

The Secretary

Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

11 April 2005

Dear Sir/Madam,

I would like to raise some of the issues my family experienced following my nephews diagnosis of a rare brain tumor cancer in 2003.

My nephew was only seven years old when he passed in 2004. He was the bravest child who underwent his cancer treatment with great dignity. There are aspects of his cancer treatment, however, that were not as good as could be.

My family was lucky to even had extra time with Justus following his diagnosis and radiation treatment. Justus had been sick for some weeks and his grandmother who was often his primary carer, had taken him to the Princess Margaret Hospital a number of times. In each instance though, they had been sent home with no diagnosis save inferences raised by medical staff that Justus may have had some emotional problems due to his home situation. My mother finally tracked down an old family doctor who demanded the hospital undertake a CT scan upon Justus who was by now very sick, and that did then reveal his tumor. Unfortunately, as Justus was not a private patient and as the PMH did not have an MRI scan it was a number of days before the hospital could tell use more about the tumor and whether an operation might be possible. The emergency doctor indicated to Justus's mother, and myself who was also present, that it was unlikely he could be treated and therefore he would die. The PMH surgeon met Justus mother at the hospital on Saturday and told us there would be no operation, and also we were lucky he had come in on his Saturday to let us know the result of the MRI. A number of days had passed between the emergency room diagnosis and the surgeon's opinion. Not once in that time had we been offered any counseling despite the overwhelming tragic news we had been given. At emergency, a doctor had told us that someone would talk to us the next day but that did not happen, Justus could not be admitted to the cancer ward (and its services) until after the MRI and neurosurgeons opinion.

Even after Justus was admitted to the cancer ward, it was really only his mother who was offered counseling and information about cancer services. This was despite the fact that his grandmother had also been a primary carer, and I had been, in the Aboriginal sense, his second mother. My family felt that the hospital did not understand the extended Aboriginal family, in which family members other than parents often had close relationships. The PMH has adopted a 'Statement of Reconciliation' however, the Aboriginal liaison officer was a non-Indigenous woman who could not even assist my sister with parking vouchers. Not surprisingly, she wasn't asked for any more assistance. I would think that the hospital, and the Cancer Foundation of WA, should work with the Derbaarl Yerrigan Aboriginal Medical Service to offer services to cancer patients and their families.

The Charles Gairdner Hospital offered alternative treatment, and once Justus (and myself) had a reiki treatment. Although Justus's steroid treatment had made him ravenous most times, I noticed after the reiki a calmness had descended on him and he walked straight past the candy bars on the way out. I really think it is children who should have first preference for alternative treatment, and PMH should talk to the Browne's treatment centre at SCGH so that children can take advantage of the treatments at the hospital. In the days that Justus was passing, It would have been good to have had alternative treatments to help him, but as it was we couldn't even seem to get toys or paints from the cancer OT.

I know that his own doctors at the hospital and the nurses, were very kind and did the best they could. I also understand a psychologist may have been appointed after Justus passed. Not long before Justus passed a baby owl flew into the hospital and was kept a few days until better. Justus had passed the morning he was to be released and all his family were there to see the baby owl fly off. We would have liked to have said something in his name, however, there was no opportunity given.

I have wondered since if Aboriginal families are just not reached out too the same way as white families, perhaps people think we deal with cancer in our own way. It's not true, we need support and help like everyone else.

Yours sincerely,

Hannah McGlade