


'Death is freedom, life is a lesson'

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By **Moira Petty**

For 36 years, Jonny Kennedy suffered from a painful, incurable skin disease. But his effect on everyone he met was inspirational

WHEN JONNY KENNEDY was born in 1966 he had no skin below the knee of his right leg. It looked like cod's roe, his father remarked, and it was two days before his mother was allowed to see her child. At the time there was no pre-natal test for epidermolysis bullosa (EB), the painful and incurable skin condition from which Jonny suffered, and as he grew up he came to have strong views on EB pregnancies.

"I was asked one time if I would carry on with a birth knowing that an EB child would be born and I said 'No. I would terminate'. It's not just a disabled child that's being born. It's disabling a whole family."

Jonny Kennedy died at 36, and no one who watches *The Boy Whose Skin Fell Off*, Channel 4's remarkable documentary about the last four months of his life, would conclude that he lived in vain. He was funny, he was mischievous, he was reflective. And in agreeing to be filmed, he not only revealed the effect that his condition had on those who cared for him, but left the distinct impression that he gained from life, and that those who knew him gained, too.

He was a practising spiritualist who saw death as "a freedom, and escape" and life as a lesson. "I came down (to earth) to understand what it is like to be in discomfort all your life and to learn about frustrations and possibly overcome that. I feel I have learnt my lessons and come to terms with it," he said.

When he fulfilled his aim of flying in a glider, his exuberance made him think

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about celestial heights. "I think I'll be bored if the angels sit about on clouds plucking their harps all day. I'll be up there, getting them off their clouds, doing drops of 1,000 feet and then pulling up. I think you need to spice things up a bit."

Yet this was a man whose skin continually shed, leaving his body covered in blisters and open wounds. By the time of his death, his hands and feet had been rendered unusable by the shedding and stretching of the skin. When his mother, Edna, changed his bandages he cried in pain.

"When he was a baby, every time I picked him up he blistered. It was like handling an over-ripe peach. I coped by putting my emotions in a box," she says. "Considering everything he went through, he was a good baby. I felt sorry for his older brother because all the attention was on Jonny and there could be no rough and tumble. Yet Jonny was always the leader. When Simon was five I gave him money to buy crisps. He turned to Jonny, who was three, and said 'Will you do it?' Before I could stop him, Jonny was up and in the shop."

When you meet Edna, it becomes clear that Jonny has inherited his candour, courage and humour from her. She is 63 and runs a farmhouse bed and breakfast business in Rochester, Northumberland, and she is open about her late husband's inability to cope with Jonny's condition, and the pressures this caused. "Every time I went out with the pram people would ask 'What's wrong with him?' Frank didn't like Jonny being an object of curiosity and tried to hide him away. When Frank had an angina attack not long before he died, we went to visit him in hospital. As soon as Jonny arrived Frank shut the curtains. It must have been hurtful for Jonny. He asked me 'Why does Dad always do that?' "

Simon recalls how their father would check on Jonny every morning. It became an ongoing joke that Jonny would cry out: "I'm still alive!" "Great," said Jonny. "Your father thinks you're going to snuff it every night you go to bed."

Jonny had charm. At his school for the disabled, he "wound the teachers round his little finger," says Edna. "They would ask me to collect him, saying he was ill, and he would walk down the corridor beaming all over his face. He

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left having learnt next to nothing but at 13 we got him a tutor and she knocked ten years of education into him in a year.”

As a consequence of his condition, Jonny did not go through puberty, and his voice was high and fluting because of scarring to the vocal cords. In the summer of 2002 he developed a rare and fatal skin cancer and decided that he wanted his last few months of life to be “extraordinary”. He would fly in a glider, host a house-warming party at the new home in Alnwick in which he was achieving independence, and visit 10 Downing Street, and organise an unforgettable funeral, “which I hope will bring a smile to people’s faces.”

In June he ordered his coffin and went to watch it being made. He wanted a tiger carved on the side, to denote strength, and “at the far end, the Heinz beans sign. I want people at my funeral nudging each other and saying what does the Heinz beans label signify? It doesn’t mean anything but it will get them talking.” Then he turned to the issue of storage. “Where would you recommend me to keep the coffin because I’m not using it straightaway,” he said deadpan.

Over a drink in his local pub with Simon, Jonny asked him to speak at the funeral. “My mother’s not going to be in a fit state to say anything,” he pointed out. “Well, who is?” Simon replied. “Oh, bollocks, you can say something,” says Jonny. “You can say: ‘Thank God that old fart has gone’.”

Later, speaking direct to the camera, Jonny said he would be happy “as long as Simon thanks everyone for coming and says ‘He was my brother’.”

Jonny died in his wheelchair on the train returning from a meeting at Downing Street with Cherie Blair. He had been so weak before going that he could barely lift his head. “But he told me to mind my own business,” says Edna. “Later I was told that Cherie Blair asked him: ‘Have you been here before?’ and he replied: ‘No, and I don’t want to come again’.

“When he was told he was dying, it seemed so cruel after all he had put up with. He showed no fear. He felt anger and frustration. He was prescribed Prozac but stopped taking it as he felt he wasn’t in his own head when he was on it. I’d always imagined that I would have been with him at his death. But there was no fuss and I think that’s what he would have wanted.”

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The family met Jonny's body off the train in their car with its hydraulic ramp. Edna sat in the back with Jonny. "I just made sure he was all right," she says. "He looked better in death than he did in the Downing Street pictures, in which he looked like a living corpse."

At his funeral, one of his chosen songs was Queen's *Don't Stop Me Now*, with the lyric: 'I'm having a good time, like a tiger defying gravity.' The tiger was his emblem, says Edna. "Nine months before his death he laid a trail of paper paw marks in the house leading to a life-sized stuffed tiger with a note: 'There's still a lot of tiger left in me'. The day after he died, I went into his safe for documents and there was a note for me which said: 'Do not be sad for I am free. I could not have done so much with my life were it not for you. I leave you with a symbol of my strength and all my love'.

"I opened the parcel and found a large gold brooch of a tiger with a ruby for an eye that he had had commissioned. I could have murdered him that he had gone to such bother." Edna's eyes glisten with pride as she touches the brooch on her lapel.

The Boy Whose Skin Fell Off, Channel 4, Thursday, March 25 9pm.

DebRA funds research into EB. To make a donation visit www.debra.org.uk or ring 01344 771961.



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