

Begins today: The true and moving story of one man's confrontation with the strong, immovable force of a mother's love

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**B**ARRY was 14 years old when I first met him, a wee thin little chap living in a wheelchair; he couldn't speak or walk . . . but his eyes were warm with deep intelligence.

His eyes were the main things I remembered about him. Rich, warm brown, like his mother's. He seemed more like a six- or seven-year-old child than 14. Small and light-boned, Barry was no more than a shadow in the corner of the room.

I seldom looked at him in those early days—it was his mother I watched, because I was in love with her. He was merely a shadow-image at the edge of her life who had no claim on my attentions.

When I asked her to marry me she was serious, solemn, with a strange withdrawn look about her, as if reliving some experience, some memory, that was not of me. "Would you want children?" she asked at last, and I shrugged. "One or two, perhaps," I said. With sadness in her eyes, she replied: "No. I can't marry you. I have Barry—he needs me." "I need you."

Dark eyes on mine. "You are fit and healthy. Barry isn't. He needs me more . . ."

"You can't go through life on your own," I said. "You need a man. You're young—and I can help to look after Barry . . . he's only a wee chap, no trouble at all."

"He won't always remain small. He'll grow. He'll need me more and more as he grows older."

I thought about it, then let my mind shrug its shoulders.

"I'm not bothered about children," I said at last, "it doesn't matter if I don't have a child . . . I'll make Barry my child."

### She invented a game to help Barry exercise

Her face softened, the warm and radiant beauty came back.

"Think about it," she said, "and tell me when you are sure."

"I'm sure now," I answered. So we were married soon after.

I used to watch her with him, him so small and thin. Every night for a couple of hours she'd take him from his wheelchair and lay him out on the floor, then massage his limbs and exercise him.

She'd make a game of it with him. Then she got two lengths of wood, like snow-skis. At the front end she fastened a pair of Barry's shoes; and at the back end she fastened a pair of her own. She'd slip her feet and his into the shoes, then supporting him from behind, she'd make Barry's legs go through the motions of walking.

No good ever came of it. Barry never learned to walk. Yet hour

after hour she'd sit with him—calm, serene, never impatient.

Sometimes I felt stabs of jealousy against the boy because he took up so much of his mother's attention. When she was with him, I felt in second place. And I wanted always to be first.

When I became aware of this jealousy I tried to destroy it, to get it out of my system. I'd clown around for him, try to make him laugh . . . entertain him to ease my own guilt.

He was still very much of a room-shadow that sometimes blocked out the light. But I tried to accept that he'd got to share his life with us, and I'd got to share my life with him because I was sharing his mother.

I watched her spoon-feeding him with egg and bread and milk whipped into a paste so that it would go into his mouth easily and without choking him. The paste oozed from the corners of his mouth and she scooped it back with the spoon. Slow, slow, she was so patient, and gentle . . .

The aspect which moved me most with silent pity for my wife was her courage and devotion.

And I worried because I knew there must be a breaking-point even for her. I could only supply the muscle-power, the physical effort of lifting and carrying Barry. Perhaps, sometimes, my services to him were tainted with irritation or frustration.

But I could escape sometimes; my job brought me some freedom. As I closed the front door I could leave the helplessness behind me for a while. For me, there could be distractions, entertainment. But not for my wife.

She is a woman of great sensibility, charm and intelligence. But the outer show of serenity is delicate and increasingly vulnerable. The years have taken their toll.

Has my wife ever hoped? I think she has. Perhaps secretly wished for that peace which would come with his death, perhaps for cure and normality. Such hope looks for miracles; the only true miracle is her constant love. This remains.

Barry weighs, now, about five-and-a-half stone; and if we could straighten his limbs, he'd measure a reach of about 5 ft. 6 in. He's so helpless that he can't even turn himself in bed; one of us has to do this for him when he whimpers from bed soreness.

Yet, from the debris of the crippled body which houses him, Barry shines through it all. Eyes quick to light with laughter, although sometimes with silent tears of frustration. His eyes will always haunt me.

Lifting, carrying, bathing, hair-washing, teeth-cleaning, shaving,

clipping his nails, toileting, unblocking his nostrils, changing his nappies . . . plodding tasks around which life must revolve. I have constantly watched my wife at these tasks and have been moved beyond pity.

I'd never met love like it before—my ideas of love had been so shallow, so self-centred. 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 and love by many other names; we know man-woman love which, as time passes and youth with it, turns into the safety of comfortable habit.

### The letter arrived—I couldn't believe my eyes

There are good and rich loves, too . . . but there are different levels and depths of love; deepest of all is this closed world of love which exists between a mother and her helpless child.

Early in our marriage I was working as a jobbing-builder. I wasn't enjoying the work, but it paid the housekeeping. Then I wrote a short story. When I'd finished it (my first) I thought it rather good; but I stuck it away in a drawer and forgot about it.

Then I came home from work one day, and there was a letter propped up on the shelf, addressed to me from the BBC. My wife said, "Open it." I couldn't believe my eyes.

"The BBC," I blurted. "They've accepted that short story I wrote." Then a thought struck me. "Hey," I said, "I never sent the story off!"

"I sent it," my wife answered. "You know how often I've said you had so much in you. Do you see why I sent it off for you?"

"I shall learn to be a writer," I answered. "And I'll keep at it until I win."

Her eyes were very warm. "Yes," she said softly, "I hoped that's what you'd say."

That year I wrote five more stories and three radio plays. They were all accepted. Life was splendid except for one small dark spot ever coming into my mind.

"Give me a child," I said to her, my wife, "I want a son of my own."

Her eyes, dark and sad, looked into mine.

"We agreed not," she answered. "It would take me away from Barry. I couldn't cope. You said a child wouldn't matter."

"It didn't matter then," I said, "but lately, it seems to matter more and more . . . I'm in my mid-thirties and I keep wanting a child of my own."

She went shopping, leaving me to tend Barry. He'd become very

real in my life, he'd stopped being a mere shadow. I sat looking at him, seeing his mother's face shining out from his; but my resentment towards him grew.

"Why do you have to exist?" I asked him heavily. "Why don't you die and make room for others?" His eyes, like his mother's, were solemn on mine . . . almost as if he understood my words. The doctor said that he couldn't understand anything.

"You do understand, don't you?" I said. "You're not my son—you're another man's son."

His face was grave at the tone of my voice; he knew there was no laughter in it. His head was angled to one side, puppet-like. He seemed so frail and vulnerable, yet his eyes were his mother's eyes looking out at me.

Then I felt a great surge of pity. I went to him, lifted him from his wheelchair, carried him to the bedroom to change his nappy, which was wet and uncomfortable.

"Poor little bugger," I said to him, "it's not your fault you got short-changed at birth." His face laughed up at me, his senses recognising the change in my voice. I put a clean nappy on him, and dressed him clumsily, big bunches of clothing hunched and lumped around his body. I picked him up and put him back into his wheelchair, placed a bib around his throat to catch the dribbles.

"I'm going to have me a child of my own," I said to him, "come hell or high water. But don't you worry—you'll still be safe here. We won't throw you out."

When she conceived my child I felt unease which grew almost into an obsession. Could she cope with the double role of responsibility? She was always calm, that was the way of her. Calm and serene, tapping personal reservoirs of serenity which I never knew existed. I used to ask myself how she recharged her emotional batteries. I knew that I could recharge mine from hers, but where did—and where does—she recharge hers?

My son was born at two-thirty one Sunday afternoon. "Is he—is he—all right?" I asked my wife anxiously.

"He's beautiful. See for yourself." She drew back his clothes as if she were opening the petals of a rose to show the loveliness of its innermost bud. I looked at my son, put my hands on him, letting my hands and my eyes search for some grossness, some disability. There he was—bawling and perfect and wholesome and complete. No blemish. No handicap. Not a single imperfection. "He's beautiful," I said, looking at my son.

Throughout his babyhood and childhood Robin became familiar with Barry's (Please turn to page 10)

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condition. He didn't ever question it; he accepted it. And as Robin grew and became more and more important in my life, it seemed to me that he acted as a catalyst to bring Barry into the focus for me too, so that gradually no distinction seemed to exist between the two.

We showed Robin gently, I think, along the years, that his brother was representative of human chance—illness. We impressed upon him that Barry wasn't a "handicapped person", but that he was a person with handicaps.

When Robin was around eight years old I became conscious that he wasn't fitting in, that he was withdrawing from other children and the social activities of his neighbourhood. He became quiet, a loner, often listless. He had no friends. His work at school started to slip, he lost interest.

From the upper window of the room in which I work at my typewriter I can see out into the lane. Often I looked out and saw that Robin was always on the outer fringes of games that kids of his own age played. They either ignored him completely, or they noticed him only to push him around and bully him. And Robin accepted the treatment, hangdog, almost fawning for favour.

Looking down on it all, watching Robin down there, lonely—I knew there was no way I could interfere. I couldn't go down to the other boys and order them to accept my son.

### Jeers from other children in the playground

It took me some time, but eventually I got to the roots of it. Some boy in the playground had shouted out to him—"Your brother's a dummy . . ."

Barry sitting there at the downstairs window in his wheelchair, watching cars and people pass, watching the kids go to school. Jerking and gurgling overtures of friendship towards them. But to at least one of them he was a "dummy". They shouted, ignorant accusation spread across the playground to wound my young son. They thought him abnormal, subnormal—by association.

I kept the secret from my wife because the knowledge of it would have torn her to pieces. Alone, I considered the problem: should I take Barry away from the window as the children passed by? Should we confine him to another room while Robin invited friends home? I asked myself these questions and felt anger boiling in my gut.

Why not go the whole hog, I thought, and lock him in the cellar? Why not chain him to the wall? Why not gag him in case he made a strange noise? Give him straw to sleep on, put the clock back to the days of Bedlam, and

charge the public twopence apiece to see what I'd got in captivity?

I took up my camera. I loaded it with colour-slide film and took pictures of Barry—happy, friendly pictures. In a few of the shots I showed some of the lesser difficulties he had to contend with. I emphasised his helplessness rather than the more grotesque aspects of his disabilities.

Then I went to Robin's school and had a word with the Headmaster; and he in his wisdom gathered the whole school into the darkened assembly hall while I projected slides on to a large screen, and then talked simply about people with handicaps.

### When I try to identify with him I am afraid

I didn't mention Robin, or say that the person in the pictures was his brother. I kept it simple and uncomplicated. Then, at the end of it all, I asked the assembled—and attentive—children what they thought they could do to help such people. Silence. Thought. Then: "Please sir, we could take him books and toys."

"Please sir, we could go to the house and ask the lady if she wanted any errands run."

They argued and discussed among themselves the best things they could do; and having aroused in them some degree of insight I left them to work out for themselves how best to use it.

Robin formed good and close friendships from then on: he started to invite his favourite mates home for tea, sometimes to stay weekends and share his bedroom. And they came to accept Barry and his abnormalities.

Sometimes I look at Barry and see a deep intelligence locked away inside him but trying to communicate with me. His eyes look at me, wise as normality. And this frightens me, because I'd rather that there was no intelligence at all imprisoned inside his body. I try to identify with it, and am afraid.

What if I were strapped helplessly inside a space capsule but with my mind diamond-sharp, and launched into the unknown void to go on and on without any control over the instruments of my vehicle, without even the power to self-destruct if I wanted?

When he had to stay in bed for a few days with a heavy cold, I sat in his wheelchair. The chair is his home, its wheels the full extent of his freedom. I pushed it to its usual position at the window and sat in it. I pretended I was Barry.

For over a quarter of a century he has sat so. I sat in it and wondered how long I could sit there. I willed myself to be helpless. When my bottom grew sore through an hour of fixed immobility, I wouldn't move, because Barry couldn't move. He had to depend on his mother or me to help him.

A fly landed on my face and explored it; I fought my hands

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from lifting to brush it away because Barry couldn't brush one away. A pigeon had splashed lime across one of the window panes, obscuring part of my vision into the garden.

If I turned my neck a mere six inches I'd have been able to see past the obstruction. But Barry couldn't turn his head, so I didn't. I heard time passing inside my mind—unhurried, monotonous time.

I wouldn't let my hands reach for the radio or television switches, because Barry's hands couldn't. Time was a funeral march inside and around me, slow-stepping, sonorous, meaningless and boring. I closed my eyes and tried to day-dream a bulk of it away, then opened my eyes because I remembered that I'd never seen Barry asleep in his chair. Always wide awake.

I couldn't see the room clock from where I was sitting. I could hear it, ticking away in tiny coughs, but couldn't read the sweep of its face because that meant turning my head, and Barry couldn't turn his head.

### 'I lasted only two hours thirty-six minutes

I thought a lot of time had passed. I thought many hours had gone by. I knew that the sun in the sky was a liar, that it had crossed more space than that. I couldn't put up with it any longer, I had to get out of the chair and move about and feel my legs under me, and scratch my face with my fingers, and go to the tap for a glass of water. I wanted to go to the toilet. I didn't want to sit in the chair and wet myself as Barry did, because he couldn't help it.

I looked at the clock. I'd been in the chair for two hours and 36 minutes. I thought it was many more hours, but two hours and 36 minutes had been as long as I could endure. I left the chair, Barry's chair, and felt shame flooding through me.

"Why don't you put him away?" people have often asked us in the past, "so that he can be cared for and you could be free?"

"No," I answer, "because if we did, what has taken my wife 27 years to preserve and protect would be dead inside six months."

"Perhaps that would be for the best?" they say.

"Perhaps. But he'll die when his time is due, and not for our convenience . . . we'll not let him die in torment, silent and lonely, wondering why we've deserted him to starved strangers in some dismal hospital ward."

We tried it once. We put him in a home for a fortnight while my wife, Robin and myself had a holiday. With disastrous results...

**NEXT WEEK: Barry teaches me a remarkable lesson.**

**'It doesn't matter if we don't have children. I'll make Barry my child, I told Violet. And I meant it. But I hadn't then felt the jealousy of her devotion to her handicapped son by a former marriage. Theirs was a closed world of love I could neither understand nor enter.'**

**By Archie Hill**