



**KEEPING AN EVEN MIND**  
Despite suffering the  
gruesome side effects  
of cancer treatment,  
David Langton-Gilks  
remained optimistic



# *‘At the moment, I’m all right. Yeah!’*

David Langton-Gilks was a remarkable teenager with brain cancer. Yet amid his suffering there was fun, joy – and journeys to unexpected places. The historian Amanda Foreman, a family friend, tells their inspiring story

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PORTRAITS: JUDE EDGINTON  
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**M**idnight on Christmas Eve, 2008. A tarpaulin covering the roof of the house had blown off in the wind and sheet rain was pouring into the twins’ bedroom, through the floorboards and into the dining room below. I had moved the cots into the corridor. The buckets needed emptying every hour, and six Christmas stockings had yet to be filled (seven if I included mine). My husband, Reg, was ill in bed. His oncologist had told us that palliative treatment for his end-stage thymus cancer would begin in the new year.

The stockings lay on our bedroom floor. Stuffing each one presented an impossible challenge. And what about the rest of it? The turkey, the present-opening, all the expected games and laughter. They required reserves of energy long since depleted. I began crying with fear; a fear of failing so visceral that it caught my breath. Somehow, however, I had to keep going, like my friend Sacha. I closed my eyes and allowed myself to be mentally transported to a little wooden house in Fontmell Magna, Dorset. I could see Sacha Langton-Gilks and her husband, Toby, in the kitchen, joking with their three children. The eldest, 13-year-old David – DD – was at the table. Smiling? Perhaps not. But he was there, though pale and bald after seven cycles of chemotherapy for brain cancer.

Sacha’s voice, a sound I have known for more than 30 years, entered the vision: “I was so tired.” It was her frequent refrain, said with a conspiratorial smile at the end of some funny but horrifying anecdote about her week. “She does it,” I thought. “Follow her example.” That night, thanks to Sacha, I did it too.

I knew of Sacha even before our parents became friends. A year above me at school, she was the perfect all-rounder. In person she was natural and open, with a quirky flamboyance that matched ►►►



her bright red hair. No one was surprised when Sacha won a choral scholarship to Trinity College, Cambridge, or that she played lacrosse for the university, or that she graduated with a starred first. It seemed quite right, too, that her boyfriend for all three years would be someone as clever, popular, good-looking and musical as her. They went to London and moved in together; Sacha and Toby, a permanent couple.

Toby began as a sound engineer for the BBC while Sacha trained to become an opera singer. A show-stopping performance at a Guildhall recital suddenly catapulted her into the limelight. Offers to study and perform came flooding in from all over the world. Expecting to hear that she was off to Vienna next, it was a terrible shock when Sacha announced she was stopping, permanently. She has never regretted the decision. She told me: "I felt like I was driving a really fast car and didn't know what most of the knobs were doing. People wanted me to race when I wasn't ready." Everyone thought she would come round; we were wrong.

**T**hey moved from London to a rented cottage in Dorset. Toby worked as an independent film and television composer, Sacha gave full rein to all the creative talents that she had been forced to neglect for her singing: gardening, cooking, even DIY. On November 17, 1995 she gave birth to DD, a boisterous redhead, just like his mother. When I stayed with them, it was like a Soviet-style episode of *The Good Life*: Sacha learning to live off the land, Toby producing music for the broader collective, both wearing overalls and listening to Mahler. All the time DD roared from his pram, throwing his arms like a demented conductor. I thought how incredible it must be to have such a fully engaged baby. Sacha remembers it differently: "I thought I was the worst mother on the planet. At mother-and-toddler groups, their children



**PULLING TOGETHER**  
Sacha and Toby Langton-Gilks with (from left) their children Holly, Rufus and DD. Below: DD with the limo provided for his school leavers' prom

would happily pick up a toy to chew. DD would chuck his on the floor and shout. He wanted to talk. He wanted to know what was going on."

Life was challenging. Toby worked every hour of the day, leaving Sacha to manage everything else. Incredibly, though, both remained avid volunteers: Toby coached football and Sacha started a choir at the local primary school. Two more children followed, Rufus in 1997 and Holly in 2002. I was down my own rabbit hole, giving birth to five children in five years. We reconvened in 2007. The years of grind were at last behind them.

The children had passed through the "terrible twos", "filthy fours" and "feisty fives". DD's towering rages had morphed into a ravening thirst for knowledge. He was a voracious reader and, like his mother, an irrepressible talker.

Sacha and Toby had bought five acres of wilderness and built their dream house, *The Waterside*. Toby had a recording studio in a separate annex, where he was working on the Channel 4 documentary series *In the Womb*. Sacha's little choir was flourishing

under her direction. She was also about to publish a book, *Red Undies & Dutchman's Trousers: Naughty Plants for Every Occasion*.

At home, though, there was a nagging problem. Somehow, 11-year-old DD and Toby had missed forging that vital father-son connection. Sacha was pained by the gulf between them: "The more Toby tried to ignore him, the more DD tried desperately to get his father's attention, and would then take it out on Rufus, who was adorable and quiet, and the apple of his father's eye. Toby would shout at DD, who'd shout at Rufus, who'd shout at the dog, then I would shout at everybody because I just knew this was not the way to go."

I missed the publication of *Red Undies* because shooting had started on the film version of my biography of the Duchess of Devonshire. I was so busy that I forgot to wish Sacha good luck, not that she noticed in the flurry of her own intense activities. At half-term, the family went on their first trip together to London to see the Terracotta exhibition at the British Museum. On the way home, Sacha and Toby realised that the incredible had happened: an outing with no fights, no nappies and no whining. "It was bliss."

The next morning, the sound of DD vomiting in the loo woke his parents at 5am.



PREVIOUS PAGES AND TOP: JUDE EDGINGTON



## MINDFUL IN THE FACE OF MORTALITY

An extract from the journal of Sacha Langton-Gilks reveals David's maturity and courage

DD's oncologist told us his chances of surviving another five years were now very poor; less than 5%. "Having said that, I do know children who are still alive."

The car journey home was an object lesson in the resilience and love of children. "Mum, did you know that the Chinese have the same word for crisis as for opportunity?" I did not know. My mind spun. Opportunity? Cancer? Do I need the westbound of the M27? "It's funny, I thought I would cry all the way home but I feel better." I glanced at my extraordinary child and wondered how he managed to be more grown-up than a grown-up. "You know what Granny says? No feeling ever lasts, however bad. I see what she means. I want to do zoology at university. I'm going to look a bit stupid if I stop doing everything and then survive, aren't I!"

"Well, I guess so!" I had to laugh.

"And you and Dad aren't going to have a breakdown or anything, are you? You'll go on doing your stuff if I'm not here?" His expression was one of such concern. I could hardly breathe. I gripped the steering wheel and tried to avoid the glare of headlights as the rush-hour traffic thundered past. He was worrying about us.

"I swear that I will carry on doing what I always do, and so will Dad. He'll carry on at the prison, I promise." This seemed to comfort him. I understood that the only way to care for my wonderful son was to listen and follow his lead.

"And I promise we will do everything in our power to keep you at school, doing your GCSEs. We will probably have to cut some inessential subjects, but we'll work out what you need to get into uni in zoology and work back from there."

"But I want to do the same as my friends."

"I know, but — listen, we have to be practical. You are going to need every drop of energy just to get through the day."

"Mmm. I just don't want to get fat on steroids. I'll look like such a freak and no one will ever go out with me. I want a girlfriend."

There was little I could say to this, but felt every syllable. I remembered instantly how ugly I had felt with slight puppy fat and flaming red hair. I admired my child so much for dealing with far more — hair loss, extreme weight loss, surgery, eye problems, sickness, let alone pain — and with such dignity. I knew it was going to get exponentially harder. I gripped the steering wheel again.

"Listen love, whatever happens, we'll manage. I love you to bits. Stick on the radio, will you? Radio 4 will keep me focused."



**'I'm going to look a bit stupid if I stop doing everything and then survive'**

He had been throwing up intermittently since starting at Shaftesbury School. It had seemed insignificant at first. Boys often react emotionally through their stomachs, and a new school can be stressful. Sacha tried the usual remedies; it was hard to tell what worked and what didn't. After six weeks she took him to the local GP, who referred DD for tests at Salisbury District Hospital. But that morning there were two new symptoms: DD's behaviour was strangely pliant, and he complained of a stiff neck. Sacha drove him straight to the hospital.

DD was admitted that night for tests. He fell asleep quickly. Sacha lay on the pull-out bed next to him, trying not to cry: "The doctor had said to me, 'Something is seriously wrong.' I was panic-stricken. I lay there wide awake, feeling this massive loneliness, knowing that

no one could do anything about it. I couldn't call someone, or pay my way out of it. No amount of money, or contacts, or anything can help you in that situation."

On October 24, 2007, an MRI scan revealed a tumour the size of a golf ball at the back of DD's brain. He was taken by ambulance to Southampton General Hospital for surgery. The night after the operation, it was Toby's turn to sleep by DD's bed. In the morning, Sacha found DD handing his father a full bottle of urine. Toby expertly swapped it for an empty one and made a note on the chart. Sacha had never seen him give so much as a teaspoon of Calpol to DD. Now, suddenly, Toby was nursing his son with the tender confidence of a professional.

Analysis of DD's tumour brought a mixed prognosis. It was aggressive medulloblastoma, a paediatric brain cancer that affects about 90 children a year in Britain, or one in every 30,000. The five-year survival rate hovers around 70% but DD's had been detected late, a common occurrence that leads to many needless deaths. More children in this country die each year from brain cancer than from meningitis or

leukaemia. The protocol for DD's cancer would involve six weeks of radiotherapy, followed by 56 weeks of chemotherapy. Toby almost fainted when the surgeon delivered the news.

The next 12 months revolved around DD's treatment. It was never straightforward. One week his brain shunt — a pump used to remove fluid from the brain — would be malfunctioning; the next, he would be having a severe reaction to one of the drugs. DD endured seven operations that year. Sacha dropped all her volunteer work except for her choir. Toby stopped looking for commissions. On chemo weeks, DD would be admitted to Southampton General while one of them slept at the Clic Haven hostel for families with paediatric cancer patients. They staved off exhaustion by operating a rota of three nights on, three nights off. Even so, Toby suffered asthma-like attacks brought on by stress.

The Langton-Gilks discovered a caring community around them. Hundreds of friends and acquaintances helped. When their car broke down, the garage owner lent Sacha his own so she could drive to the hospital.

"I'm doing fine. I'm not feeling brilliant but I'm doing fine," wrote DD, even though the effects of the chemo left him in a wheelchair for much of the time. A week at the Over the >>>





**WRITER'S FLOCK**  
Amanda Foreman with her five children and husband, Reg, who was also diagnosed with cancer



"Everyone had plans when they got out to go to record labels and send them their stuff," said Dean Stacey, aka Minus Da Greez. Stacey has since signed to the hip-hop label Apparition Records and is working on an album; his mixes can be found at [datpiff.com](http://datpiff.com).

On September 9, 2010, an MRI scan showed that DD's cancer had returned, this time in his spine. He cried as the oncologist informed them that his chance of surviving for five years was now less than 5%. Nevertheless, the chance did exist, if he chose to go through another round of chemotherapy. The weekend after the bombshell news, the family went to Durdle Bay in Dorset. DD had already lost the feeling in his right foot, but refused to be stymied by the hard descent to the beach. The sun was still blazing hot and they all stripped off and plunged into the sea. Sacha lay on her back, allowing the water to support her when her heart could not.

The treatment began. Incredibly, the night before the first scan result, Sacha came to the dinner for my book launch of *A World on Fire*. She talked animatedly; no one had the slightest inkling that she was waiting for the kind of news no mother or father should have to bear. The next morning, Reg and I listened mutely while she spoke on the phone to Toby. The tumours had almost disappeared. DD had defied all expectation and responded to the chemotherapy. The oncologist wanted intense high-dose chemo combined with stem-cell rescue. It would mean six weeks in an isolation ward, and any number of agonising side effects.

**B**y March 2011, they were dealing with the reality of stem-cell rescue. "The trouble with any of these procedures is that you have nothing to measure them against," Sacha said. "When your oncologist says he will have a sore mouth, you think, OK, we've done tonsillitis and strep throats." DD blistered from his stomach lining through the oesophagus and into his mouth and nasal passages. The chemo drugs oozed from his pores, causing his skin to pucker and turn livid. He was moved to an air mattress to ensure his weight was supported evenly. For the last two weeks of treatment, the pain became so intolerable that he was partially sedated. They brought him home on March 29. "We'll just take it day by day," wrote Sacha. "Toby and I are so knackered from all the stress we have to help each other finish our sentences, because our short-term memories are shot." The oncologist gave DD a fifty-fifty chance of being fully cured. "Just go and have a life," he told them.

## The cancer had returned. DD was given six to 12 weeks to live

Sacha's work for the HeadSmart campaign required her to speak out about DD. For Toby, the opposite was true. It was against prison policy for any personal details to be shared with the prisoners. The men knew nothing about Toby's recent trials, nor of his joy over DD's recovery. They had no idea that DD stunned everyone by going windsurfing in June; or that in September he returned to school to begin his A-level course. As far as the inmates were concerned, Obi-Wan, as they affectionately called him, had no competing interests to interfere with his devotion to them.

We saw something of Toby's strength when we came for a visit in April 2012. Sacha had written: "My God, it's still so hard for DD sometimes, I really just can't stand it." But we encountered a loving family that exuded a genuine *joie de vivre*. I understood for the first time Toby's special relationship with DD.

In mid-May, DD and Sacha recorded a video for the HeadSmart campaign. DD described all the treatment he had endured between the ages of 11 and 16 in order to become well again. He ended by smiling directly at the camera: "At the moment, I'm all right. Yeah!" A few days after the video went live, a scan revealed that the cancer had returned. DD was given six to 12 weeks to live. "You can't win them all," he said in an interview. Toby informed the prison authorities that he was stopping the course to spend what precious time there was left with his son. The prisoners knew only that Obi had no immediate plans to return. Sacha, Toby and DD decided to make those final weeks count by using his story to publicise the HeadSmart campaign. On June 6, one of the inmates at Guys Marsh saw them being interviewed by BBC Points West. The news spread through the prison like wildfire. So many prisoners wanted to show their support for Toby and his family

that, with the governor's permission, a small core organised a talent contest. The winners would get to write and record a song, and release it on the internet for charity.

The five men who wrote Song for DD named their band Bigger than Us, highlighting the fact that they were doing this not for themselves, but for a cause. Men who had never previously given a thought about charity worked together to make Toby proud. Ironically, this coincided with the prison losing its funding for Toby's course.

DD slipped away a little more each week. His memory crumbled piece by piece. Yet Sacha was always able to find ways to comfort and soothe him, even when he became increasingly confused. On August 6 he asked her: "Do I know you? You look very like my mother." A week later, DD fell into a coma; he died at 6.10am on August 14.

In September, after DD's memorial service had taken place, Toby was asked whether he felt strong enough to visit Guys Marsh. The prisoners had a song they wanted to play for him. Walking through its now familiar corridors almost reduced him to tears. Warders offered their condolences, prisoners vied for his attention. Toby arrived at the chapel to find the group, the head of security, the chaplain and other familiar faces all anxiously waiting. The prisoners were terrified of disappointing him. They began nervously until the words carried them along: "I will run. I'm gonna fly. I will swim the seven oceans just to keep you by my side." It was a song about a father's love for his son. Toby's self-control broke. The prisoners struggled to continue as the rest of the room also began to weep. Toby promised to help them add the finishing touches and liaise with the cancer charities.

Soon after his visit to the prison chapel, Toby decided that, regardless of the budget cut, he could not desert the men. He offered to resume teaching the course without pay. Sacha had found her cause in HeadSmart, and Toby had found his. Loving and caring for DD had led each of them onto entirely new and unexpected paths. "Life is suffering," DD used to remind them; in his later years, he would also add, "but every second of life is a miracle." ■  
© Amanda Foreman. Her latest book, *The World Made by Women: A History of Women from Cleopatra to Clinton* (Allen Lane), will be published in 2015. You can buy *Song for DD* for £1.29 on Amazon, iTunes, Spotify and other download sites from March 4, marking the start of Brain Tumour Awareness Month. Proceeds will be split between the Brain Tumour Charity's HeadSmart campaign and Clic Sargent