

My Long Weekend

Though he was known to our service for over 6 months, I met Peter, his wife Dee and their teenage son for the first time on the show public holiday last Friday.

Peter had been into the specialist palliative care clinic only the week before – showing more signs and symptoms of his brain tumour progression. He was finding he was slowing down in his responses, had a decreased appetite and was experiencing new pain. His medications had been adjusted, his steroids increased.

He had asked for a guitar on the day before I met him and had spent part of the evening in the lounge playing it with his son.

On the Friday before I arrived his wife had spoken to me on the phone saying Peter had vomited his tablets, was in a lot of pain and unable to get out of bed. As she was a midwife I talked her through giving a Sub Cutaneous (S/C) injection of Morphine which quickly worked and he was able to make it up to the toilet. I arrived with extra equipment and items to care for him if he became bed bound.

We managed to get him back into bed – taking a long time as he was hypersensitive to any touch and the process of the messages from his brain to his body were very slow. We were patient with him and eventually he was sitting up in bed. He was a very private gentle man but he showed a great amount of courage and was even a bit cheeky with us. I put in a S/C line and gave him some medication for nausea and pain. He settled for some time whilst I spoke at length with his wife and son. His family were very worried about how quickly he had deteriorated in his condition and wanted to know what to expect. I spoke about the trajectory of his disease and how things might move along quickly if he was unable to take his steroids. His son was scared and swung from ‘do something to save him’ to quite matter of fact ‘what’s the point of doing anything to him at all?’ He asked a lot of questions.

During this visit Peter developed a severe pain that took a good deal of time and three more injections to settle. We discussed with Peter what his wishes were – did he want to go to hospital, what investigations may be offered, how far he wanted to take things? Peter told us he wanted to stay at home. Finally the medication we had given him started to work and he settled to sleep.

I left after 4 hours, leaving his wife with breakthrough medication she could give for pain, nausea or restlessness. I phoned later in the day and made a plan to arrange the GP to visit in the morning and we would assess his condition and maybe start a syringe driver once we knew what Peter’s requirements were. We also spoke of the supportive church community who were visiting, praying, bringing food and standing by if she needed anything.

The next morning his GP did an early home visit and by this time Peter was not speaking and barely rousable. He had had a ‘bad’ night with pain and Dee had needed to give a lot of breakthrough Morphine injections to keep him comfortable. She was tired, anxious and upset. We started the driver and then gently gave Peter a wash and helped him to sit on the side of the bed to wee. She was so worried that he would be embarrassed but we tried to keep his dignity and he was relieved to be in fresh clothes. He continued to sleep peacefully.

More time was spent with his son, talking about if Dad could hear him, how he could help, his concerns about Dad not eating or drinking and what the driver was for. One of our respite Volunteers dropped in to bring a urinal, she was also arranged to pick up medication if needed.

Dee had a cry and accepted a cuddle and a cup of tea. She had let their family in the UK know Peter didn't have long. Peter remained peaceful for the rest of the night and into the next morning. Dee got some sleep. She knew that when Peter died she would call us. She also knew when she did this was up to her. Peter was hers, and we could wash, shave and dress him at her pace. She was mindful of her son and wanted to spend the time but didn't want to upset him. We talked about how her son was watching her care for his father right up to the last moment and beyond. He was losing his Dad, it was going to be hard and he would grieve, but he could see that she was doing all she could do in love, gentleness and upholding his dignity.

Peter died peacefully about 3 in the afternoon with Dee and two friends sitting praying with him. They said he reached up towards the sky with both hands and had a single tear run down his face. The friends helped Dee to prepare Peter to leave the house. She called me once he was ready. He was dressed in a beautiful suit and tie and would have been happy to know he was presented well – he was fussy like that.

When I arrived D was almost brimming with joy. She was so pleased he had remained at home to die. Home was where he wanted to be. He was peaceful.

Carolyn Mandersloot 23/5/18