

TWO ARTICLES FROM THE CHRISTMAS 'TABLET' VIVIDLY HIGHLIGHT A MAJOR PRO-LIFE CONVERN

In an age when we discriminate at our peril on the grounds of gender, ethnicity or sexuality, babies with certain disabilities can be legally aborted up to birth in Britain / By **MAGGIE FERGUSON**

On the side of the angels

ON 16 JUNE 1986, my brother rang from Tokyo to say that his wife had given birth to their first child, Mary. She had Down's syndrome and severe congenital heart defects. The prognosis was bleak.

It was a blessing that Mary was born in Japan. Standing by her incubator, the paediatrician told my brother and sister-in-law that the Japanese call people with Down's syndrome *tenshi* - "angels"; but Mary was weak, and grew weaker. At three months, it was clear that, without successful surgery, she had only a short time to live. Mary would have been outside any British surgeon's criteria for operability, but a Japanese cardiac surgeon was prepared to carry out open-heart surgery. She weighed less than two pounds, and there was a 50 per cent chance she would die in the operating theatre. When the surgeon opened her up he found the walls of her heart "thin as cellophane". But she pulled through. Six months old, Mary came home for Christmas.

Fast forward, and Mary is now a 36-year-old woman living a very full life in a community in Eastbourne, mad about drama, dance, clothes and shopping, and enriching all who know her. Her brother Joe says this:

"My sister's theatre group recently put on a musical. Even when she wasn't in a scene, she refused to leave the stage. That's Mary in a nutshell: hilarious, infuriating, a shameless show-stealer, determined to be right in the thick of things, a constant reminder to everyone around her that the joy of life is in really living it, getting stuck in, not watching from the wings."

So it was Mary I was thinking about when, on 25 November, I heard the news that Heidi Crowter, a 27-year-old woman with Down's syndrome, had lost her appeal in the UK High Court. She had been protesting against the current law, which allows abortion right up to the second before birth for foetuses likely to be born with severe physical and mental abnormalities - including Down's.

BRITAIN IS one of only a handful of European countries in which this kind of abortion to term is legal. And surely, as a matter of common sense, and whatever the legal technicalities, the law as it stands is sad, shocking and shameful. In an age when



Mary dances with Francis Walmsley, bishop of the military ordinariate

we discriminate at our peril on the grounds of gender, ethnicity or sexuality, how can we uphold a law which discriminates against unborn children with what are considered severe disabilities, treating them differently from other unborn children, to the point of life or death? As Bishop John Sherrington said in the wake of the ruling: "It is illogical and unjust."

Keen to know whether others shared my sense of outrage, I sought the opinions of a number of people whose wisdom and opinions I respect. Here are some of their voices.

First up, Heidi Crowter. Compared with many people with Down's syndrome, Heidi is extremely able: quick-thinking, articulate, spirited. In 2020, she married James, who also has Down's, and he joins in the conversation as she chats over Zoom from their home in Coventry. I ask how Heidi felt about the ruling:

"Angry, but more upset than angry."

Will she keep on fighting?

"Of course!"

Has she had difficult times in her life?

"Yes! My husband James: he can be very difficult!" Gales of laughter. I tell her that my husband is also called James, and he too can be very difficult. Much merriment.

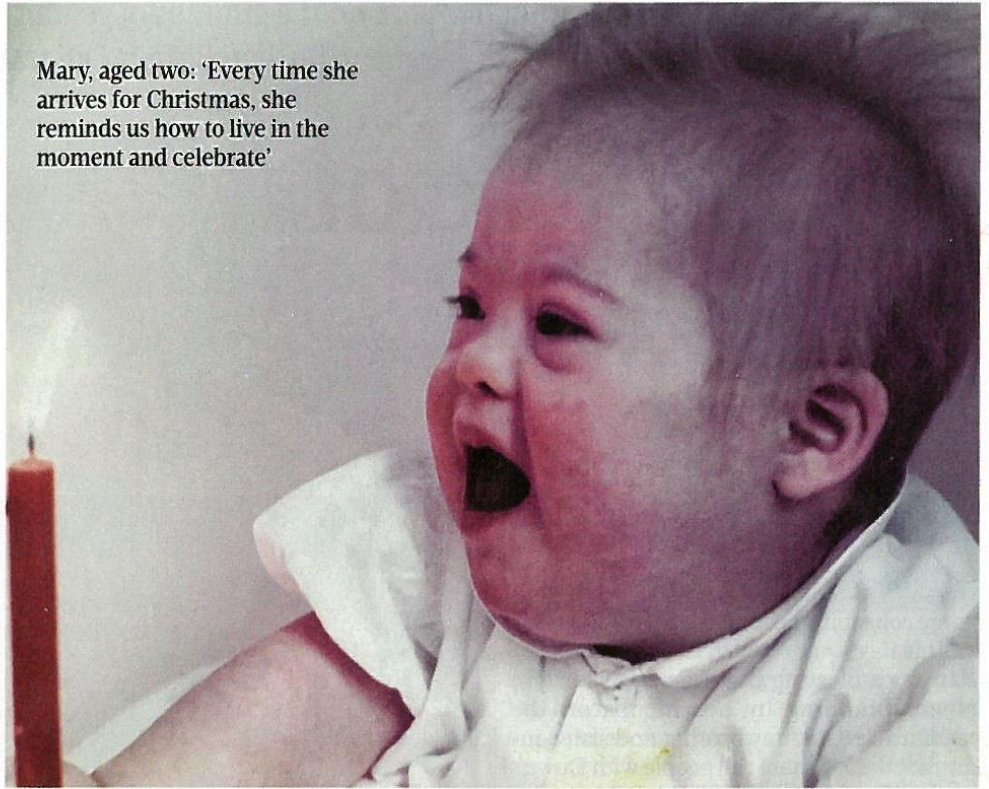
Heidi's family are Baptists, and I ask what her faith means to her. She replies by sharing one of her favourite lines in the Bible, from

Dogmas, rules and plans are important but maybe God's untidiness is important too. Maybe too much competence in running the show our way could prevent God running the show His way.

Brian Green



Mary, aged two: 'Every time she arrives for Christmas, she reminds us how to live in the moment and celebrate'



Psalm 139: "I praise you because I am fearfully and wonderfully made."

Heidi's mother, Liz, tells me it was a complete shock when Heidi was born. "We'd always been very blasé that whatever God sent us we'd love. But when Heidi arrived we were upset and angry – angry with God. Then, at two and a half months, Heidi developed leukaemia and, faced with the possibility of losing her, we realised how deeply we loved her. We asked everyone we could think of to pray for her. When she got better, the doctor said there was no human explanation for her recovery."

Finally, I ask Heidi what she would say to a woman expecting a baby with Down's syndrome, and feeling that she simply wouldn't be able to cope when it was born. "My husband, James, was adopted," she says. "So, in their shoes, I'd consider adoption."

HEIDI CROWTER'S family, like my niece Mary's, is fortunate in many ways: strong, solid, with a firm faith. Many – perhaps most – stories are very different. Chris Nancollas, a regular *Tablet* contributor, is a retired GP who was also an anaesthetist, and participated in many terminations. "It was the only part of the job which made me uneasy," he says. "I had a sneaking admiration for my Catholic colleagues who refused to have anything to do with them." Having said that, many of the cases he dealt with were "teenage girls from poor families, who felt trapped and helpless. I knew what faced them as single mothers on sink estates, and it was not pretty." The outlook could be even more bleak if the child was to be born with a disability: "Giving birth to a seriously disabled child can be awful, not just

Mary is now a 36-year-old living a very full life, mad about drama, dance, clothes and shopping

for the parents, but for everyone involved in their care. I know of nurses who left neonatal intensive care because they could no longer deal with nursing babies with no quality of life and a hopeless prognosis. Modern medicine is very good at prolonging life at the expense of quality of life. And then you get faced with the awful dilemma of withdrawing care, to which the parents have to agree, making them complicit in their child's death."

I feel Chris is nudging towards telling me that he's relieved Heidi lost her legal battle, and that there's good reason for the law as it stands. Not a bit of it. Particularly given the efficiency of modern testing, he says, an abortion

beyond 24 weeks simply shouldn't ever be necessary. "And termination at term looks an awful lot like murder, and owes more to eugenics than medicine."

Author and screenwriter Frank Cottrell-Boyce also detects "an element of eugenics" in the current law: "It's like, who deserves to live?" He has known a number of people with Down's syndrome, and his relationships with them have always been "enriching" – "but actually, that isn't really the point, is it? The point is, you shouldn't have to qualify to be allowed to live."

A gynaecologist who asks to remain anonymous says this: "The more I think about Heidi Crowter's case, the more I realise how outrageous it is. The message is loud and clear: we are discriminating against babies with Down's syndrome. In a civilised society, this is abhorrent. It's a modern form of [that word again] eugenics." She believes that "the vast majority of the public are unaware that babies with Down's syndrome can be terminated until

term”, and most people don’t know the grim details of what is involved in very late feticide. She talks me through what happens. It is too horrible to relay.

She is ambivalent about developments in screening. “With the improved sensitivity, there’s no doubt that more women are opting in, resulting in more terminations. This will lead to fewer babies being born with Down’s syndrome, and a domino effect of increased isolation and fear for couples having babies with Down’s. The resources that are ploughed into screening could be diverted into doing more to help these people.”

Short of the law being changed, she advocates better information about Down’s syndrome being circulated to parents and medical staff. “I remember the Down’s Syndrome Society once coming to speak in the hospital where I was working. They gave candid, balanced information which I have never forgotten. Educating medical students, student midwives, nurses and healthcare professionals is an area which could be developed much more. If you can help dispel fear, support and enable a woman to bond with and love her unborn child, she is more likely to choose life and avoid screening tests, which serve no therapeutic benefit, and simply result in abortion.”

TABLET REVIEWER Carina Murphy heartily agrees that people need guidance when speaking to the mothers of children with disabilities. Her 14-year-old son Laurie has trisomy 8 mosaicism, a chromosome disorder affecting one in 30,000 people. “I find it astonishing that people think it’s OK to ask me whether I’d still have had him *if I’d known*,” she says. Part of the reason she has become a Catholic is in order to move in a community that won’t question her in this way. “Yes, my son has speech and learning difficulties, but he enjoys his life, is laid-back and is game for anything. He’s known in most circles as ‘Lovely Laurie’ because of his kind, empathetic nature.”

Sara Miller had been trying for a baby for five years, and was on a second round of IVF when she became pregnant with Sophie, now 19, and discovered she had Down’s syndrome. She and her husband agreed they should carry on with the pregnancy, and she is appalled that the law allows the termination of babies like Sophie to term: “I feel some people just don’t think what they’re actually doing.” Bringing up her daughter has been demanding, she says, “and the unknown is always difficult. But you learn to take each day as it comes. And Sophie is so loving, and always has been.”

Which brings us full circle back to Mary. As the decorations go up in his home in Kent, my brother writes:

“This Christmas will be our thirty-seventh with Mary. Every time she arrives for Christmas, she fills the family with joy, and reminds us how to live in the moment and celebrate – just as she did when we brought her home for her first Christmas, a tiny, determined survivor embarking on a life full of love.”

‘Something inside me shifted: I came to feel extraordinarily lucky, as though I’d been given a sudden, sharp insight into what it was to be fully human’ / **By LUCY LETHBRIDGE**

One exhilarating truth

ABOUT 12 years ago, a few weeks into my pregnancy, I learned that the baby I was carrying had Down’s syndrome. I was upset, of course I was. I was ushered into the hush of the “fetal abnormalities” wing where everyone was anxious and concerned. There was talk of “options”. “You have to think of the welfare of the child,” said a doctor perplexingly. But I knew I wanted to keep my baby: I knew I would never be happy again if I decided otherwise. At some very deep and unconscious level, I think I felt I was being given something. At first I thought it was a challenge, but later on I realised that it was perhaps a gift.

It took a while. Early on, I wanted to feel the baby as a character rather than a case study in disability, a cross to shoulder – which is why I wanted to know her sex. We called her Katherine Zuleika, to be known as Kitty. I began to learn about Down’s syndrome – a process I found painful as nothing in my comfortable experience had prepared me for it. I had never met anyone with Down’s syndrome: in the town where I had lived as a child, there was an elderly mother often seen holding hands with her middle-aged daughter with Down’s: I had assumed them to be unfortunate. But over the months ahead, which were full of appointments with doctors and specialists (Kitty had the heart defect common to babies with Down’s syndrome), something inside me shifted: I came to feel extraordinarily lucky, as though I’d been given a sudden, sharp insight into what it was to be fully human.

About four months into my pregnancy we went to live in New York and I joined a buzzing local Down’s syndrome group which met for picnics and playdates. I loved these occasions because I saw not only how adored and wanted these children were but what immeasurable love and pleasure they gave in return. It was like the discovery of a society whose members had learned one exhilarating truth – which is that we have so much more to learn from people with Down’s syndrome than they can learn from us. People with Down’s are as varied in character as people without – but they do seem to share a capacity for uncomplicated affection, an artlessness, without side or self-consciousness; the “thing itself”. I sensed in them an uncanny intuition about loneliness or anxiety, an instinct for protectiveness. Feeling my uncertainty (and sometimes my sadness),

the children would often run over and fling their arms about me. They seemed to be saying “Welcome”. One memory is particularly piercing, of nine-year-old Joey, on a wintry Brooklyn street, leaning out of a car window, shouting after me as I lumbered home through the snow: “Good-bye, goodbye, goodbye, I love you, I love you.”

Before we left for America, we had visited the Camphill Community near Stroud and saw how young people with Down’s syndrome lived and worked productively with others. I had a DVD about Down’s which I watched a million times, pausing on a moment when a therapist and a toddler laughed uproariously together: both looked radiant. “It’s like having a tribe,” is how a group member, a mother, happily described it to me. A tribe for all sorts, all classes, all types, political persuasions, incomes and religions.

By the time the baby was due to be delivered, I was excited: I knew the tribe and I loved everyone in it. But Kitty died during labour, before I could meet her (although I had already felt her friendship). Perhaps it was her heart (though doctors had been optimistic that surgery would put it right), but no one could say why. When they told me she was dead, I heard myself crying out “bring her back”, as if she had slipped away down a path leaving me behind. We buried her in a cemetery in Long Island for still-born children, beside a roaring freeway, in a green sward like a golf course covered with markers tied with rain-soaked teddy bears. An undertaker called Mr Jones carried the coffin, no bigger than a shoebox. I remember the tenderness and delicacy of his huge hands as he lowered her into the ground.

So I went back to life as it was before. We returned to Britain, I took up my work, went back to my flat. Life as before and yet utterly changed. Kitty is always with me – not just as my daughter, but as the Down’s syndrome child who jolted the world for me, changed my perspective, shook the kaleidoscope of life into an unexpected new pattern. I have so much to thank her for. In pontificating, fulminating moments, when I am puffed up with censoriousness and certainty, I often think I feel a little tug, a reminder to look sideways, shake the pattern. I like to think it’s Kitty.

Lucy Lethbridge is The Tablet’s television critic.

.. AND, IN LAST WEEK'S 'TABLET', A FOLLOW-UP TO MAGGIE FERGUSON'S ARTICLE

WORD FROM THE CLOISTERS

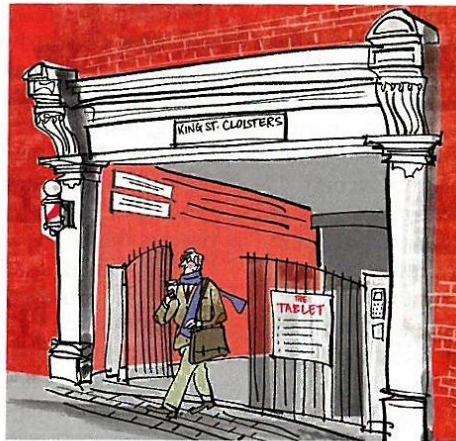
diary@thetablet.co.uk

Dancing with Mary

IN THE CHRISTMAS issue Maggie Fergusson writes about the law that permits abortion up to term if the mother is carrying a baby with Down's syndrome. It's accompanied by a photograph of Francis Walmsley, Bishop of the Military Ordinariate, dancing with Maggie's niece Mary, who was born with Down's 36 years ago. The two of them are obviously enjoying themselves enormously. Except it's not Walmsley at all, but his successor as Bishop of the Forces, Tom Burns.

Bishop Burns doesn't remember when he and Mary danced together – "it would be my turn to be wrong if I tried to estimate the actual date and year" – but it was an occasion he'll never forget.

"It was the HCPT [Hosanna House and Children's Pilgrimage Trust] annual pilgrimage to Lourdes in Easter Week, and this was the time of the homily at the HCPT Mass in the Underground Basilica. No matter how often I try to assure people that Mary's intervention was unexpected and unscripted, the more they think it was all planned and rehearsed. Far from it. The theme of the Mass was 'gifts' – particularly the human gifts who broke out of the huge cardboard



never have known how Mary was getting on over the last 20 years or so, if you had not got in touch," Burns tells us. "Oh happy fault!"

boxes scattered across the sanctuary. Mary turned out to be the most popular gift of them all. She stole the show! The musicians soon picked up what was going on and took up the beat. The congregation followed with their applause and singing, which raised the roof. The prepared homily went out the window. Mary, alive and happy, was much better than anything scripted."

Six years after he had become Bishop of the Forces in 2002, Burns was appointed Bishop of Menevia. He retired in 2019. Mary is now a 36-year-old woman, mad about drama, dance, clothes and shopping. "I would

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