

Story Eight

We were left in no doubt she had 12 months to live.....

Aoife was five and she died about six months after diagnosis. The only treatment offered was radium. She had chicken pox we thought, or a post chicken pox virus. But her gait was gone. She would take a stagger. A relative said there is something else. We went to the GP. He still said she had middle-ear infection. We went to the Eye and Ear and they said go to the children's hospital.

When the Eye and Ear said go the children's hospital, we had a feeling. Every so often she had the wobbles, but she was feeling great. A consultant said it was a classic case of chicken pox infection. But a little registrar, a foreigner, kept saying she should be getting better. They could have sent us home, the consultant said go home.

We said no, unless we see the neurologist, we will not go home. We got to the neurologist: he listened to us. He looked at Aoife, he said I think something is going on, we will send her for a scan. On Thursday, she cried for the first time. She had to get a local injection for the MRI. We took a taxi for the MRI.

She was recovering and the consultant was to come down [to talk to us]. He didn't. A nurse who had come from the children's hospital said we were going to go back. So I said to my husband that he should go [on a planned business trip]. He would not.

When you looked around you, you saw a nurse talking to the team. There were no smiles. We knew it was serious. We went back to the children's hospital at about 2pm. We waited and waited. We were called into a room at about 5pm. His face said it all.

Maybe he was the one to tell us. He was the primary consultant. This consultant said it very, very clearly. If you had hit us with a sledgehammer, he said there was no hope. I remember he did have one young member of the team and she was upset and hysterical. I remember looking at her, felling sorry for her, she was young with light hair.

There was no rush. We were in a bit of a broom cupboard near a ward. He told us a specialist nurse would talk to us, would go through the plan. He left us in no doubt she had 12 months to live. He said they did not know a lot about it, the condition. They had discovered another child with it and this child was ten or 12. He was trying to say 'you never know'.

So they moved us to a private room. The consultant spoke to my relative and I went back to my family. I should not have driven the car, but I went very slowly. The nurse gave us the plan. We had been told to be as honest as we could with Aoife. Everyone, we said, has good and bad cells. We gave her a very simplistic explanation.

We did not tell the kids initially. Aoife was grand at this stage. We sat them down and told them. We had been given guidelines: we knew not to lie to the other children. They

asked if she would die. We said we hoped not. They were very visibly upset. I told my mother and brothers.

Aoife had a year done in school. She went back to school after six weeks of radiation. The school were fantastic. I went in there in the guise of a teacher to help. She was there for about two weeks but it was evident the radiation had not worked, although I would not have admitted it then. It held the tumour but did not shrink it. Her left hand was not great and her eyesight was affected.

We went back to the hospital for various visits. They would talk to us about this and the other but they did not look at her, did not re-examine her. Why bring them in? Aoife could go for a walk because we had someone [with us]. We were assigned a specialist nurse but we did not get on and a change was made.

When Aoife got to the stage she was not well enough for school, we brought her to Lourdes. We also went to a healer in the West. He was very realistic. He said if the radium worked I give it a 50-50 chance. He was the only person who gave us some hope. He did not rip us off.

We also went to another alternative guy. I found him terrific. He was keen on diet and staying away from certain foods. At least you felt you were doing something.

Aoife was great. She loved being at home, doing art. She was very much as always, without the mobility. Later we went to Disney. She was in good form.

On the Saturday before she died she said could she have coco pops and ice cream. I said wait until the hospice nurse came. She loved her food and she said can I have my yucky medicine.....probably she realised she was not getting better.

In November we went to the hospital. They were under pressure. They were a little bit astounded. Three children had been diagnosed on the same day. They said we normally get one or two a year. It was obvious Aoife was not doing good, others got remission.

They asked to send her for another MRI. I had promised her no more injections. I said what was the purpose, what will it tell us? We decided against it. They offered us a scan. We went into a room and a consultant told us they could do a "shunt". He said the decision is yours. My husband said "what would you do if it was your child". The consultant said it is *your* child.

So we sat and talked about it. Aoife was not uncomfortable, she was coping. She died three weeks later. She would have died anyway.

Two weeks before she died, Aoife was at home. She took a turn for the worse. The GP thought we should send her to the children's hospital. My husband said it was time to call the hospice. He rang the hospice. A doctor and a nurse came up. They were lovely. They

got to know us and Aoife. The hospice anticipated everything what was going to happen. We had every possible contraption, medicine and care, every day.

She was never on morphine. The only pain was lying in a bed or couch. Her speech would have gone. We would bring her down every day. She had full call on the TV. She liked Shrek, Nemo and Beethoven. We let no one into the house, only family. The family did the nursing.

She was getting weaker. We had a birthday and we had a bit of a party.

The following day we told the other children she was going to die. Aoife would sleep in her room. Then we brought in another bed. Sometimes she might wake up and watch a movie. She might get the days and nights confused, but we just went with it.

On the Monday Aoife did not want to go downstairs. We always had somebody with her and over a period of time she said she did not want to die and did not want to grow old. At night she would kick a lot. The Sunday before the hospice came in, she said 'I am staying'. It could have been in bed, or whatever.

The hospice came in on the Monday. She was weaker. I said [to them] 'how is it?' I said she is very comfortable. She [the nurse] said she is not going anywhere. I said what is happening next, she has not eaten? She could see how she was wasting. She said the next stage could be a coma, up to three weeks. I said 'Oh God'.

I did not want to give her an injection. They told us what could happen and not to worry. My pharmacist knew more about the medicine than the doctors: she sourced things, told us about the medical card, and got phone numbers. I think the GP should have a bigger role to play.

We knew ourselves she was not going anywhere. I rang a friend, a Shaman who said you need to say the light will always be there for her. We had a low lamp and we brought a candle up instead. And said the light will always be here with you. I said do you see any horses, Aoife indicated yes.

They are all waiting for you, I said. And when you feel like it, feed that horse some grass.

My husband was awake. I was asleep. We turned her over, rotated her. I woke up at 2. She was fine. I woke at 3 and my husband was dozing. She was very quiet. My husband felt her. And said she is going.... get the kids. We got them to the bed, told them what was happening, not to cry. . We got back into the bed. She let out as sigh, and went.

We stayed with her a half an hour. We rang a friend and she came over. She died on Tuesday and we kept her till Thursday. For three days we did not want callers, only family. The consultant from the children's hospital rang and the nurse was on to us. They spent an hour talking to me.

We had the removal from the house, with Mass the following day. The priest cried, it meant a lot to us.