



(who's there?)

'Me'

KNOCK, KNOCK!

CARING FOR TWINS WITH SPECIAL NEEDS

Gwen and **Barry Evans** share the trials and triumphs of parenting their two sons.



Gwen Evans is a psychoanalytic psychotherapist from a nursing background and **Barry Evans** was an infectious disease epidemiologist

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hat follows is a brief account of our experience of attempting to access necessary provision from medical and care services for our twin sons over a 42-year period. This involved contact with

four teaching hospitals in London, another outside London, three district general hospitals (DGHS), and two hospices near where our sons were in care during the last years of their lives. Over the years we met hundreds of people who, had it not been for the

twins, we would never have met. Alongside health professionals were many care staff at their boarding school houses and in their adult care homes. With few exceptions these environments mostly worked well, and we are especially grateful for the excellent standard of care and support they and we received during the terminal stages of their lives at their care homes.

parents not doctors

The experience of caring for our twins, both of whom had complex special needs, was often of an intensity and complexity that it is difficult to convey. ►



key points



- Caring for children with multiple special needs on into adulthood places them and their parents/carers in the hands of many health, care, and educational professionals – the experiences of which can vary widely.
- Navigating care needs in a resource-stretched health and social care system puts ongoing and considerable strains on all family members, including other children.
- Receiving and demonstrating the love of God in all of life's challenges is vital to our journey of faith. However hard the struggle, there is profound beauty to be found in brokenness and the knowledge that we are so precious to God that he sent his only Son for our salvation.

◀ Being 'on the other end of the stethoscope' entailed the management and monitoring of their various medical needs, attending numerous appointments, coping with acute episodes of illness, and ultimately dealing with the terminal phase of each of their lives. They repeatedly benefitted from a great deal of expertise and treatment to which they were fortunate to have access.

Being their parents rather than their doctors sometimes led to a blurring of roles. We probably share that in common with many who want the best for their children or ageing parents. While we hold a great deal of gratitude for so much of their care, there were occasions when we were confronted with inadequate provision, unsafe practice, ignorance, and hostility. We once felt so let down and angry with a senior member of staff that we made a formal complaint.

homeward bound

We had been working in Bangladesh (where our older son was born), returning to the UK because of complications with the next pregnancy. Here we were without a home or jobs and living with a great deal of uncertainty. David and Robbie were non-identical twins born at 37-weeks' gestation. During his earliest months, David spent weeks in an oxygen tent with a serious chest infection. Over time their developmental delay became increasingly obvious, though when seeking a professional opinion, a GP told us there was nothing wrong with Robbie and we were neurotic medical parents. David and Robbie had some language skills at the level of two-to-three-year-olds, which was consistent with their global developmental level.

Throughout their childhood we were fortunate enough to have regular appointments with a chest physician at a centre of excellence. David had seizures that were problematic to control. He benefitted from a term-time placement at a residential school specialising in managing neurological disorders, with a hospital facility on site for complex epilepsy. He was there term-time between the ages of five to eighteen.

Slowly we adjusted to the demands with which we were confronted. Immediate and very demanding practical needs left little space to think through what the future held for us as a family. The essay, *Welcome to Holland*¹ encapsulates something of our experience at that time.

It became clear that it was not going to be possible to return to Bangladesh, which we found

unsettling. What to do with our dashed hopes and how to reorientate ourselves professionally? For years we were seriously sleep deprived (often doing two-hour night shifts to relieve each other) and stressed. Most adversely affected in all this was not one of the twins, or even our marriage, but our oldest son, although we tried to do our best for him too. The challenges to our faith were numerous (not least around seeking God for 'healing').

Because we needed to communicate with David and Robbie in ways they could understand, we kept it simple and repeatedly spoke to the truth that Jesus loved them. Over time we found we took this in again and again for ourselves, finding it to be profound rather than simplistic. Although our twins in this life could never understand the concept theologically, we experienced and bore witness to the meaning it held for them at the core of their being. This was, and continues to be, truly precious and comforting.

A member of David's care staff often accompanied him to a church local to his care home and commented that, although he 'did not believe' himself, he was very aware of what being there meant to David. Very sadly the same church had a particular view on healing that the care home staff later deemed inappropriate, and so the residents were no longer taken there. It had been possible to take Robbie to church during his early years, but over time he became extremely disruptive. At the hospital where he had nine admissions in the last 18 months of his life, there is a multifaith chapel

(which Robbie called church). He wanted to go and would identify the cross on the wall, ask for the very large and heavy Bible from the lectern, and sat quietly when we opened it at John 3:16 and told him it said Jesus loves Robbie very much. On one occasion it was very noticeable that the tension he had been holding lessened considerably.

The twins had an undiagnosed (probably very rare) genetic syndrome. Along with neurological impairment they both had bronchiectasis with frequent episodes of pneumonia. The entirety of their schooling was geared around their special needs, and much of this input was outstandingly good. Robbie was more clearly on the autistic spectrum, and at the age of eight he joined David at the same term-time boarding school. He knew the site from being with us during our weekly visits to see David. They were not in the same residential house, as they were better managed apart. This was possibly not the best placement for Robbie, but we had neither the time nor energy to cope with a different geographical location and school ethos.

being their parents rather than their doctors sometimes led to a blurring of roles



However, managing the school holidays was extremely stressful and each one had to be planned for on a daily basis.

nearing the end of our tether

Towards the end of their lives they were frequently admitted to hospital by ambulance with an acute deterioration in lung function. Robbie attended Accident and Emergency (A&E) on more occasions than David, requiring at least one member of his care staff and/or at least one of us to attend with him. In general, our experience of paramedic and A&E staff was excellent.

Hospital admissions were problematic. Would there be a suitable bed, if any? The wait was often very hard. As were the trolleys, and Robbie resolutely refused to ever go to sleep on one! This often happened at night. On one occasion at a London Hospital we were told that it was very unlikely that a bed would be available that night. Having been up most of the previous night and spending all day with him in a very busy A&E, which was unsettling for Robbie, we were near the end of our tether. The environment was totally incomprehensible to him, as was the level of noise. We chose to bring him home, very aware of the risks, and had to sign the self-discharge papers. Although an appropriate and necessary protocol, this was not easy to do, but we made it clear we would take him back the following day when a bed became available. The incident was reported to Social Services – again due protocol, but tough. This is what ‘being at the other end of the stethoscope’ meant for us at the time.

Our experience on the wards of two large DGHS was mixed. In general, the medical management was good, but other aspects were patchy. For every hour of every day and night of every admission, the boys had a member of their care staff, or one or both of us with them. This degree of continuity acted to protect them from the often-bewildering frequency of changes in the ward staff. Many were kind, but their ongoing contact was usually short-lived – a contributory factor to which was the frequent changes of ward to which they were admitted.

Some staff could be thoughtless. For example, on separate occasions a nurse provided a clean sheet to change a wet bed in the middle of the night but did not offer to help with the task. Despite sophisticated computer systems for medication, we bore witness to human error and potential error on a number of occasions. Mercifully, the twins’ care staff observed this too and averted some of the potential errors. The quick skill of a radiographer, who somehow managed to get a scan of Robbie’s chest done without a fight, meant so much. Such too was the care of a physio who looked nonplussed when

Robbie did not respond to ‘roll over’. She persevered and came back the next day to say hi (much to Robbie’s delight). All in a day’s work for them but they brought skill, a can-do attitude, and even an element of fun, and in so doing gave more than they will ever know. However, caring for adult patients with severe learning disabilities on general medical wards was very challenging.

facing the end

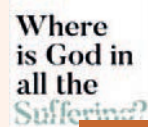
David died in October 2016 aged 36 following 10 years of progressive neurological deterioration with probable MND. He was a wheelchair user for five years. Despite having a gastrostomy peg for around a month, his inability to swallow meant he could not stop saliva going into his lungs. He died with many of those close to him around his hospital bedside.

Robbie’s bronchiectasis caused right heart failure, which in the last four months of his life became much more severe. In September 2022, he died peacefully, aged 42, with us by his side in his care home.

The journey for us would not have been possible without support from family, friends, church, and care staff, including the prayer support of many. Even though we knew this, there were times we felt isolated. More recently, we have found reading Psalms helpful, especially reading a complete Psalm. Psalms of orientation, disorientation, and new orientation have ministered to us in fresh and deep ways. At other times, there was a great deal of fun, but also, perhaps inevitably, tensions. Sometimes managing expectations (both ways) proved way harder than we could ever have imagined. We hold so many memories, including David’s joy at attending Christian house-parties when videos were made of his participation, and an album of photos was looked at most days until the next event a year on. Robbie had one joke on repeat - ‘Knock, Knock’ (who’s there?) ‘Me’. He never tired of it! Someone who knew his propensity for the knock, knock lines sent a card to us after his death stating that heaven’s gate is open wide – no need to knock.

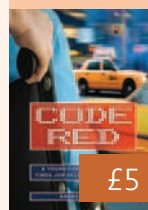
We were usually on the same page over decisions and supported each other when needing to act unilaterally. It was not always easy to ask for support, and we tried not to take it for granted, but we had limits, and being extremely weary is hard. We identified this in others too. Along the way we have become aware of many folk who struggle with major life challenges (often long-term). Our experiences have made us more open to diversity and what it means to be human. We loved our sons dearly and our loss is indescribable. Throughout we have clung to knowing God has not abandoned us. He has been with us, and ‘*he who promised is faithful*’. (Hebrews 10:23) All through the storm, God’s love has been the anchor and our hope for eternity is in him alone. ●

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References (accessed 20/11/2023)

1. Kingsley E P. Welcome to Holland. 1987. bit.ly/49LdpEk