



BOOK EXTRACT

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Chapter 10

Confirmation of the relapse hit Jess understandably hard and her first dose of chemotherapy had been very difficult to tolerate. She didn't want to return to school again; she felt weak and sick, unable to walk any distance without using a wheelchair. Her operation for a new Hickman line came up quickly and we were all relieved once this was done, Jess included. Her fear of needles had escalated to such an extent that monitoring her blood had become near impossible. I tried to persuade her to return to school, if only for an hour or so here and there, but she had lost confidence in herself and worried about how her new friends would perceive her. Jess had some lovely friends and I felt she needed their friendship and support. By the time she had recovered from her Hickman line operation, two weeks had passed since her first dose of chemotherapy and the side effects of the drugs were starting to become evident. When Jess had had treatment before, her hair had fallen out gradually, getting thinner and thinner until eventually she was left with a few wispy bits. This time her hair loss was rather more dramatic, perhaps a sign that her body was not so resilient and she was more vulnerable to this regime of chemotherapy than we had first thought.

Jess was lying on the sofa watching television, her head on a cushion, while I was in the kitchen cooking the tea. Suddenly she screamed. I ran to her immediately and she met me halfway in the hall. The hair that had been in contact with the cushion was still on the cushion, leaving poor Jess with half a head of hair. As she walked towards me, further clumps were falling from her head and leaving a trail on the carpet behind her. The sadness in her eyes was immeasurable; she had willed this hair to grow with every ounce of her strength. Tears welled as she ran her hand over her head and all the hair she touched separated from her scalp. Crying bitterly, she sat back down and removed the rest of it, angrily placing it in a pile on her lap; within minutes it had all gone. She was completely shocked and ran upstairs to her room as neither Gemma nor Stewart had noticed and she dreaded their reaction. Seeing Jess pull her hair out like that stands out in my memory as one of the single most heart-rending moments of our last few months together. To Jess her hair was a symbol of her return to health and her confidence in her new school, so to lose it again was completely devastating for her. The shock of losing it so quickly affected her deeply and it was some good while before she was able to look at herself in the mirror again.

I followed her upstairs in an attempt to offer some comfort and we sifted through her cupboard to find some of the hats she had relied on before. She choked back the tears in favour of her anger, barely able to speak and visibly shaken. She didn't like any of these hats anymore, and I had to agree she seemed to have grown up such

a lot over the past few months and her fashion sense had changed beyond recognition. We agreed to go to town as soon as possible and try to find some hats that suited her more mature look. She found this thought comforting, although she wanted to lie quietly in her room for a while and listen to some music. I gave her a hug and left her alone, coming downstairs to have a chat with Gemma and Stewart. I warned them both that Jess had lost her hair very suddenly and they must be careful not to upset her about it. They felt really sad for her and when she did appear they both hugged her, trying to comfort her in their own way. Gemma went to give Jess a kiss, which Jess found a bit odd as she never liked to be too close, and her reaction sent all three of them into fits of laughter. It was good to see them all laughing, it was such a tonic, and it helped us all to make light of this very awkward situation.

Despite this light-hearted moment, Jess would not return to school, as she couldn't face her friends in case her changed appearance should provoke an unwanted reaction. Preferring to hide away at home, Jess opted to have visits from the home tutor once again. I know she missed her friends and it must have been painful for her, but her fears won over. It was difficult for her and it was also difficult for me to know what to do for the best, but I lived in hope that I could persuade her to pluck up the courage to spend time with her friends again.

Following Jess's relapse I contacted the Make-a-Wish Foundation again. Our trip to Florida had been postponed due to the horrific attack on the World Trade Center in New York on 11 September 2001. The uncertainty surrounding further terrorist activity, particularly involving aeroplanes, had led to the Foundation's decision to cancel all trips to America until further notice. Jess had been happy to wait and see whether this decision would be reversed in the New Year, but she was well at that point and now things were very different. The Foundation agreed to arrange another wish for Jess and so planned for her to meet the band members of Hear'Say. Much of the trip was kept a secret from Jess until the last minute in case we weren't able to make it, and we nearly didn't. Jess's immunity started to wane and she became very neutropenic again, and she also needed another blood transfusion. She developed a very high temperature and had to be admitted to hospital for intravenous antibiotics over the weekend prior to her surprise trip. We were due to travel to Manchester on the Wednesday and stay there until Friday. Nicky had not expected Jess to react so dramatically to just one dose of chemo, but her previous course of treatment had damaged her bone marrow along with her kidneys and her body was obviously much less able to cope this time around. There was some positive news, however: on examination, Nicky could not feel the presence of one of the tumours quite so clearly and it was thought that there may have been a positive response to the treatment despite Jess's poor condition.

This response, however small, was very encouraging and we tried to hang on to that. Jess and I often talked about her illness but I tried to persuade her to remain positive, and I promised I would never give up hope no matter what anyone said. We tried to concentrate on willing Jess's condition to pick up in time to go to Manchester. We had learned to live for the moment and nothing else mattered to Jess at that time. As those few days went by, Jess got more and more excited, although Nicky didn't actually give her permission for Jess to make the trip until the Tuesday when, right at the last minute, her blood results showed a marked improvement. Jess was overjoyed and her euphoric celebrations lifted the spirits of everyone around her. Nicky certainly breathed a sigh of relief, as she had dreaded having to deny her consent for the trip. Jess was in a huge hurry to leave the ward and, in ritualistic style, freewheeled down the corridor, yet again defiant of the rules but celebrating not only freedom but also a dream that really was coming true!

We had quite a schedule to keep. The uncertainty as to whether we would be going on the trip or not had meant I was not as organised as I would have liked. Jerzy was unfortunately unable to join us on the trip due to work commitments, so my brother, Kevin, kindly offered to drive us to Manchester. He arrived early on the Wednesday morning in a brand new people carrier supplied by the Make-a-Wish Foundation for our use over those few days. Jess was so very happy, excited and in tremendously high spirits. It was wonderful to see her so smiley; if she had any sad thoughts on her mind she certainly didn't show it. So, together with Gemma and Stewart, we set off in eager anticipation of our unfolding adventure.

We had to stop several times on the way up to Manchester, eventually arriving at our hotel around 4.00 p.m. And what a hotel it was! It had been arranged for us to stay in five-star accommodation for two nights in one of the most expensive hotels in Manchester and Jess was treated like royalty. Kevin and Stewart shared one room and Jess, Gemma and I shared the other. The rooms were en suite and had a minibar, much to the children's delight - over the time we were there they ate all the jelly beans!