

Blog of the Month

December 2019 Written by Rosie Holdsworth Leicester Medical School

Short Story:

1. "Pyjamas"

by Rosie Holdsworth, Medical Student, Leicester Medical School

"Pyjamas"

"I'm so glad you came, doctor", says our patient's wife as she opens the front door. Her eyes are pink and shiny. In the living room, her husband moans softly in bed. His face has taken the shape of the skull underneath, but in the photographs on the mantelpiece, his cheeks are fat with life. A child's painting reads: "for the best grandad in the world". The doctor has brought him some medicine in her battered leather bag, and she has brought our patient's wife some medicine: a hug. His wife is crying again, feeling desperately out of her depth, wanting someone to reassure her that she is doing right by the man she loves.

My mother felt the same when I visited her in my grandfather's dying days. She was so relieved by my presence that she started to cry as she emptied the washing machine. The place was spotless; evidently, cleaning was a comforting ritual. She wanted my appraisal of the calm environment and the care she was providing, needing me to say that she had done well. All this was new to her. I climbed the stairs, expecting a palliative patient, knowing the drill from my training, but finding my grandfather. He, too, was shaped like the skeleton under his skin. I was greeted by an adjustable bed, a cardboard tube for urination, and little wet sponges on sticks. The things that I left on the ward had grown feet and chased us into our family home. My patients allowed me to help them when they needed to go to the toilet, but this was my grandad, and he waved me out. He was ashamed to see me, and the embarrassment made him distressed, so I left. You have a sense of "goodbye" in your head, the things you will say, wrongs righted, a pressure for poignancy. But I said "goodbye grandad", and walked down the stairs to help my mother wash his pyjamas.

Our patient is calmer after the medication goes in, and so is his wife. He is quiet, sleeping under the cottage beams. A card with a puppy on it reads "get well soon". Once in the living room, the doctor explains what will happen when our patient dies, and the patient's wife nods along. Information fills her up like a shot of whiskey, and she is strengthened by it. "Sorry for being so emotional. I was trying to get him into his favourite pyjamas, but he was so heavy I couldn't get them on", she said, fresh tears coming at the corner of her eyes. "I'm meant to be his wife, and I couldn't even do that for him. And then he struggled to breathe. I know he will die, but I just don't want him to suffer, doctor". She stops, unable to go on. Of course, she did get the favourite pyjamas on him in the end: love is stronger than muscle. He died before she needed to change them again.



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On the ward, our patient is making high-pitched keening sounds. The handover sheet reads: learning difficulties, end of life. He doesn't need to give us words to show he is in pain. We have been trying to contact his family, but he has no one left. The only person who loves him is a paid carer, and she is on her way. The doctors prescribe anticipatories, and our patient's high-pitched noises follow us on the ward round, steadily decreasing in volume and frequency.

In a care home, our patient had been on an end of life pathway for years. Every few months, she rallied, sat out in an armchair and had a cup of tea. Then she returned to bed to rest for a long time. Her bedroom was bright pink and everyone knew her by a nickname. On the day she died, the undertaker's listed her formal name on the cabinet, and it took me a while to find her. We visited the care home after completing the cremation forms, and the manager cried. Our patient had been part of the carers' lives throughout the final years of her own, so being without her was strange. We went into her room and looked at the empty bed. A pragmatic woman, ungiven to sentimentality, the manager said "we turned her every hour at the end. She left without a single pressure sore". And her expression added: because we loved her.

Our ward patient is quiet now, sleeping in bed and no longer making those high-pitched sounds. A blonde lady with a faux fur jacket sits on a chair at the side of his bed and introduces herself as his carer. She has brought his favourite cosy pyjamas with her to hospital, and our patient looks peaceful in a magenta velour dressing gown. With enthusiasm, she describes the way his bedroom is set up at home: a favourite nightlight switched on, fresh bedding, soft blankets, a book she likes to read to him. She plans to cook his favourite meal once they get back. The doctor gently suggests that our patient probably won't be up to eating, and might not even wake up again. She understands. "I'm just glad to have him back, even if it's only for a while - he's my favourite". The TTO is completed unusually swiftly because we don't want him to die on this ward, surrounded by bright lights, unpleasant smells and alarms. We want her to take him to that cosy bedroom, and he leaves us just in time.

Our palliative patients have symptoms, but those who care for the dying have their own symptoms, too. One of these symptoms is the need for things to be "just right". Perhaps anxiety and fear drive these compulsive deathbed preparations, maybe it is pure love. But everyone deserves to die in their favourite pyjamas, and our loved ones make this possible.