

BEYOND THE RED DOOR BY JANET SHAW
CHAPTER 1: WAITING AND WATCHING

In some ways it's probably a lucky thing that I was born with cancer. If the tumours had started to grow later in my life — say at age three or four, or even eight or nine — I would have been aware of the many things that happened to me, as well as being witness to the effects on my parents. I would have watched the blackness creep stealthily into my world as the tumours multiplied in my right eye, robbing it of all vision. I would have sensed the shock and great sadness of my parents when the diagnosis was made. I would have stood by helplessly as my mother grew thinner and thinner and my father more distracted and worried. Maybe I would have shared their fear of death. As it was, the only thing I might have been aware of as a thirteen month old baby was the frustration of bumping into invisible objects on my right while crawling around on the floor.

I was born with a rare form of cancer called retinoblastoma. It is a hereditary condition, caused by the mutation of the retinoblastoma gene. Such a mutation triggers the growth of cancer cells on one or both retinas of the eyes. Being an adopted child, it was impossible for the doctors to say why it had happened, but they decided it was just a freak of nature, a spontaneous mutation. The disease had infiltrated both my eyes. My right eye was riddled with tumours and beyond saving, and my left had four tumours. To confirm the diagnosis that the lesions were indeed malignant, and therefore life-threatening, my right eye had to be removed and a biopsy performed. Although this eye was totally blind, the impact of losing it was not lessened for my parents. I would receive my first of a series of artificial eyes once the socket had healed, but would have to wear a patch in the meantime.

But there was no time for waiting, no time for coming to terms with it. If the tumours were malignant rather than benign, it was only a short distance for them to invade my optic nerve and my brain.

They were.

Because the cancer was so advanced, the doctors held little hope for my survival. A decision had to be made quickly about how to treat the tumours in my remaining eye. The simplest solution would be to remove it as well. But such a traumatic procedure was felt to be pointless and cruel if the cancer had spread and the predicted outcome was right. And there was just a slim chance, a small speck of hope, that the cancer might be beaten. With that hope as a focus, an intensive course of radiotherapy was proposed so that not only my life, but also maybe some of my vision, might be saved. Even then my chances of survival would only be about one in four.

Finding out that I had retinoblastoma naturally was a great shock to my parents. But for my mother, an unnerving sense of déjà vu was aroused. Before I was born, a story on the

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television news had caught her attention. The story had been about a child with this rare cancer, retinoblastoma. It had touched her so deeply, triggering such a strong desire to know more, that she had taken several trips to the library to do some research. No other story about children's medical conditions had ever caused her to respond this way.

Another blessing — albeit in a strange form — of having cancer at such a young age is that I thankfully have no memory of the six weeks of radiotherapy treatment that followed. For my parents, there was no escape; the memory would haunt them for years.

I was given ten days to recover from the surgery before the daily treatment began. The threat that hovers in the shadow of cancer does not allow time for the niceties of life, the traditions of Christmas and New Year. I was discharged from Perth's Princess Margaret Hospital in time to spend Christmas Day at home with my family, but that's where the celebrations ended. My first treatment session was scheduled for Boxing Day 1967.

The linear accelerator, the machine that would direct the radiation waves at my tumours, was at another hospital, Sir Charles Gairdner Hospital. My grandparents, who lived close by, took care of my two older brothers and my sister while my parents drove me to the hospital. The scene in the waiting room sent a fresh wave of shock through my mother. The room was full of parents nursing unusually quiet babies or placating restless young children. She could not stop the tears that began to trickle down her cheeks.

A young woman cuddling a sleeping baby in a nearby chair noticed my mother's distress and asked her if she was all right.

'No,' she sobbed, 'my baby has cancer.'

Without hesitating, the woman replied, 'That's what everyone here has.' The starkness of these words surprised my mother. She suddenly realised she was not alone, that others were experiencing the same agonies, that others had found the strength and courage to keep going.

It was at this time that my stubborn streak really showed itself. The radiotherapy could only be administered while I was asleep, my head needing to be kept still as the rays homed in on their target. A strong sleeping drug was given to me by a nurse, and the waiting began. My parents took it in turns to pace up and down the corridor with me in their arms, expecting the drug to take effect quickly. But no-one had read me the rules, and if they had I would have fought them anyway. In my desperate efforts to fend off the sandman, I bit hard into my mother's unprotected arms, leaving nasty red teeth marks which would later develop into bruises. There was no way I was going to give in.

The sleeping drug's dosage was increased, but to no

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avail. Sighing and shaking their heads, the doctors told my parents to take me home. No treatment could happen that day. Try again tomorrow, they said. Once safely in the car, lulled by the gentle motion as we drove home, I fell blissfully asleep. Turning the car around, my parents made a dash back to the hospital. They were in luck: they had not lost their place in the queue. The first treatment went ahead as planned.

I repeated this performance every time I went to hospital for my radiotherapy. Even with the sleeping drug — now adult strength — being given to me at home before the trek to the hospital, I still refused to comply. My mother's arms became more bruised with my ongoing struggle and my parents' stress levels grew steadily. My determination to stay awake only made it harder for them to endure the long weeks of radiotherapy, and to witness its effects — the vomiting, the circular red patches on my cheeks. By the end of each weekend, the effects of the drugs and the radiation itself would have worn off enough to allow some normality to return to our lives. But this was short-lived. On Monday mornings, the pattern would begin again as I was doped up for the next round of treatment.

At the end of six weeks the treatment was ceased. Then came the hardest part of all, the waiting and watching. The maximum amount of radiotherapy that a baby can handle had been given to me, with a little extra thrown in in desperation. If the tumours didn't respond, no more radiotherapy could be administered safely. Some other treatment that was even more radical would have to be tried.

At first the tumours showed no sign of change. As the days passed plans were made to combat them by way of a radium implant. But before my parents could completely absorb this new information and prepare themselves for the added risks, things started to happen. All but one of the tumours began to shrink.

My parents' emotions swung between excitement, hope and fear as the waiting and watching went on. The unchanged tumour stayed stubbornly the same size while the others continued to grow smaller and smaller. As time wore on and the biggest tumour showed no signs of change, the specialists reluctantly made plans to use a radium implant. Almost on cue, as though giving in to pressure, the last tumour began to shrink. And it didn't stop. It gradually kept reducing in size until it disappeared. My eye was now clear of any tumours. But the cancer had not left it unscathed: my vision had been affected and I did not have full sight in that eye.

Being free of cancer didn't mean I was cured: it didn't mean that everyone could relax, forget about the threat and go back to normal life. Cancer is like an invisible bomb that can go off at any time. It would be five years before I could be given the all clear, five years before the hollow echo of the bomb's

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ticking no longer haunted my parents.

The waiting and watching continued. My eye specialist kept me under close observation, with regular check-ups every three weeks, then six weeks, three months and finally six months. These examinations to monitor the situation should have been short and simple: a brief visit to the eye specialist's rooms where a bright light and magnifying lens would allow him to study my retina where the tumours had been. But the doll made of silver bottle tops that tinkled merrily when shaken could not distract me from the light that hovered like a blinding monster in front of my screwed-up eye. My struggles to get away from the monster made it impossible for my doctor to see anything. The outcome was always the same: the sympathetic shaking of heads, yet another hospital admission booked for an examination under anaesthetic, and as I grew old enough to understand, the shedding of my tears.

And so my introduction to hospitals, doctors, nurses and anaesthetics began at an early age. As the saying goes, first impressions are lasting, and my first impressions of hospital certainly have left a clear imprint on my mind. The memory of one stay is particularly vivid. On that occasion, not even my Raggedy-Ann doll, the one specially chosen from all my other dolls and animals to come with me, could provide any comfort.

The bed was hard, its crackly white sheets distinctly stiff and unfriendly. The fair-haired, skinny little girl with soulful eyes that I was at the time surveyed the scene around her little desert island. Both sides of the long rectangular room that seemed to have no beginning or end were lined with beds like mine. In each bed was a child, whimpering, screaming or just lying quietly. White uniforms bustled to-and-fro, some of them pushing rattling steel trolleys, others carrying clipboards. I looked down at the grey floor, the familiar tile pattern, and tried not to cry. I knew the routine, what lay ahead. Nothing had changed. The bath had been just as big and unwelcoming as I remembered it from last time, and the time before ... I huddled miserably in one corner while the compulsory wash took place. Afterwards, I had to hold up the hospital pyjamas, so flimsy and baggy, as I walked to the scales. I hated those cold metal scales. Sitting on them made me feel like a handful of mince being weighed at the butcher's. The walk back to my bed always seemed to take an eternity. Fear stopped me from looking at the other children as I passed their beds. Instead I concentrated on the long legs which strode purposefully in front of me, the white shoes matching the crisp white skirt.

The unforgettable taste of the antiseptic thermometer revolted me as always. 'Try not to bite it,' the nurse would chant. But I never quite succeeded in keeping the thin glass tube away from my teeth. The task was made even harder when

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the nurse wandered off, forgetting to come back.

'Oh, have you still got that!' was the surprised exclamation when she eventually did return.

I hugged my Raggedy-Ann doll tightly and bit my lip.

But the tears came anyway. I had cried when my mother left only minutes before. And now the total isolation was closing in, the sea around my little island growing wilder and more vast. Loneliness, fear and dread were my only companions.

My dislike of hospitals not only haunted my waking hours, but also troubled me when I was asleep. A recurring dream, or rather nightmare, I had between admissions was a regular and terrifying visitor.

In the dream a filtered light, its source unknown, illuminated the room just enough for me to see. Everything looked normal: the chairs, wall-hangings and below-bench cupboards were in the right place. But there was something strange, something terrifyingly different. Something was making my heart beat louder and louder, tightening my throat so that I could not scream. The door to my parents' bedroom stood at the far end of the room. It was the middle of the night. They would be asleep, but a burning urge told me to reach them, now!