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My Brother His Stepson Barry

Archie Hill

Life within a prison of flesh

In the first programme in the series, 'The Light of Experience' (BBC 2), Archie Hill described his relationship with his stepson, a 26-year-old spastic.

I wasted the first 30 years of my life. Those years took me into many personal dark corners, where I existed inside a vacuum. I seemed always to be on the outside of life, looking in at things to envy. I think I was more of a wound than a person. When I was a young man, I travelled a hard road as a drunk, lived rough for longer than I care to remember, sat in the stagnancy of prison cells and alcoholic institutions.

I was the eldest but one of 11 children brought up in the lean days of the pre-war depression, and you do not go down on your knees in that sort of environment and thank God for his blessings. You are too intent making sure you have got a place in the street-corner free-soup queue, too busy surviving to worry about the here-after. God did not seem to be sharing my life and I was not much concerned with Him.

It is only very recently that I did accept God as being as real as the churches would have me believe, and I was filled with loathing, hatred and contempt for this God. I wanted to meet Him face to face, to spit on Him, to throttle Him slowly with my own two hands. I wanted God to be real, so that I could do that to Him. My hatred for Him was the most intense I have ever experienced, including six years with the armed forces, including time spent as a homeless drop-out and a convict. It came about because of my 26-year-old stepson, born to my wife's first marriage. He is 100 per cent physically and mentally handicapped—a number wiped off God's blackboard. He cannot walk, talk, feed or toilet himself, or do any solitary thing. He is 26 years old and, still, my wife has to wash him, just like a baby. Sometimes, his eyes are bright with knowledge, but his body gets weaker and weaker, and more and more useless. I marvelled that such a body could have kept the flame of life burning for so long. Every morning, the slow ritual of undressing—stripping off his pyjamas. This is a task he resents strangers doing for him, but, when my wife and I do it, his eyes tell us that he trusts us. Perhaps he feels the affection in our hands.

I estimate that my wife has changed 35,000 nappies in his lifetime. For 20 years, she had to wash those nappies after use; it is only recently that she learnt that disposable nappies were available. Happiness for my wife became a disposable nappy. We have to cut slits into Barry's shoes so my wife can make sure his toes are not doubled over. If they are, it is painful; he will be in pain all day, and he won't be able to tell

us. He is not heavy to lift (he only weighs five stone), but it is difficult to manage him. Sometimes, his limbs convulse and you could drop him. Death is not necessarily the worst thing that can happen, providing it is peaceful; but we are frightened of making his existing disabilities worse. And four or five times a day he has to be fed. Sometimes, a meal takes an hour, because he has difficulty in swallowing.

There is a great bond of life between mother and son, and a deep, closed world

'I have learned rich things from Barry. Things I could never have learned from Bible or pulpit or churches'

of love; and I love him too, as if he were my own flesh and blood. Recently, he was operated on to have a lump removed from his groin, and it turned out to be cancer. So now we take each day at a time and wait for him to die. When I learned of the cancer, I felt that Christ's words 'Suffer little children to come unto me' were not true. The words were 'Let little children suffer', as Barry has suffered for so many long, droning years. I could not see any 'God's purpose' in what was happening to Barry and my wife, only God's spite and malice. If there is a God, then when He made my wife's son, His hands trembled with some dark malice. He was in an angry, indifferent mood, filled with private petulances. My wife believes in God. 'God will love him,' she said. And I am angry that she thinks this, because this God she believes in is the Ugliness which rejected him in the first place, and gave her a treadmill to walk for more than 26 years.

My wife and I watched a television programme about thalidomide children, and my wife said: 'I wish Barry had been born thalidomide; it would be a 90 per cent improvement upon what he is.' And her quiet remark hit me between the eyes and stunned my brain, so that I could have sat down and wept blood. For 26 years to be locked inside a useless prison of flesh; no external signs to indicate whether the computer of his mind is fully at work. I hope it is not. Because if it is, if it has been, then he has been a castaway isolated on a tiny strip of land poking up from a dark, deep sea, deep and dreadful. And lonely. I hope he has a quick and not a lingering death to wipe him clean, to blow his candleflame out.

And how can we tell our young son that his brother is dying? His mouth will droop to sadness because he will not under-

stand, because I do not understand. I shall dredge up empty clichés, comforting homilies. I shall give him verse and text and chapter. But the poison which is filling me must not infect him. When we first came to live here and my young son started school, he seemed so alone and forlorn, so devoid of friends. And I wondered about it, and felt sad because of it, perhaps because it reminded me of my own lonely boyhood. I think I found the answer for the loneliness in his brother, who spends so much time sitting in his wheelchair, watching the world go by. Kids passing to and from school could see him there, and I heard one of them say to another that Barry was 'a dummy'. And I knew then that that was why Robin was not making friends, that our crippled boy was the barrier between Robin and other boys of his age. And I wondered if I should keep Barry out of sight as the children passed by, and then thought: 'If I do that, why not go the whole hog and put Barry in the cellar and chain him to the wall, and give him straw to sleep on?' I went to my young son's school and showed slides to the children. I showed them slides of handicapped people who were cut off from social life. Not violent or unpleasant pictures, but 'pretty' pictures. And I explained to the kids what being handicapped was and asked them what they could do if they had someone in their street who was handicapped. 'Please, sir,' they said, 'we could knock on the door and ask the lady of the house if we could run errands for her.' 'Please, sir, we could ask to take the cripple out in his wheelchair for a walk.' It worked. Robin has many friends now, and brings his special pals home for meals, or even to stay weekends with him. They accept Barry for what he is—a human being who got short-changed by fate. But the period was a difficult one.

Robin could have grown up to resent his brother, be ashamed of him. Equally, my wife and I could have foisted responsibilities on to him like 'Barry-sitting' and things like that. But, from the very start, when Robin was born, we knew that Barry was our responsibility and not Rob's. What Robin does for Barry he does unselfishly, not from a sense of duty; and he enjoys it.

Some time ago, I stood behind Barry's wheelchair in the front room and tried to see what he could see. I mentally locked my feet against the floor, so that I was helplessly fixed in a single position; dependent upon someone's charity to move me. And I tried to see what he could see. What I could see was a small enough world. His wasted neck-muscles gave him no more than 30 degrees of head-turn; they narrowed his frontal vision to almost straight ahead. He could see people and events pass in front of his eyes, but could not turn his head to follow them to some sort of conclusion. Housewives with shopping-bags passed up and down the street. He knew many of them by sight, through long hours at the window, and gurgled greetings to them which they could not hear. As I stood there, I willed one or two to look up our pathway to the window where he sat, to smile for him and wave

a greeting. But passers-by were too absorbed in their own problems to see a boy at a window. They were just brush-strokes upon the small canvas of Barry's frontal vision. Each stroke separate, with no plan or purpose or relationship.

'Put Barry away,' the doctor told my wife when he was 11 months old. 'He will never walk or talk or do anything for himself. Put him away and forget about him, and have another.' And I remembered when I was a boy in a farmyard near my home, and the sow had farrowed and given out more piglets than she had dug to feed from, and the weak chap of the litter grew weaker and weaker. A runt from birth, a loser, and his siblings pushed him to one side, and he and they squealed for the milk-dugs. 'He winna mek it, gaffer,' the pigman said to the farmer, and the farmer shrugged like God. 'Put it down, then,' he said, 'and let the sow get on with it.' And I saw the pigman take the piglet by its hind-legs, it squealing and pleading to be allowed to live, and he dashed its head against a wall. The piglet died while its community of brothers and sisters gurgled and grunted at the pleasurable udders. 'Put him away,' the doctors said. To her, his mother, my wife. And they did not look at her when they said it; they looked away. Because, if they had looked at her, they would have seen God-hope in her eyes; and they knew that God had gone away.

She did not 'put him away'. She took him away—she took him away to her secret places of motherhood and womanhood. She took him away and kept him and, in the keeping, relinquished most of her own life. She gave her own life as an extension of her son's. She even plans the planting of the garden each year, so that she can take him around it when the flowers are in bloom. She plants them, so that they are the right height for him to see them from his chair. Does he take it in? Can he appreciate it? I don't know, but it is an attempt to stimulate his mind, to involve him as far as we can in the normalities of life and nature. The normalities which life and nature have denied him.

He was such a beautiful baby, clean-limbed and perfectly formed. He was a dark-haired baby, with brown eyes that laughed out at the world. She doted upon a miniature of perfection which would soon show the development of gross imperfection, the decay in the bud. I do not think that she thought then her son would be imprisoned in a wheelchair all of his life, and she prisoner with him, never able to develop her own creativities.

But, in her mind, she was not tied by fetters of duty, but by love. A closed world of love. So rich a world, it is beyond description.

I had never met love like this before. My ideas of love had been so shallow. What privileged few amongst us really know what love is? We know self-love, pride-love, power-love, money-love, comfort-love, dependent-love. We know shallow-love and glitter-love. These are good and rich loves, most of them. But there are different levels of love, and the deepest depth of all is this closed world of love between a mother and



Barry: 'His has been the purer life'

a useless creature which was the child drawn in pain from her body into a poisoned light of day.

A 16-year age gap exists between Barry and Robin. But, in every respect of development except actual age, Robin is now 'older' than Barry. But Barry was firmly established in his needs and dependence when Robin was born, and perhaps my wife didn't want Robin to be born. Perhaps, partly because she secretly feared that he, like Barry, might be born imperfect, and partly because she knew that Barry was a full-time responsibility. But, equally, she was sad for me, knowing a man's proudness in a son to fulfil the dreams, perhaps, that he himself has not achieved. When she conceived my young son, I tortured myself with guilt because of the conception. Could she cope with the dual role of responsibility, had she enough of herself to share? Would, after all, a twisted, ugly fate duplicate the errors of Barry in the new life to come? The Fates were kind, they gave normality.

Perhaps I love Robin more than I love Barry; I do not know. I do not think so. But Robin is a boy who runs to me, happy in the coming, joyful in the union of dad and son. Barry I have to go to. Lean over, make comfortable, Help care for his body-needs,

constantly aware that I must often be in his arms and legs. I can enter into Robin's life and share it, but I cannot enter into Barry's; only guess what goes on inside his mind. I wonder if he is lonely in there, cut off. And, sometimes, in his eyes, I see a deep, dark aliveness staring out at me with an equal intelligence, and I find myself almost expecting him to speak. A few nights ago, I wrapped him in a blanket and took him on to the back porch and let him look at the sky. I had not thought to do this before. But, suddenly, I wanted to give him new experiences, to share with him some deepness from inside myself. I wanted to fill his mind with happy wonder. Things I had taken for granted, like moon and stars and night, suddenly seemed filled with magic. Sitting with him on the porch, I felt some strange awe. An explanation of how I had become me. How millions of sperm-like seeds were sent on a long journey, millions of microscopic seeds. How, for a full-grown man to compete with this sperm-journey, he would have to cross the Sahara on foot, swim ten miles up a stream against a raging current, climb the Alps and walk halfway across Siberia—at one go, without pause or rest and without help beyond his own physical resources. If any one of the seeds had reached the egg instead of my seed, I would not have come into existence. And I looked at Barry and marvelled that the seed which became him had won through. And it came to me suddenly, that the end of life, Barry's mine, was not important. The miracle of everything came about with the seed's journey, which brought life into being. Sitting with Barry, I looked at the stars and knew that we are both part of that same system.

I have learned rich things from Barry. Things I could never have learned from the Bible or pulpit or churches. I think I have learned a treasure, always, the trust and affection Barry had for me. I will remember, always, the way his eyes lit up as I walked toward him.

I asked my wife what I must do when Barry dies. 'A handful of family,' she answered, 'and cremate him. I can't bear to think of him underground.' So open the prison and let him blow free and ride the wind until the ashes settle and, maybe next year, next spring, he will nourish flowers.

I think of those years that I have watched and about people whom I have hurt, and I measure this, myself, against Barry's years of physically helpless existence, and I know then that his has been the purer life. Everything about him, exudes gentleness. He has not known hate or malice, greed or spite or self-pity. And now, when selfishness or self-pity start to poison my thoughts of Barry. And, from his helplessness, I find a strength and tenacity of purpose filling me up. And then I do not seek to question 'God's will', but I trust in the Sacred Woman, Nature, and I know that the feeling of heartbreak in the heart of things is but a moment's hesitation on the threshold of a deeper, serene, purposeful unknown. And then, so, I almost touch that peace which passes understanding.