the Wilms tumour is that it can grow back overnight.

I didn't say a word I just ran back in the villa where I vomited and sobbed says Mark .He drove Leah Beth to nearest children's hospital.

This time the swelling was on the right hand but there was no doubt what it was as the tumour showed up on the screen , the radiologist looked over at me and I said you don't have to tell me Leah Beth cried , the I did and even the had tears in his eyes.

The doctors put her on a very strong form of chemotherapy called ICE, a combination of three drugs of ifosfamine, carboplatin and etoposide, which basically kill everything.

We were told this was a last treatment that could be given just once to children or adults when the cancer was proving particularly aggressive.

But it also destroys the immune system; he says .Within a few days of the treatment starting Leah Beth experienced shocking side effects, nausea, hair loss, loss of appetite and extreme fatigue.

She was as close to death as she could be says Mark.

After four weeks of chemotherapy and several weeks recovering in isolation the remaining tumour was removed by a surgeon. Leah Beth was allowed home.

As an outpatient she was then to start a course of high dose radiotherapy to mop up any undetected cancerous cells lurking in her body.

She had only three doses left when she decided she could not face any more.

The radiotherapy had been carefully calculated and to miss the last three doses could be costly in terms of Leah Beth's life expectancy.

Despite his wife's pleading and daughter's tears two days later he took Leah Beth to hospital for radiotherapy.

When Mark and his daughter reached the hospital, events took what he calls a suspicious turn.

As soon as I got there the oncologist came up to me, he says Leah Beth was underweight and had to be re-admitted.

I think this was the doctor's way of keeping her in the hospital so if necessary the hospital could carry out the treatment against her wishes. It was also a way of making sure we understood exactly who was the boss.

Throughout her final three treatments Leah Beth was quiet and compliant.

But a few days later she turned on her father, she said she would never trust me again says Mark with tears in his eyes, now she won't even let me take her to the dentist.

Today a few months on Leah Beth is back at school and through she get tired easily is enjoying life again.

Only time will tell if that last bout of radiotherapy was successful in preventing a recurrence of yet another tumour. There is a strong chance another will appear.

If that happens because she had the strongest chemotherapy possible Leah Beth will be offered only palliative care to ease her pain and her parents are now united in their determination that their daughter will decide what treatment she receives.

The next time they try to force my child to have a treatment against her wishes they will have a battle on their hands. I will go to prison for her if necessary.